Witness Name: Caroline Abrahams
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UK COVID-19 INQUIRY

WITNESS STATEMENT OF CAROLINE ABRAHAMS, CHARITY DIRECTOR, AGE UK

I, Caroline Abrahams, will say as follows: -

Brief description of Age UK, including its role, aims and functions

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. 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.

2. 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.

3. 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 social 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.

4. Age UK has obtained the information and testimony about older people's experiences described in the following statement via a range of different sources, including older people and their families, community networks, professionals working in key public services and our own frontline workforce and volunteers. Specific examples cited in this work have been selected as typical of the type of stories Age UK has heard and that we hope will help illustrate for the Inquiry the issues described.

5. Age UK uses a range of methods and opportunities to gather and analyse the insight and intelligence from older people, their families and supporters. This includes the Age UK information and advice services – where each year we receive around 15,000 written enquiries and 200,000 calls to the national advice line service alone – and The Silver Line, a free confidential support line for older people, that received 270,000 calls between March 2020 and March 2021 a huge increase in the volume of calls to the advice line – peaking at an 88% increase at the height of concerns. During the specified period between 1 March 2020 and 28 June 2022, which is the date on which the final Covid-19 restrictions were lifted in the United Kingdom ("the relevant period"), Age UK received an estimated 94,000 enquiries about social care. For enquiries where further advice was needed, social care concerns constituted an average of 40% of total enquiries. Age UK also received a large volume of calls about health (and these categories of health and social care overlap), introducing a Covid-specific call code from 1 April 2020. Our advice line colleagues indicate that the most common enquiry themes relating to Covid were around 1) Family/friends being unable to access care homes and hospitals to visit loved ones either due to an outbreak or as a preventative measure to stop the spread of Covid, 2) Family having to talk to loved one's resident in care homes through a window and 3) Deterioration in mental health due to visits being prevented in care homes and hospitals (both to family and the resident).

6. Given the unique impact of the pandemic on older people, Age UK also established a major qualitative and quantitative research programme to ensure we fully understood the depth and breadth of experiences, including those of minoritised older people and those experiencing social exclusion. Our work has included several waves of in-depth research and survey work, qualitative data collection and polling. Taken together, we have collected 100s of 1000s of individual insights and stories from older people and the people close to them. We also receive a significant number of direct communications from individuals sharing their experiences and concerns.

7. We preface this witness statement with the understanding that in documenting the systemic challenges and deficits in the care of older people during the period of time between 1 March 2020 and 28 June 2022 ("the relevant period"), we are also clear that this was not every older person's experience. We have also heard a huge number of positive stories from older people about excellent experiences, where health and care professionals across all parts of the system worked hard to care for older people with great compassion and sensitivity, whilst under extreme pressure and at significant personal risk. We also know that many organisations and systems innovated at great speed to keep essential support in place – many of these innovations should be built on and the good practice shared for the future. However, there were also many instances where individual care or systemic responses fell short, and where it is essential that lessons are learned.

8. For us at Age UK it is the systemic failings on which the pandemic shone some light that are our principal interest. However good their intentions, individuals will always make mistakes, especially when under exceptional pressure as during a pandemic, but if we're to minimise the risks of terrible things happening again it is policies, processes, resource levels, cultures and attitudes which above all we need to scrutinise and, where necessary, seek to change for good. I am afraid that some terrible things definitely did happen during the two years in question, particularly early on, and particularly to some older people. At Age UK we know about these things because older people and their families have told us about them, and sometimes clinicians and care staff and managers too.

9. We know that there are some people in Health and Care, and in Government, in particular, who, looking back, feel deeply uncomfortable about decisions they made or didn't make, or their own or other people's actions, or the limited and incredibly difficult choices available to

them or others as they tried to navigate their way through a nightmarish time, in the best and fairest way possible. Nonetheless, I think it is also fair to suggest that it is at times of crisis that the fundamental values in a society shine through. And herein lies the rub: for us at Age UK it quite often seemed during those early weeks and months that the rights and interests of older people were an afterthought, and that sometimes their lives were considered to be worth less because they were older. My comments here are about the position in England, but throughout the pandemic I was in frequent communication with colleagues across the UK and they quite often expressed similar concerns.

Description of Age UK's respective members and those that they support as it relates to the adult social care sector.

10. The Age UK Network plays a crucial role in providing social care to thousands of older people across England. Of Age UK's 120 local member organisations, there are 26 separate registered care services provided by 21 Age UK partners. Of these, two are Care Homes, four provide Foot Care (only) in people's homes and twenty provide home care (either with or without foot care). As a federation we provide standard home care registration, or personal care with accommodation that covers personal care, caring for adults 60+, dementia, mental health conditions, physical disabilities and sensory impairments. None of these support services are tailored for a single specific health condition, although there is one end of life specialised service. Our wide range of direct services and support brings us into contact with large numbers of older people in our communities and their own homes. For many older people, 'social care' means personal care, which can include help with washing, dressing, getting out of bed in the morning, help taking medicine, and help with the housework. It can also refer to help with broader activities within the community and maintaining contact with family and friends. A much larger number of provider services support wider social care functions ranging from home from hospital and reablement schemes, day centres, home help as well as preventative services like falls avoidance and independent living which try to stop older people needing formal care support in the first place.

Description of the adult social care sector as it relates to older people

11. Social care is on the front line when it comes to keeping older people, disabled people and people with long-term health conditions safe and well. Social care usually refers to a variety of extra support and professional help to carry out daily tasks and live comfortably. It includes

people who are frail, have disability or neurodiversity, mental health challenges and the people who care for them. Social care includes support in people's own homes (home care or 'domiciliary care'); support in day centres; care provided by care homes and nursing homes ('residential care'); 'reablement' services to help people regain independence; providing aids and adaptations for people's homes; providing information and advice; and providing support for family carers. Social care also seeks to safeguard and protect people from harm and neglect.

12. Social care encompasses a range of support services, but it is important to note that the majority of care is delivered to older people. There were 1.32 million new requests for support from older people in 2017/18, accounting for 71.6 per cent of all requests received by adult social services departments Exhibit CA4/01[INQ000502183]. There was a steady year on year increase leading up to the pandemic (1.36 in 2018/19 & 1.37 in 2019/2020), but the number of clients receiving support has been decreasing year on year since 2015/16, due to a decrease in those over 65 receiving long term care. As previously indicated, the care sector is bigger than just care homes and includes home care and live in care agencies providing support in people's own homes (home care or 'domiciliary care') too. We also incorporate both local authority and self-funded care within this definition. For context, 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 Exhibit CA4/02 [INQ000509352]. According to pre-pandemic Age UK analysis, more than 1 in 10 (12 per cent) of people aged over 65 in the UK received some form of formal help or care in their homes – including domiciliary care, help with household tasks and reablement – from local authority, voluntary or private sources. This increased to 1 in 5 (20 per cent) people aged 85 and over Exhibit CA4/03 [INQ000509353]. While data on the self-funding population drawing on care and support is somewhat limited and was not collected prior to the pandemic, ONS estimate that, from 1 March 2021 to 28 February 2022, 33.2% of services providing regulated community care for older people (aged 65 years or older) were self-funded. Care homes providing care for older people had the highest proportion of self-funders (47.1%) across England, but for Community Care and Care Homes there is significant variation across the country, and in areas of deprivation, the state-funded population tends to be larger.

Working with advisory bodies, government departments, arms-length bodies and professional organisations during the pandemic

13. Our organisations work closely with public services, professionals and policy makers at both national and local level and held regular discussions about key issues and challenges. Throughout the pandemic we enhanced our usual processes for sharing information and insight into the real time challenges experienced by older people that emerged through our work and engagement in these networks. We had sustained engagement with national government and officials, including at DHSC, government bodies such as NHS England and the Care Quality Commission, Royal Colleges and other representative or standard setting organisations. We met regularly with the NHS National Clinical Director for Older People and Integrated Person-Centred Care as well as other senior stakeholders.

14. We also worked directly with NHS and social care organisations – including providers and commissioners – across England directly and in collaboration with our network of Local Age UK charities. We gathered and shared feedback from older people, families, and local organisations with the relevant organisations. There were both formal and informal opportunities to comment on draft guidance and plans, as well as provide advice on emerging challenges and communications.

15. Our national professional and policy leads worked within a range of professional networks, and participated in a range of regular meetings and conversations that were established in direct response to the challenges of the pandemic where frontline staff came together to share experiences and information. These included groups of clinicians, other healthcare professions and care home managers and care workers. We provided many written responses to select committees and other consultation responses, parliamentary briefings and correspondence with ministers. Age UK also conducted our own polling and research on the topic.

16. A list of representations provided by Age UK to the organisations mentioned above, as well as our research and reports, so far as is relevant to the Provisional Outline of Scope for Module 6, is provided at Exhibit CA4/04 [INQ000509809]. These documents (Exhibits CA4/05 - CA4/31) are listed in the exhibits schedule appended at the end of this statement.

Pre-pandemic structure and capacity of the adult social care sector in the UK

17. Pre-pandemic the social care system was broadly considered to be unfit for purpose. It was widely accepted that the way in which the state supports and funds people to meet their care needs was not working effectively, and Age UK has a long history in campaigning, policy and advocacy work aimed at shining light on this issue. Age UK's work on this topic over the past decade has repeatedly raised the alarm regarding the lack of capacity of adult social care and the percentage of people either not receiving any help with basic tasks like getting in and out of bed, using the toilet, and eating, or receiving help that does not fully meet their needs. So, whilst the pandemic has had a significant impact on social care, the challenges stretch back years.

18. Since 1998, there have been 12 green papers, white papers and other consultations, as well as five independent commissions, all attempting to grapple with the problem of creating a fair and sustainable adult social care system. Age UK has published a large body of work making the case for social care reform and corresponding policy change. Our campaigning falls into three key areas1) the need to increase funding to both expand access to state-funded care and stabilise the sector, enabling providers to attract, retain and train the staff needed to meet rising demand, 2) the need to implement funding and eligibility reforms to make the system fairer and 3) the need to undertake reforms to improve quality and outcomes, including for carers. We have summarised these challenges below.

Lack of funding for adult social care

19. For many years, Adult Social Care services in England have faced significant funding pressures due to the combination of a growing and ageing population, increasingly complex care needs, reductions in government funding to local authorities and increases in care costs. Public spending on local authority provided and/or arranged care in England is significantly lower than on the NHS in England. Local authorities with higher levels of deprivation tend to have a lower local tax take and therefore raise less revenue per head from the Social Care Precept and, in the years leading up to the pandemic, we warned that inverse resource allocation would lead to increasing levels of inequality between areas if nothing more was done.

20. The Care Act 2014 introduced new standard assessment criteria for local authority funded care and support. The Act replaced the previous locally determined criteria with a national threshold designed to ensure that assessments of eligibility are applied uniformly. However, significant reductions in funding for local authorities and increasing demand have resulted in proportionally fewer people being able to access essential services. In a public policy briefing from May 2019, Age UK pointed out that significant funding challenges had led to gross current expenditure on adult social care falling from £19.2 billion in 2009/10 to £17.9 billion in 2017/18, a real-terms cut of six per cent Exhibit CA4/32 [INQ000502185] which contributed to 1.5 million older people now living with unmet care needs. Since 2017, there has been an almost 20% (18.2%) growth in people aged 75+ (i.e. those most likely to need care).

21. Age UK's 2019 report State of Health and Care raised serious questions about the existing model of social care provision Exhibit CA4/01 [INQ000502183]: *"There is now widespread consensus among older and disabled people, families, policy makers and practitioners that there is urgent need for reform to deliver a sustainable system capable of providing the care people need, when they need it"*. We were not alone in this view. The Housing, Communities and Local Government Committee and the Health and Social Care Committee June 2018 joint report on the long-term funding of adult social care concluded that "*in its present state, the system is not fit to respond to current needs, let alone predicted future needs as a result of demographic trends*". This was just one of many such reports published prior to the pandemic.

Reduction in provision of publicly funded social care

22. The huge reduction in the provision of publicly funded social care has had a severe impact on older people, their families and carers in recent years, resulting in high levels of unmet need. In 2016 nearly one in eight people were struggling without all the help they need to carry out activities of daily living (ADL) – essential everyday tasks, such as getting out of bed, going to the toilet or getting dressed. In 2018 this had risen to nearly one in seven older people. There was a 1.6 per cent rise in requests for care support between 2015/16 and 2017/18, equivalent to an additional 5,000 requests received per day. However, supply has not kept pace with demand. In 2017/18, 676,430 requests – or 51.2 per cent of the total – resulted in either no services being received or people being sign-posted to universal services or elsewhere.

The impact of social care cuts on the sustainability of the social care market

23. The squeeze on funding has affected the viability of the care home market, with the Competition and Markets Authority's care home market study uncovering significant problems, including the huge cross-subsidy of local authorities by those that fund their own care, as evidenced in Age UK's social care reform and funding policy position Exhibit CA4/33 [INQ000502187]. A key concern raised prior to the pandemic was the sustainability of many local care markets, with examples of providers handing back loss-making contracts, exiting the market or collapsing completely. In the decade preceding the pandemic, two major providers collapsed – *Southern Cross* in 2012 and *Four Seasons* in 2019.

24. In the decade leading up to the pandemic the number of care homes and care home beds were both in decline. The number of registered locations fell by around 8.3 per cent between April 2013 and April 2018, from 17,502 to 16,037, while the number of beds available fell by 0.8 per cent from 462,624 (218,506 of these with nursing) to 458,905 (220,639 of these with nursing). Areas that saw a significant decline in the number of beds tended to have the lowest number of self-funding service users, while those that gained beds tended to have among the highest. This is reflected in the findings of a 2019 'deep dive' report looking at the state of the care market in five areas of England, which again found the most significant reductions in care home beds in areas with more publicly funded clients and greater difficulties in recruiting skilled workers Exhibit CA4/34 [INQ000502188].

25. The unequal pattern of change across the country was, and remains, arguably even more worrying. According to the CQC, across a two-year period, from April 2016 to 2018, changes in nursing home bed numbers ranged from a 44% rise in one local authority to a 58% reduction in another. In 2018 Directors of Social Services in 58 local authorities reported having at least one care home closure in their area, and 17 had contracts handed back Exhibit CA4/35 [INQ000080753].

26. The data suggests that the home care market was, and is, in a state of considerable flux. Over 97 per cent of home care is provided by independent providers, with around 70 per cent of services commissioned by local authorities. In total an estimated 80 per cent of domiciliary care funding comes from the public sector once NHS sources are considered. As a result, the home care market was significantly exposed to challenges in public funding. Overall, the total amount of home care delivered fell by 3 million hours between 2015 and 2018. Many older

people were, and remain, living in 'care deserts' with little to no choice in access to high-quality care. These challenges remain.

27. In the lead up to the pandemic, the Ombudsman had also found continuing errors relating to top-up fees, with people and their families being incorrectly charged for care. This growing concern about third-party top-ups sat alongside evidence that older people were being asked to shoulder more of the cost burden through client contributions. In 2018 more than three-quarters (78 per cent) of Directors of Adult Social Services reported concern about their ability to meet the statutory duty to ensure market sustainability within existing budgets.

28. Access to health services in care homes was already a challenge prior to the pandemic. One of the main reasons the Enhanced Health in Care Homes (EHCH) framework was set up as part of the NHS Five Year Forward View (2014) and NHS Long Term Plan (2019) was to address inadequate access to health services in these settings, particularly for people with Dementia. For example, care homes often had to pay GPs to do routine primary care and access to rehabilitation services was not always made available. The results included short-term stays becoming permanent and significant numbers of avoidable admissions to hospital. The EHCH framework was designed to deliver high-quality personalised care in care homes and support care home residents to ensure appropriate access to healthcare services in the place of their choosing, promote health for people living in care homes, their loved ones and staff and to optimise their quality of life.

Workforce capacity, retention and vacancy rates

29. Prior to the pandemic, the adequacy of care provision was further undermined by severe staffing shortages and high levels of workforce turnover. The vacancy rate had risen by 2.5 per cent between 2012/13 and 2017/18. It was estimated that 8 per cent of roles in adult social care were vacant, meaning that at any time there were approximately 110,000 vacancies. This rise in vacancies, especially in the context of a workforce that has grown at a slower rate in recent years, suggests that the sector was struggling to keep up with demand as the population ages, and this challenge remains. The sector was particularly struggling to recruit registered nurses, with care homes seeing a sharp rise in vacancy rates. Turnover rates increased steadily between 2012/13 and 2017/18 by a total of 7.6 percentage points and this churn indicates that employers were struggling to find, recruit and retain staff to the sector.

The estimated staff turnover rate of directly employed staff working in the adult social care sector is 30.8 per cent Exhibit CA4/37 [INQ000103564].

30. A large proportion of staff turnover in the lead up to the pandemic was a result of people leaving jobs soon after joining. Poor terms and conditions were a widely acknowledged cause and turnover was highest amongst the lowest paid and least qualified. Where reasons for leaving were known, career development was one of the most commonly cited reasons. There was also concern within the adult social care sector that the 2018 pay rises for the lowest paid NHS staff across England would have the unintended consequence of exacerbating recruitment and retention challenges as social care struggled to compete with the terms and conditions on offer to NHS employed healthcare assistants. Unfortunately, these challenges remain, and the funding currently available for the care sector is unable to sustain a well-trained, motivated and effective workforce.

The impact on carers

31. Prior to the pandemic, Age UK repeatedly raised the issue that it is often family members who face the consequences of reduced access to publicly funded social care. Whilst local authorities have a duty to provide Carer's Assessments, care packages are often devised without due consideration of the ability and willingness of family members to provide the intensive levels of support many older people require. The Care Act requires eligibility assessments to be 'carer blind' with needs assessed regardless of the support available from a carer. However, in practice, the allocation of resources is strongly determined by the level of informal support available as well as individual living arrangements. That this was not widely known isn't surprising since social care is not well understood by most members of the public who have no direct experience of it. A consequence was that many people who act as informal and unpaid carers for older people were left without support when the pandemic struck.

32. In summary, undoubtedly the parlous state of social care at the start of 2020, a result of years of under-funding and policy neglect, had a negative impact on the sector's ability to respond to the pandemic. As we stated in our 2018 evidence submission to evidence to the Health Committee and Communities and Local Government Committee joint inquiry on long term funding of adult social care; *"Social care is in crisis and only by acceptance of this will a sustainable solution be reached to fund its long-term future. Furthermore, the need to find a*

solution is urgent – trends driving growth in demand are only going to accelerate and become more acute over the next decade. Successive governments have kicked this issue into the long grass, but we have reached a tipping point whereby the crisis is so significant that its effects are far reaching and profound, particularly for ordinary families and the NHS" Exhibit CA4/36 [INQ000502190].

Key concerns raised to Age UK regarding the impact of the pandemic on recipients of care

Access to routine health and care services

33. Age UK raised a number of concerns regarding the impact of the pandemic on care recipients, many of which could be described as safeguarding failures. As already described, older people in receipt of social care are, by very definition of these circumstances, more likely to be living with complex care needs, pre-existing long-term conditions, disability, or frailty and therefore likely to be far more reliant on routine health and care services. As a consequence, older people were always going to be disproportionately impacted by measures that would impact the usual running of those health and care services.

34. To a great extent, caring for the health of many older people makes health and social care services indivisible in practical terms. At some point in their lives, most often towards the end, many older people 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 either in care homes, assisted living facilities or in their own homes. 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. Therefore, 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 sustain their health and independence. Large-scale disruption to the usual functioning of NHS services therefore equalled large-scale disruption to social care.

35. In our May 2020 response to the Joint Committee on Human Rights Exhibit CA4/38 [INQ000176646] we explained that The Coronavirus Act 2020 meant that many duties

contained in the Care Act 2014 were suspended (regulations to expire the Care act eased on 21 April 2021), enabling local authorities to temporarily stop or reduce the support someone received. Small numbers of local authorities triggered those powers, leaving older people reliant on care and assistance at home and in the community unattended or with less support. Removing support perceived to be 'low level', such as help with cooking, tipped some older people into greater need. In fact, fewer local authorities formally utilised these powers than expected, but instead there was a widespread perception that some took action along similar lines, but informally.

36. We noted a marked deterioration amongst older people with care needs as well as a general decline in the health of informal carers with many more people reporting a range of challenges including physical and mental deconditioning, accumulation of chronic illness, loss of cognitive function, decreased confidence and reduction in their overall quality of life and wellbeing. During the height of the pandemic, in some instances, older people lost their usual networks of informal support or decided to discontinue their domiciliary care services to avoid the risk of infection, leaving them struggling to manage essential tasks, including personal care. Informal carers, many of whom are women, were often left to carry a greater burden of care, with reduced access to health care professionals and other services or forms of social support.

Access to essential clinical care

37. We were aware of places where there were no visits to care homes being made by the GPs, Pharmacists, Allied Health Professionals, Physiotherapists, Speech and language therapists (who also support with swallowing problems), or Community nurses. This was very difficult in care homes where there were nursing staff, but even more problematic in residential care homes without clinical staff, some of which were left in dire conditions. Residential care homes rely on NHS community teams to deliver all clinical interventions, for example diabetic care including insulin injections, regular dressing for serious wound care etc. In some cases, unqualified 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, falls, cuts and wounds.

38. There were difficulties in administration and shortages of medicines used at the end of life for pain relief and symptom control too. Age UK heard of residential care homes that were not

able to administer controlled drugs for pain and symptom control of people at the end of their life because there was no registered community nursing staff available. In nursing homes, shortages were made worse because of the rules for the administration of controlled drugs. Controlled drugs can only be administered to the person for whom they are prescribed. When people died, their unused medication was wasted, despite it being in short supply. The consequence was that some older people missed out on end-of-life pain relief and symptom control and tragically will not have experienced a dignified or pain-free death. For the first two months of the pandemic, these issues were particularly severe. Although new administration and prescribing guidance was issued at the end of April 2020 Exhibit CA4/039 [INQ000509354] it took some while for better systems to be put in place, and this guidance was unable to address the core challenge in practice, which was the lack of qualified staff to administer the medications.

Physical health and wellbeing

39. Throughout the pandemic, Age UK has been listening and responding to the views of older people and their relatives. We have conducted several waves of in depth research into the impact of Covid-19 on older people's mental and physical health. Findings have shown that for many older people in receipt of social care, physical deconditioning and loss of cognition was a major risk. Once an older person has lost muscle mass, cardiovascular fitness or strength and balance, it is very difficult to recover them. Deconditioning can lead to increased frailty, reduced mobility, loss of independence and an increased risk of falls. This in turn compromises people's ability to manage their everyday tasks or engage in normal community life. Many older people have also found it hard to recover from the effects of withdrawal of routine care and support services, long periods of isolation and loss of access to facilities and support, suffering irreversible loss of health, physical function and independence as a result.

40. Even as we moved out of the first wave of Covid-19 and restrictions began to be lifted, many older people continued to be extremely cautious and did not leave their home, and for some that caution remains even 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 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 Exhibit CA4/04 [INQ000502184]. It seems that this kind of impact was given little if any meaningful consideration in risk modelling lockdown and other similar measures. These impacts were particularly felt by people living with frailty. Frailty is a biopsychosocial phenomenon that at its root impacts resilience and the ability to bounce back from physical and psychological shocks. It is predominantly experienced by older people. The impact of both existing and prospective frailty in the community was likewise not considered in any meaningful sense, nor was the expert advice of geriatricians sought at the early stages of the pandemic. This was a terrible mistake in our view; had it happened, policymakers would have benefited from advice that was properly informed about the needs of older people, helping them to make better decisions.

Impact on dementia care

41. People with dementia living at home with carers also experienced extremely difficult circumstances, with memory clinics no longer functioning and mental health community services scant. There was no one to ask for help to manage worsening symptoms of dementia at home. We were 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 example, 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. As a result, this confusion led to some people getting less support than was allowed within the rules and that they badly needed.

Impact on mental health

42. Many older people have seen their mental health plummet, with a clear link evident between withdrawal of key social support services on which many older people rely and deteriorating mental health. We heard from older people who had lost all pleasure in their lives and were experiencing low mood, anxiety and depression. Rates of depression among over 70s have doubled since the start of the pandemic and in Age UK polling 36% of older people told us they had lost motivation to do the things which they used to enjoy. 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. Sadly, a minority of older people told us that they were unable to cope with the situation and were considering suicide. We also 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).

43. This 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. Covid-19 and the governmental response to the pandemic has exacerbated this situation. Severe anxiety was found to be twice as common among those who had been shielding than those who had not, 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.

Access to urgent and emergency care

44. We heard extensively from older people both in care homes and community settings who were either unable or unwilling to access urgent or emergency care for acute health conditions when they needed it. Age UK was particularly concerned by non-conveyance practices and was involved in protracted arguments about these with responsible organisations. At worst these meant a lack of access to urgent services in hospital for older 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 cases, this was because they were discouraged or prevented from accessing services, amounting to direct discrimination against older persons. 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.

45. Some care home residents were denied admission to hospital for any reason (including fractures, strokes and injuries) as a result. In one example, we were told by a senior clinician overseeing a community hub through the pandemic that any older resident 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 a resident he in fact judged to have a case of treatable pneumonia. I believe that a contributory factor in these decisions was ageism embedded deep within our culture and society, as shown by attitudes both within the NHS, and also far beyond it, as to who should be a priority within health when resources came under acute strain, particularly early on in the pandemic.

Imposition of Do Not Attempt Cardiopulmonary Resuscitation notices

46. There was other evidence of 'blanket' policies being applied to older people (orders imposed without considering a person's individual circumstances or wishes, meaning that those 65+ would likely have been denied access to care and treatment). Unfortunately, in some cases individuals told us they felt under pressure to agree to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices and/or to decline the option of being admitted to hospital in an emergency. In some cases, relatives were sent letters to sign on a relative's behalf, with no assessment of an individual's capacity to make their own decisions. 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. Age alone should never justify the application of a DNACPR or be used as a proxy for health status.

47. We are also aware of cases where older people and their families were directly discouraged from accessing healthcare services by clinicians or healthcare providers, or simply told that in the event of a health event they would not be given access to services. 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 would not 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 she felt it left her not knowing what to do if her husband experienced breathing difficulties.

48. Following pressure from Age UK and others Government and NHS England took steps to make clear that such approaches are unacceptable. However, Age UK is aware that even

when these policies were supposedly withdrawn, there was evidence that such practices continued in some places. A series of joint statements was issued from Age UK between March and November 2020 on emerging and concerning issues related to the pandemic. These statements related to the rights of older people in the UK to treatment during the pandemic (March, 2020), older people being pressurised into signing do not attempt CPR forms (April, 2020) and protecting older people's rights in the next phase of the pandemic (November, 2020). They are summarised here CA4/04 [INQ000502184].

Healthcare services for older people living at home

49. Alongside concerns about the availability of clinical care in residential and care home settings there were concerns about care in the community and for those living in their own homes. Specific challenges were identified in home care, supported living and extra care housing, where people died in unprecedented numbers behind closed doors. Since the start of the Covid-19 pandemic, a third more people have died at home in England, raising significant questions about whether people were able to access the care they needed at home and the quality of that care Exhibit CA4/40 [INQ000502192]. Lack of palliative care resources (both availability of workforce and medicines) meant that many of these older people were not afforded the dignified, comfortable, pain-free death that they should have been. 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.

Access to 'lifeline' social support services

50. The importance of 'lower level' social support for older people with care and support needs was highlighted by the adverse impact of shutting down universal services. The confusion and lack of clarity over social distancing rules caused many services and forms of support to close down or withdraw over this period, including day centres, support groups and other home visitors. The impact of this was sometimes equal to or greater than the lack of access to healthcare. For older people with care and support needs, closures of clubs, classes, facilities, churches, leisure centres (many of which either haven't reopened or have reopened in ways inaccessible to those communities) have had a massive impact on health and wellbeing.

51. Some older people and families cancelled their existing care packages in order to protect themselves or their loved ones from infection. Others worried about breaking the law and non-resident family and friends stepped back from providing essential support, unclear about what was allowed (for example 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 to stay well. The consequences were that many older people with care and support needs did not receive the support they needed. Others, who developed new care needs during the pandemic, struggled to access any support at all. These types of social support may be 'less formalised', but the pandemic has taught us that they should not be regarded as 'less important'.

Medicines management and the inappropriate use of anti-psychotic drugs

52. 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 1 in 4 people over 85 on eight medicines or more Exhibit CA4/41 [INQ000502193]. In the early months of the pandemic, many older people had to forgo medicines reviews leaving them at higher risk of inappropriate polypharmacy. We heard that medications with contraindications and side effects were prescribed by clinics and the polypharmacy was not adequately joined up. Further, a reduction in routine monitoring increased older people's risk of experiencing inappropriate polypharmacy, including unnecessary or adverse side effects, contraindications and associated health risks.

53. The use of mental health medications was a particular worry, with concerns raised over a perceived rise in prescribing 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. Specific concerns were raised over the prescribing of anti-psychotic medication. Most of the calls Age UK received on this topic were from residential care homes (less from nursing homes), and we were aware that some care home staff described feeling 'abandoned' by healthcare professionals and asked to carry out interventions that they were not trained or experienced to perform.

54. Care staff told us that they found it hard to care for residents safely. Many people who had a diagnosis of dementia and/or behavioural difficulties were struggling when they were confined to their rooms for long periods and prevented from walking along corridors. Some very challenging behaviour and symptoms emerged as dementia patients became disorientated, frustrated and upset and were consequently more prone to anxiety, aggression and sometimes violent behaviour. Sadly, the only treatment available 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). Visits by GP and other healthcare professionals had ceased and the only contact was by a virtual round (often irregularly scheduled). Anti psychotics such as haloperidol (Haldol) and Risperidone (Risperdal) were prescribed as a tool to manage behaviours, often on a PRN basis ('as needed'), which was not ideal as it was given at irregular times, for example, when personal care was needed, and residents could not co-operate.

55. Use of these types of medications also brought with it side effects (including dizziness, blurred vision, drowsiness and fatigue, dry mouth, constipation and changes in appetite) leading to an increased risk to residents of trips and falls. These side effects also resulted in many older people becoming more anxious, confused and agitated and even less able to understand their living environment. Some residents were restrained in chairs (for example, with the use of cot sides to prevent them getting up and falling). The severity of side effects of anti-psychotic medication for older people is well documented and guidance states that the smallest dose is generally the most appropriate. Some older people had become so heavily sedated that they were unable to drink or eat and they were dehydrated, lost weight and muscle mass and were experiencing malnutrition. This information was brought to our attention from reports from relatives, calls from care home practitioners, and other feedback, including from Age UK's Information and Advice line. Age UK shared this information with NHS colleagues, CQC, GPs, Royal Colleges and Ministers in real time, mainly via ad hoc communications, including phone calls. Age UK used its established channels of communication with those institutions and individuals identified above to convey such concerns, including relaying concerns to appropriate clinical leads to pass on.

56. The DHSC National Overprescribing Review published its report in September 2021 outlining the extent of the wider problem of general medicines management, suggesting that at least

10% of all prescribed items need not have been issued Exhibit CA4/42 [INQ000217383]. Prescriptions for people over 60 years of age represent the majority of all prescribed items. 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.

Unequal impacts experienced by recipients of care

57. As some of the experiences described above highlight, ageism was (and remains) a real and present threat to the health of older people, alongside the threat of Covid-19. As ageing is a universal experience its interaction with other risk factors is often overlooked. Although age was the dominant risk factor, additional factors across the older population such as individual characteristics (including ethnicity, income, sex, sexual orientation or disability) appeared to go unrecognised. Some older people had less of a safety net around them to protect against the risks, direct and indirect, posed by the virus and impact of the pandemic on the usual functioning of social care services. Just as there is a social gradient in health across the adult population, there is also a social gradient in healthy ageing. For example, 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. We also heard troubling stories from members of the LGBTQ+ community, people from minority ethnicities and disabled people, many of whom faced extra barriers to get the support they needed. Ageism can intersect with other forms of prejudice and discrimination, meaning that some older people are at higher risk of 'ageism plus' other forms of inequity.

Impact on older people from ethnic minorities

58. Older people from minoritised ethnic communities have experienced higher mortality from COVID-19 for the majority of the pandemic than white older people. This difference was particularly stark during the first wave of the epidemic, through the spring and summer of 2020, but disparities persisted in the second wave and only diminished from the Omicron period onwards. These health inequalities, exacerbated by Covid-19, are due to experiences of social and economic inequity, including racism and discrimination, across the life course which drives poorer health outcomes for a number of different reasons. For example,

structural racism impacts upon people's chances of being in a job or having employment conditions which put them at risk of contracting coronavirus, of having other health conditions, or of living in an area or in circumstances that put them at risk. Further, cultural stereotypes can impact upon the health care people seek and are offered and stand in the way of older people receiving the care they need. Evidence shows that GPs are less likely to refer patients from minoritised ethnic communities to care services and social workers are less likely to check in on their patients' care. In November 2020 Age UK submitted a consultation response to the Commission on Race and Ethnic Disparities on this topic Exhibit CA4/43 [INQ000217401], calling for the enactment of the combined discrimination duty under Section 14 of the Equality Act 2010, to recognise that discrimination can take place based on more than one characteristic at a time.

Impact on highly vulnerable groups of older people

59. When we think of older people we do not tend to consider issues such as homelessness, poverty, 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 social care they needed. Older people with low or no income, living in insecure and unsafe housing and highly reliant on local social care services died in the greatest numbers. We have heard extensive testimony from older people experiencing neglect, self-harm, suicidal ideation, malnutrition and substance misuse at home. Government and many services did not initially understand or take account of the specific challenges of keeping excluded older people safe and well, and these people were overlooked in the policies designed with a younger population profile in mind. Another example was the lack of consideration of the psychological and physical impact on older prisoners of being socially isolated in their cells, particularly for those prisoners with dementia. Lack of representation across national structures has led to the relative invisibility of these issues to decision-makers and meant that the Government's strategies for helping socially excluded people did not understand or engage with the intersections with age.

Domestic abuse and stay at home orders when home isn't safe

60. The pandemic meant that many older people were asked to stay at home at all times. This not only made them more vulnerable to abuse by those they were dependent on, but it also

posed a barrier to them seeking help. People tend to think of victim-survivors of domestic abuse as young women, often with young children. However, at Age UK we know that there are gaps in the data, which reinforce the myth of a 'typical' victim-survivor. Like younger people, older people may be subjected to domestic abuse that is physical, sexual, emotional, or economic. But there are also some important age-related differences that specifically affect victim-survivors as they age. For example, many older people subjected to abuse have a health condition or disability, which may mean they rely on their abuser for care and support. With the closure of day centres, the important role they play in older adult safeguarding and opportunity for issues like this to be identified, monitored and remedied, was lost. These challenges did not appear to be well recognised by policy-makers when stay at home orders were issued.

Key decisions made by the UK Government and Devolved Administrations

Discharge of asymptomatic patients into care homes

61. The first wave of the pandemic was witness to particularly devastating outcomes in care homes and places where people were receiving domiciliary or home-based care. The policies and guidance at the time failed to consider the highly relevant risk to care home residents or staff from asymptomatic transmission until mid-April 2020. By then a huge amount of damage had been done. 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. These people required isolation, but early on in the pandemic care homes did not have the necessary PPE, nor access to regular testing. 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.

62. 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, as described in a parliamentary briefing from Age UK Exhibit CA4/44 [INQ000101412], between 2 March and 12 June 2020 there were more than 19,000 deaths of care home residents attributable to Covid-19. 45% of deaths involving Covid-19 of people aged 70+ were care home residents. There were 79% more deaths of care home residents than in the same period in 2019. This impact was not restricted to care homes, and between 2nd March and 12th June 2020 in England and Wales,

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 Exhibit CA4/45 [INQ000104086]. Older people's rights were breached through the unsafe discharge of infected Covid-19 patients into care home facilities. In future, discharge to vulnerable settings should only happen where measures are in place to ensure the safety of the patient leaving hospital and the safety of people at the discharge address.

Lack of understanding of the care sector within government

63. The lack of representation across national governing structures has led to the relative invisibility of issues specific to older age groups to decision-makers. 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. 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 terms of policy or practice in the early stages of the pandemic. Specific challenges were also identified in home care, supported living and extra care housing, which received even less governmental attention.

64. Government did not publish a strategy for the social care sector until April 16 2020, by which time the virus had already taken firm hold. It is also our view that even at that stage the strategy failed to adequately address the scale and severity of the challenge, feedback that Age UK provided in advance of its publication. There seemed to be a 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. There were unrealistic expectations about the skills and capabilities of staff and the operational capacities and resources of providers.

65. The Government did not collect any routine, real time data from the care sector to guide decision making. Nor did it have access to comprehensive historic data (as data collection has routinely only captured local authority commissioned services). In the early days of the pandemic, government had no means of communicating with providers, relying on Care Quality Commission registration lists. There is also no register of care workers, making it

impossible for government to communicate with them directly. The absence of high-quality data meant at the outset of the pandemic Government and other public bodies lacked any kind of granular understanding of the lives and experiences of older people and the service providers supporting them, and had no access to reliable real time data on the impact of the pandemic across the care sector. Further, there was clearly some resistance on the part of government to intervene in or provide strategic support to essential public services which are predominantly provided by the private or voluntary sector, rather than the State. This hesitancy led to repeated delays and vacillation.

66. The UK Scientific Advisory Group for Emergencies (SAGE) itself belatedly recognised that it lacked representation and expertise from the social care sector and associated bodies for gerontology and did not know enough about care homes in particular. For example, the Health and Social Care Committee and Science and Technology Committee Joint Inquiry itself found that; *"Until the social care working group was established in May 2020, SAGE either did not have sufficient representation from social care or did not give enough weight to the impact on the social care sector. Without such input and broader expertise, Ministers lacked important advice when making crucial decisions."* Exhibit CA4/46 [INQ000509355]. Coupled with this there was significant turbulence within senior leadership in the social care civil service. 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. 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 a lack of operational expertise.

67. The serious lack of knowledge and understanding within government, and many of those advising government, about the needs of the social care sector (and within it the needs of older people and people living with disabilities) was evident. Subsequent waves of the pandemic were considerably better managed and communication between Government and the care sector greatly improved. The Department also introduced the capacity tracker, began soliciting routine data and set up a process to develop a 'winter plan' in August 2020.

Restrictions on visits to recipients of care by their loved ones

68. Following the first wave of the pandemic, care home visiting was repeatedly halted or restricted (many care homes implemented a 'no visitor policy'), in an effort to prevent the virus from spreading, and was then very slow to restart Exhibit CA4/54 [INQ000509358]. These decisions were made with insufficient 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, revealed that decision makers and those whose advice they were listening to the most, including the public health community, did not know enough about 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, a fact we highlighted multiple times. Age UK and other organisations spent many hours over the course of the pandemic trying repeatedly to persuade officials and their public health advisers to seek a better balance between the risk of infection on the one hand, and the risk of loss of hope among care home residents on the other. We were told the problem with our approach was that there was little or no scientific evidence to support the importance of visiting in care homes, whereas there was a lot of scientific evidence confirming the risk to older people from COVID-19 and its propensity to spread. We understood this view but felt it rather missed the point. As the pandemic continued it appeared to be, at least in part, a belated over-reaction to the failure to protect older people in care homes during the first wave; unfortunately, by 'solving' one problem it created many others.

69. 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. 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. Again, specific challenges were also identified in home care, supported living and extra care housing, all of which received even less governmental attention. Unfortunately, the appropriate balance between keeping people physically safe, ensuring their wellbeing and quality of life, and respecting individual preferences, was not achieved.

70. In exceptional circumstances, such as where a care home resident was nearing the end of their life, next of kin were able to visit. However, we know that with the pressures facing care homes, family members were not always able to visit or even speak to residents, even when

they were at the end of life. This was made worse where family members had little or no access to the internet. It was not until later in 2020 that visiting guidance in care homes and hospitals was adapted to ensure in-person visits for people at the end of life, meaning thousands of people were left to die without the support of their loved ones.

71. Providers interpreted advice that was issued by Government and Local Authority Public Health teams in the context of their own risk analysis and insurance arrangements. In some cases, it didn't matter what the local authority advised was possible, because the homes themselves were not sufficiently staffed, or registered managers were concerned about risks to their staff and residents and whether or not they would be held liable. These decisions on visiting restrictions caused huge tensions between families and care staff. In meetings with officials there were repeated pleas to Government from providers, and others, including Age UK, to stand behind them to guarantee their insurance positions, thereby giving them the scope to take more risks.

72. Balancing the need to keep people physically safe against quality of life and the risk of wider harm to their health and wellbeing is not easy, and the balance of risk was continually shifting as more information emerged and the pandemic evolved. However, the lack of clarity around legal changes, and their lack of timeliness, made undertaking a balanced risk assessment and appropriate mitigation extremely challenging for local services to get right. It was clear that there was a lack of consideration given to the rights of residents and, moreover, the absence of any established rights framework in care settings to guide decision-makers or enable residents and their families to challenge those decisions was a major problem. 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 in general or care homes in particular.

73. Restrictions on visiting and the consequential negative impact on the rights of residents were a concern before Covid, and we would not want to see blanket visiting bans of the type that were imposed in the early part of the pandemic re-emerge in response to any future crisis. The public conversation about this was not helped by the term 'visiting', which fails to capture

what many relatives and friends often do for people in care homes to supplement the care available from staff. It is not unusual, for example, for the partner of a resident with dementia to spend many hours with them, helping them very slowly to eat and drink sufficiently. Social care is a holistic service – it is concerned with people's mental and physical health alongside their spiritual and emotional wellbeing – we lose sense of the balance of all these elements at our peril.

Matters relating to end of life care

74. As briefly touched on earlier in this statement, we heard reports that older people in care homes were left to die of Covid-19 and other illnesses without sufficient clinical support or sometimes access to palliative care teams or palliative care medicines. Age UK heard reports of care staff being told that their job was to provide end of life care for residents who were sadly dying from the virus, 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. Such prescribing and treatment expectations were often beyond residential care staff training and experience. Residential care services were not able to give anticipatory medicines (as these are controlled drugs) and in some places supplies of end-of-life medication ran out. These are serious breaches of accepted practice. 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. Age UK contributed its expertise to weekly meetings of the RCGP COVID End of Life Care (EOLC) Advisory Group chaired by Dr Adrian Tookman and Dr Catherine Millington Saunders. Age UK also attended the AMBITIONS for EOL partnership meeting, chaired by Professor Bee Wee, National clinical director for EOLC. The purpose of this meeting was for clinical staff to discuss their worries and concerns about clinical practice, to share intelligence from the previous week and raise or escalate concerns and issues. Guidance was issued in late April 2020, but it is unclear when changes in practice filtered out throughout the Care Home sector. Sadly, we know change came too late for many older people.

75. Visitation restrictions also had a profound impact on people receiving palliative care. It was not until later in July 2020 that visiting guidance in care homes and hospitals was adapted to ensure in-person visits for people at the end of life, leaving thousands of people dying without the support of their loved ones. Lockdown and shielding restrictions meant that many people

have suffered as a result of not being able to say goodbye to their loved ones, or attend their funeral accompanied by friends and family. Many older people, their families and loved ones, have experienced complex traumatic bereavement (even in cases where deaths were anticipated) as a result of not being with them in the last months of their lives, or due to the manner in which they died.

76. 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. 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, health and care systems failed that test many times over the course of the pandemic, across all care settings.

Changes to the regulatory inspection regime

77. Age UK did not raise significant concerns regarding the changes to the regulatory inspection regime during the pandemic, understanding the need to stand down routine in-person inspection under the circumstances. However, we were concerned that CQC struggled to reinstate inspections and processes effectively because there was a lot of change in the quality profile of services over the pandemic period (for example, key staff left, and services that were previously good struggled). Quality of social care declined during the pandemic, and has not recovered, as evidenced by current levels of staff burnout and turnover. We remain concerned about this as it is imperative that the regulator is able to ensure that people in receipt of Adult Social Care are safe, and their human rights are maintained.

Infection prevention and control measures ('IPC') and isolation measures

78. The Government was slow to understand the risks that communal areas might present to older people in care homes, sheltered and extra care housing. Many facilities did not have the practical capacity to implement isolation measures, for example, to ensure isolation of recipients of care following discharge from hospital and/or symptoms of Covid-19, and/or a positive Covid-19 test. Congregate settings are designed by definition to be communal and, as such, implementation of infection control measures was very challenging. Added to which,

the level of understanding of the design and layout of residential care homes and the ability to implement isolation measures was low. Many of these settings were in older buildings that were not purpose built too, adding to these difficulties.

Infection prevention and control measures ('IPC') and staff shortages

79. 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. Within domiciliary care many care workers visit several clients each day, so the obvious risk was that someone who contracted the virus unintentionally would spread it to a number of older people whose health was already compromised. Care homes struggled to rota enough of their own staff to fill shifts. This was made worse by pre-existing recruitment issues, exacerbated by sickness and self-isolation. Historically poor terms and conditions were also a major issue. Staff shortages necessitated regular staff moving between homes in the same group and much use of agency staff, many of whom worked across multiple care establishments, which was slow to be identified as a key factor in the rapid spread between homes, as was the lack of adequate or appropriate Personal Protective Equipment (PPE).

80. We heard stories of infected or symptomatic care workers continuing to report for duty because they couldn't afford to stay off work due to lack of sick pay. Government did introduce some measures to try and address these challenges later on, through the Infection Control Fund, distributed through Local Authorities in May and July 2020. The fact that this had to be done at all shows how undervalued the sector was, but its effective distribution to the frontline and ultimately into the pockets of care workers would have depended on how effectively the Local Authority distributed it, and how the provider then passed it on. Many care workers experienced issues, including those key workers with young children in school. While key workers were enabled to have access to face to face schooling, their children would have been required to isolate in much the same way as anyone else if they developed symptoms or were identified as a contact.

Infection prevention and control measures ('IPC') and lack of PPE

81. Many care homes had a continual struggle to source enough PPE. The reality here was that staff at times had no real protection. Lack of 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. The cost of what PPE was available rocketed, so only older people receiving care at home who were affluent, or whose families were affluent, were able to purchase it, certainly early on. Distribution of PPE via local resilience forums and councils was erratic and unreliable as those bodies themselves experienced issues with supply. Care homes had to rapidly establish new supply chains and often paid hugely inflated prices. Again, specific challenges were identified in home care, supported living and extra care housing but these appeared to receive less governmental attention than the NHS. We certainly heard some reports of PPE ordered by care providers being requisitioned and diverted to NHS bodies instead.

82. Hands on personal care unavoidably exposes vulnerable older people to the risk of infection. The consequence of this lack of PPE was to put many older people's lives at risk, along with those of frontline workers across health, social care and voluntary sector services who were caring for them. 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. Voluntary sector services and partnerships are an essential building-block for the holistic support of older people (and of other groups too) and warrant parity of access to IPC measures.

Infection prevention and control measures ('IPC') and lack of testing

83. Many care workers and care recipients did not have access to testing in the early stages of the pandemic, itself a significant limitation on effective IPC. In our May response to the Joint Committee on Human Rights Exhibit CA4/38 [INQ000176646] we noted that the collection of data on care home deaths had by that time improved, although problems with testing remained and would still be leading to Covid-19 being under-reported on death certificates. Age UK intelligence from mid-May 2020, in the period in which Care Homes required a negative test for admission, highlighted testing was difficult if not impossible to book, particularly for those people unable to leave home. We were aware that, by late-May 2020, Care Homes were being pressured to take people as NHS Trusts had nowhere else to house them, leading to large concentrations of Covid-positive residents, placing staff at increased risk too.

Matters specific to Age UK

84. I issued a statement on behalf of Age UK on 10 March 2020 which stated 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."* The concerns that led to publication of this statement were based on a growing sense of unease rooted in our understanding of the tendency for social care to be treated as a second-class citizen compared to the NHS. Even before the pandemic hit, worries about financial and workforce capacity were writ large. Given how unwell most care home residents already were, and the fact residents were in communal living quarters, it was self-evidently important to make sure everything reasonable was done quickly to help care homes keep the virus out and, if and when it got in, fight it effectively so it infected as few older people and staff as possible.

85. It's also true that when it comes to the kind of emergency planning that's needed, the structure of the social care system is an impediment rather than a help. That's because the vast majority of providers are small independent operators, and with the market so fragmented, this makes communication difficult. A lot depends on the effectiveness of local resilience forums convened by local authorities that have lost people and strategic capacity due to budget cuts. Because the sector is so fragmented, delivering any kind of national response to an emergency like a pandemic was always going to be challenging, and in early March we were not seeing the kind of strategic response at national level equal to the threat posed by the virus.

86. Unfortunately, it took significant time for any of those issues to be recognised and worked out, and a month later that sense of unease had turned to real alarm. On 10 April 2020 Age UK issued a further statement in which I said; *"In short, it's a mess and one that means care home residents, their families and staff are being badly let down. It would not be an exaggeration to say that some are paying with their lives".* The concerns which led to publication of this statement related to the very apparent struggles care homes were having, described in detail in the paragraphs above. These included, but were not limited to, lack of access to PPE, non conveyance to urgent and emergency care, lack of access to routine healthcare and the blanket use of DNACPR notices. We felt there was a marked degree of hesitation over the

willingness of Government to accept responsibility for this sector which, despite being largely operated by the private and third sector, provides an essential public service akin to the NHS.

Involvement of Age UK with the Department of Health and Social Care's Moral and Ethical Advisory Group (MEAG)

87. We did not attend any formal meetings of MEAG and were not members of it. We were approached informally for our view of the evolving national guidance criteria for decision making. We had a number of robust email exchanges and telephone conversations with an advisor to MEAG, to whom we expressed our very strong concerns. These mostly took place over a weekend, and altogether between 25th and 29th March 2020 Exhibits CA4/47 [INQ000508521], CA4/48 [INQ000508522], CA4/49 [INQ000508523], CA4/50 [INQ000508524] and CA4/51[INQ000508525]. 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 largely of their age. Thankfully, the Guidance and resource allocation tool associated with it were not formally endorsed or published by the Department, but we subsequently became aware that it was used in some acute settings. Age UK made clear to the adviser our outrage about age ever being used as a good proxy for health status and prospects of survival, and our determination to stop it at all costs. 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 known to the public.

Involvement of Age NI with the Department of Communities (Northern Ireland) Emergencies Leadership Group Communications and Engagement Subgroup

88. Age NI attended the Communications and Engagement Subgroup, which was facilitated by NICVA (NI Council for Voluntary Action). Paschal McKeown, Charity Director, attended the meetings on behalf of Age NI. Age NI do not have a record of the dates or frequency of meetings with the Department of Communities (Northern Ireland) Emergencies Leadership Group Communications and Engagement Subgroup. A list of the subgroups established is

recorded here: https://www.nicva.org/article/representing-your-covid-19-concerns-to-government.

89. The Department for Communities was primarily concerned with support to vulnerable people in communities e.g. on distribution of food, advice, access to pharmacy prescriptions, etc. The Communications and Engagement Subgroup enabled updates to be provided to the voluntary and community sector on actions being taken by the Department and community and voluntary organisations who were leading on different strands of work. Concerns were raised by Age NI regarding the impact of isolation, loneliness and deconditioning being experienced by older people. Age NI received funding through the Warm, Well-Connected programme to deliver a Good Vibrations programme, which aimed to improve the wellbeing of older people and reduce isolation and loneliness. As to whether Age NI considers that those concerns were appropriately addressed or resolved, this is difficult to establish as Age NI was not a member of decision-making bodies set up by the NI Executive.

90. The Department of Health was responsible for responding to the needs of people who received care. Meetings with the Department of Health would have been on an ad hoc basis. The Department of Health funding was allocated to Age NI's helpline to strengthen our response to the practical and emotional needs of older people due to isolation and loneliness.

Involvement of Age Scotland with the Scottish Government concerning the provision of helpline services for older people in Scotland

91. Age Scotland worked with the Scottish Government to scale up existing provision of helpline services for older people in Scotland. In early March 2020, before the first national lockdown, officials from the Scottish Government, got in touch with Age Scotland's former Chief Executive to explore how the charity might be able to help older people with information and advice about Covid-19 if the spread of the virus became more serious. This included how Age Scotland's national helpline might be able to scale up capacity to handle an increased number of calls, and how many calls Age Scotland felt that it was possible to manage daily. The, then, First Minister, Nicola Sturgeon visited Age Scotland's HQ on 18 March 2020 to announce funding of £80,000 to assist with turning the Age Scotland helpline into a virtual call centre. This meant that staff could work from home, have the necessary equipment to do so, implement a VOIP phone service and database, and scale up capacity. She described the

helpline service as "invaluable" and while speaking with staff said that she believed that for many it would be like a "fourth emergency service".

92. Hundreds of thousands of older people in Scotland weren't online, living alone, and with few places to turn for support. There needed to be a non-digital means for older people to find out more information, ask questions and seek advice. In response, and with the assistance of government grant funding, Age Scotland redesigned and scaled up helpline operations. From receiving on average eighty calls per day, the helpline was able to deal with up to 1,500 calls per day and Age Scotland received around about 800 calls per day at the height of the first wave of the pandemic. In addition to help with interpreting Government guidance and practical support, the helpline also afforded callers a friendly and compassionate ear. Some of the older people who got in touch with Age Scotland had not spoken to anybody in weeks. To support and sustain the scaled-up helpline service, the Scottish Government provided extra funding to Age Scotland in the 2020/21 financial year. Age Scotland continue to deliver the helpline service with financial support from the Scottish Government.

Issues which may have impacted upon the utility of the helpline

93. For many older people the main route for information, particularly at the start of the pandemic, was through the broadcast briefings undertaken by the Scottish Government and UK Government. Calls to Age Scotland's helpline would spike in the moments after the televised briefings concluded. However, the absence of simple, timely communications from the Scottish Government meant that Age Scotland only had a very short time to prepare documents or briefings for colleagues who were on our helpline. It frequently took hours for the Scottish Government website to provide the detail of these broadcast briefings, Age Scotland teams often waiting until 3-4pm for the words contained in the lunchtime briefing to be available. They then had to read, understand, and get a summary of what was said to be prepared enough to effectively answer the huge number of calls from older people. Broadly speaking, at the start of the pandemic the public health messaging, and asks of the public, was simple, because it was the same from the Scottish Government and the UK Government. However, as guidance began to vary, new initiatives or policies were launched, or new slogans were introduced (for example, "Hands, Face, Space") we would receive calls immediately afterwards from large numbers of people seeking clarification of what that meant or whose

directive they should follow - UK Government or Scottish Government. It was occasionally quite confusing.

Perspectives of Age Cymru

94. In Wales, Welsh Government proactively sought the views and experiences of older people living in care homes via the Tell Me More care home resident engagement project Exhibit CA4/52 [INQ000509356]. Through this project Age Cymru were funded to gather insights into the lived experience of care home residents during the Covid-19 pandemic. The project produced a report detailing the key themes that featured in the conversations with older people living in care homes during 2021, one of the most challenging times that care homes have experienced. The report reflected the range of perspectives voiced by residents on care home life, through the restrictions that were in place because of regulation, guidance, or care home policy. The project recorded residents' voices via Zoom video and recoded resident's faces in the form of 2D and 3D portraits to produce a short film. This supported the sharing of the important views of older care home residents, stories, and insights with a wider audience.

95. In addition, Age Cymru were aware of and were involved in initiatives to support care home managers at this significantly difficult time. Throughout the pandemic, Age Cymru partnered with Care Home Cymru, (part of Improvement Cymru the improvement service for NHS Wales), Social Care Wales and Digital Communities Wales to develop a platform, Care Home Cwtch, that offered regular peer to peer support sessions for care home managers. This was a call once a week which invited care home managers in Wales to join a discussion and offer peer support.

96. Welsh Government also funded research in the form of three annual surveys carried out by Age Cymru into the experiences of people aged 50 or over in Wales of the Covid pandemic. The feedback was honest, stark and laid out a picture of the impact the first Covid-19 national lockdown and subsequent lockdowns and continuing impact of the pandemic. There was some reflection on the positive experiences of lockdown with people enjoying the help from family and friends or from the local community, or having more time and less pressure. However, the picture for most people was that of difficulty, and concern for the future, whether this was trying to access healthcare, employment, issues with physical health and mental wellbeing, worries about engaging with the community again, being impacted by scams, or

not seeing family and friends. This research included a specific focus on access to social care, and the experiences of unpaid carers. The information gathered was fed back directly into Welsh Government response and policy.

97. Throughout the pandemic Age Cymru were in regular communication with Welsh Government, both through the formal membership of groups and communities such as Welsh Government Covid-19 Social Care Planning and Response Sub-group, as well as in regular informal on-going communication about the needs of older people during the pandemic.

Age UK publications, surveys and public statements

98. A chronological list and short summary of surveys conducted and reports prepared by Age UK that focused on the impact of the Covid-19 pandemic on recipients of care has been prepared and can be found at Exhibit CA4/04 [INQ000502184]. This list includes the report 'Impact of Covid-19 on Older People's Mental and Physical Health' (October 2020) and 'Impact of Covid-19 on Older People's Mental and Physical Health: One Year On' (July 2021) which detail the challenges set out in the preceding paragraphs. This document also sets out a chronological list of all statements issued by Age UK on emerging concerns and issues, including statements related to the rights of older people who were recipients of care.

Age UK's summaries of relevant government guidance

99. At the outset and throughout the pandemic Age UK understood the need to provide rapid advice to those living with health conditions and disabilities (including physical frailty) who rely on social care. Age UK published extensive guidance for older people, as well as providing guidance to our advice line colleagues who were receiving calls from older people, seeking to help them make sense of complex and often unclear rules which varied according to local alert level, and that also quite frequently changed. We undertook a huge amount of work to clarify and communicate every piece of government guidance, including changes to that guidance, to older people and their families and carers. Where Age UK identified gaps in the guidance we would try to fill those where we could, including through engagement with relevant government departments and officials to raise issues that were unclear or needed further explanation.

100. We received a large volume of questions and requests for help from those people impacted. As previously stated, our helpline received 270,000 calls between March 2020 and March 2021 a huge increase in the volume of calls to the advice line – reaching an 88% increase at the height of concerns. These ranged from a need for more detailed information and guidance in how to apply the advice to their specific circumstances – for example from those who relied on formal and informal forms of care and support – to others who were in urgent need of practical help and were finding themselves unable to access support (e.g. access to food and medication). Confusion over the 'Support for Shielding guidance' was a particular example of note, with communications often arriving after the fact. 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 (31 May 2020) changes to national shielding guidance were announced over a weekend for implementation the following Monday, via a tweet from the former Health Minister, linking to a paywalled Telegraph article Exhibit CA4/53 [INQ000509357]. 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). We were told that these delays were usually due to the need for senior decision-makers in Government to sign off changes.

101. Later, the re-classification of the language to describe shielded groups ('clinically vulnerable' or 'clinically extremely vulnerable'(CEV) individuals) added to the confusion. Many older people did not understand the distinction between the two categories, and, given all those aged over 70 were considered 'clinically vulnerable' both classifications caused people to adopt a 'shielding-lite' strategy, whether they had been advised to or not. Responsibility for communicating risk and mitigations was unclear. We drew these concerns to the Government's attention, but no action resulted. We saw little evidence that the Guidance was informed by the lived experience of those who were shielding, or the organisations supporting them.

102. Communications from Government were also confusing for those caring for older people, particularly if they did not live with the person they were caring for. Many carers were anxious about how to care for their loved ones while keeping them and themselves safe and how to cope with the extra responsibilities and isolation. 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. In the early phases of the pandemic Age UK received a large number of queries from older people and families seeking clarification. This reflected the hugely important role that informal or low-level support plays in enabling older people with care and support needs to manage safely at home, yet government communications routinely failed to either address or provide clear guidance on what was within the rules. Fearful of infection or of breaking the law, many older people put their health and welfare at risk by foregoing help and support they urgently needed.

103. 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 or little notice, 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. The emotional and practical pressure on carers as a consequence was immense.

104. Age UK provided extensive advice to government bodies over this period on how best to communicate with older people and made 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. To the best of our knowledge, Government did not proactively seek expert advice on messaging and communications to older people from any source. We would 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 sentiment) could have significantly strengthened public communication efforts.

Other concerns or issues raised by Age UK included;

The impact on staff wellbeing and morale

105. Staff working in care 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 of which

they had no previous 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 residential population. There was, and remains, huge frustration about the continued lack of recognition of the skills of care workers, 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 and continue to play an important part).

The impact on unpaid carers

106. Similar challenges to those described above faced unpaid carers who reported, and continue to report, high levels of burn-out and exhaustion. In 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 social care support carers indirectly and indirectly relied on suddenly disappeared. Carers were trying to manage deteriorating health and escalating needs of the person they cared for with limited, if any, access to health and care services. Furthermore, many 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.

Malnutrition in older people

107. 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 Taskforce, are aware of a rise in malnutrition. 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. Food parcels sent to shielding people were in many cases seriously substandard (for example, we heard of people receiving parcels

containing mouldy bread, orange squash in huge cartons too heavy for frail older people to lift), and that took no account of dietary or cultural requirements.

Lack of data

108. We noted a resistance on the part of Government to engage with data or insight generated outside of academic bodies or official collections. 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 including large gaps in social care data. As I note earlier in this statement, 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, something even DHSC lacked. Similarly, there was no register for sheltered and extra care housing, and in the absence of any register of providers of this type of accommodation, local authorities were less able to plan for vulnerable citizens. There is also no register of care workers, making it impossible for government to communicate with them directly. The UK and devolved governments were aware of data deficiencies before the pandemic. In January 2020, the Office for Statistical Regulation (OSR) published a report on the state of adult social care statistics in England Exhibit CA4/55 [INQ000502199].

Lack of knowledge and understanding about ageing and the lives of older people

109. At the outset of the pandemic Government and other public bodies lacked any kind of granular understanding of the lives and experiences of older people. Within government and key advisory bodies, the older population were treated as a homogenous and biomedically-framed group, overlooking differences within and between age groups with measures formulated solely on the basis of chronological age. It is the view of Age UK that if more people with a deeper understanding of the care sector and the needs of older people had been advising government, there would have been greater recognition of the challenges that the sector – predictably – faced and the need to plan mitigation strategies accordingly. Ideally, these relationships would have been developed and tested in 'peacetime' so that systems were already established and functional when emergency struck. Much greater weight was given to information or expert input derived from a relatively small number of channels, often

from the research and science communities – but notably, not from those with expertise in the lives of older people – while little if any weight or consideration was given to other sources.

110. In general, Government did not seem to value insight from the voluntary and community sector, older people themselves and other wider sources of knowledge that could have provided much needed understanding of the real-world application of policy measures. It meant advice was drawn from a 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 challenges. For example, Age UK remains concerned that symptom presentation of Covid and Long-Covid in older people can be different and that this has been poorly understood and articulated. Differential presentation of Covid-19 symptoms, including probable delirium, were recognised by geriatricians, care professionals and others who had been working with older people long before the possibility was more broadly considered in guidance. The use of local knowledge, practices and context, as appropriate, should complement scientific knowledge wherever possible.

Lack of understanding of the voluntary and community sector

111. From Age UK's own experience, there was a lack of recognition of the scale and scope of its offer and reach to both older people and systems leaders as a trusted source of information. For the many older people advised to shield in their own homes for extended periods of time during the pandemic, the specialist advice Age UK offers around personal safety, protection from domestic abuse, digital connectivity, keeping safe from scams and staying safe at home (including falls avoidance), preventing deconditioning, preventing malnutrition and managing health and wellbeing– all safeguarding issues that became urgent during the pandemic – were highly relevant to older audiences. Small community groups also have a vital role in doing the kind of detailed, targeted social support work that emergency services cannot and as such the breadth and depth of the voluntary sector should be recognised as an integral part of the social care system.

Policies based on chronological age

112. As we entered October 2020, Age UK argued against the use of age-based definitions of 'vulnerability' for older people and policies enacted on this basis (the blanket application of DNACPRs based on chronological age being one of the most egregious examples of this). 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. 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 pandemic receded.

Aspects of the response to the pandemic that Age UK considers went well or was a success in how the adult social care sector responded during the relevant period

113. Day in, day out, the staff working in health and care services made, and continue to make, a huge difference to people's lives. Since the start of the pandemic, the health and care workforce has 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 and raise the profile of the largely invisible social care workforce. A comprehensive funding package for the social care system must deliver a new deal for unpaid carers, which provides the services and support needed to help deliver care, while recognising the personal and financial implications of unpaid carers.

114. 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 stay well. These services were greatly impacted by many of the same challenges as those that hit statutory services. In rebuilding from the pandemic there is an opportunity to be much more strategic in connecting national and local voluntary sector offers in partnership with health and care teams across the UK. Where it worked well, the voluntary sector support was invaluable. However, more could have been done, and we should seize the opportunity to move from pockets of excellence towards meaningful VCSE partnerships becoming fully embedded across the health and care system. Unfortunately, we are seeing a lost opportunity to build

those relationships through Integrated Care Systems as local health and local authority leaders are diverted back into entrenched silos to manage the ongoing demands of the 'winter' crisis that increasingly straddles all four seasons.

In conclusion

115. The coronavirus pandemic has laid bare the deep and systemic inadequacies of the current social care system and revealed the true extent of the impact underfunding, workforce shortages and market instability have had on the system's ability to respond and protect older people at a time of crisis. In 2018 Age UK published a report called The Failing Safety Net Exhibit CA4/56 [INQ000217400]. The 'failing safety net' of the title referred to a series of missed opportunities whereby NHS and social care services were not there to catch someone when they needed it. The outcome was usually an admission to hospital, the final resort for many people who had simply deteriorated too far or who were put at frequent risk of a crisis. The pandemic may have created some new challenges but the nature of what older people describe was often there all along: that is, a health and care system that is clunky and under-resourced, especially but not exclusively within its social care and community health service components. Care that can support and sustain older people to stay well at home can be the foundation of an effective and sustainable health and care system. At the moment, these foundations are often broken or simply not there at all.

116. The pandemic has shown us that we have a fragile and highly fragmented, underfunded system reliant on unpaid carers and piecemeal local arrangements. There is now widespread consensus among older and disabled people, families, policy makers and practitioners that there is urgent need for reform to deliver a sustainable system capable of providing the care people need, when they need it. 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. The enduring crisis across health and social care services threatens consequences of a

similar order of magnitude for older people. The tragedy is that many of the consequences of the pandemic for older people were largely avoidable.

117. These challenges continue to unfold in the context of an ageing population – the number of people over 75 years of age is projected to double in the next 30 years – and a sicker one too, with earlier onset of multimorbidity also on the rise. We need to shift focus upstream to invest in prevention strategies that are cost effective, protect health and reduce health inequalities. We must also manage the legacy of the Covid-19 pandemic itself. 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. This includes proactive research to optimise prevention, treatment and rehabilitation strategies alongside social strategies to help people to cope with a legacy of social isolation, increased frailty, traumatic bereavement and mental ill-health. If any good is to come from the pandemic, let it be decisive action to prevent a recurrence of these mistakes. 'Never again' must be our watchword and at Age UK we will do everything we can to ensure the official Covid-19 Inquiry delivers the justice our older population deserves. We will also consider very carefully what all this means for our own work and priorities as a charity dedicated to serving older people, especially at the times when they most need us.

Recommendations that Age UK would seek in order to improve conditions for care recipients and providers in the event of a future pandemic

118. **Make clear the State's responsibility for social care as an essential public service** on which hundreds of thousands of people depend for current and future government. The principle of considering health and care services as an interdependent whole should be embedded into policy and decision-making. Stabilise the social care sector and act quickly to consult on putting funding on a sustainable footing to enable local authorities and others to plan and deliver safe and effective services. In the long term, Age UK wants to see a solution based on all of us paying into a national funding pot for social care, so that we all collectively share the risk of developing care needs and know support will be there for us if and when we need it. This would go a long way towards helping older people to live dignified and fulfilled later lives.

119. **Establish and new and higher standard of social care** that offers long-term investment in comprehensive social care reform, a comprehensive community offer for older people and strategies for ageing well. The case for a comprehensive social care workforce strategy, investment in fit-for-purpose premises and systems, support for unpaid carers, and measures to resolve market instability is well made and must be urgently addressed. Establish accessible alternative housing options for older people (such as extra care and retirement living), and access to aids and adaptions in order to enable people to live longer in the place they call home. System leaders should maintain an up to date understanding of older populations and invest in specialist expertise, and advice and engagement with experts on older people, including meaningful engagement with the voluntary and community sector.

120. **Age should not be used as a proxy for the health status or vulnerability of any individual.** No blanket policies based on age should be applied to individual decision making about treatment, care or access to services. At the same time, policy makers should adopt precautionary principles rather than relying on definitive scientific proof before implementing changes (mask wearing, asymptomatic transmission). Evidential thresholds are high in the scientific community, but that shouldn't be a barrier to making good policy decisions when the risks of implementing changes (like mask wearing) are low.

121. **Implement a rights-based framework for older people;** rights and dignity must be at the core of adult social care reform. If older people's human rights had been more expansive, better defined and properly communicated and understood, we believe that outcomes might have been different. Ethics advice should be incorporated into operational decision-making frameworks that are widely used and understood in and outside of times of crisis. Redress mechanisms should also be put in place for those receiving social care, including for people who pay and arrange their own care (who cannot currently make a claim under the Human Rights Act). The UK Government should champion the development of a UN Human Rights Convention for Older Persons to reflect a shared ethical consensus and benefit older people everywhere, including here.

122. **Address urgent data deficiencies related to older people** including development of a national register of all care workers and social care providers of sheltered and extra care housing. Address timeliness and accuracy of reporting, including, but not limited to, adult social care statistics and improve national data collection and analytical methods (statistics

on 'age +' other individual characteristics) so policy makers can better understand and act on equity issues facing older people. This would enable better understanding of diverse experiences across the older population, particularly those of minoritised groups, as is currently possible with official poverty statistics. Too often data on older people is presented in the category 'over 65/65+' with no further breakdowns beyond that age cut-off.

123. **Address endemic ageism and health inequalities**. Tackle the combined discrimination older people face because they have other personal and protected characteristics, such as being LGBTQ+, by implementing the provision in law (section 14 of The Equality Act) which is yet to be enacted. Enforce existing age discrimination law and provide guidance to ensure employers treat older workers fairly. Legislate to enhance the rights of older people who rely on others for care and implement an effective scheme for protecting those who lack mental capacity.

124. **Address ageism, representation and expertise in government structures.** We must ensure that the needs and rights of older people are properly represented in government structures so that at times of crisis, when policymakers are unable or unwilling to look beyond government for advice, there are informed voices within government who understand the needs of older people. Government should undertake a review of the membership and role of the Moral and Ethical Advisory Committee and create a Commissioner for Older People in England to contribute to a network of such Commissioners across the UK, alongside a Minister for Older People in Westminster.

125. **Drive forward a national recovery strategy for ageing well** and support the care sector to recover from the effects of the pandemic. Make sure older people are able to stay active and engaged in their communities and invest in strategies to protect health and wellbeing. Promote the role of the VCSE in delivering local services. This includes ensuring the long-term funding is there so organisations like councils and the NHS can work with charities and volunteers in a sustainable way. The impact of Covid-19 on older people must continue to be monitored now and in the coming months and years. This should include ongoing data collection and analysis of how Covid-19 and Long Covid affects the financial wellbeing, physical and mental health of older people.

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: 17 October 2024

Module 6 of the UK Covid-19 Public Inquiry ("the Inquiry")

Request for Evidence under Rule 9 of the Inquiry Rules 2006

Reference for Request - M6/AUK/01

Exhibits Schedule

Exhibit Reference	Paragraph number	Description	Inquiry reference
CA4/01	12	Briefing from Age UK titled Health and Care of Older People in England 2019, dated July 2019 [Publicly Available].	INQ000502183
CA4/02	12	Briefing from Age UK titled Policy Position Paper - Care Homes (England), dated May 2019. [Publicly Available]	INQ000509352
CA4/03	12	Report from Age UK titled Behind the Headlines: the battle to get care at home , dated May 2018. [Publicly Available]	INQ000509353
CA4/04	16	A chronological list and short summary of external engagement, surveys conducted, consultation responses, media statements and reports prepared and feedback obtained by Age UK between March 2020 and June 2022.	INQ000509809
CA4/05	See CA4/04	Letter from Rachael Maskell (Chair of the All-Party Parliamentary Group on Ageing and Older People) to the Secretary of State, regarding Older People's Access to Health and Social Care during the Covid-19 Pandemic, undated. [File name indicates date of 16/04/2020].	INQ000508508
CA4/06	See CA4/04	Minutes from the APPG Ageing and Older People Meeting, Chaired by Rachael Maskell MP, regarding Impact the Covid-19 Pandemic has had directly and indirectly on older people, dated 08/07/2020.	INQ000508509

CA4/07	See CA4/04	Letter from All Party Parliamentary Group for Aging and Older People (APPG) to the Rt Hon Matt Hancock (Minister for Health, DHSC), regarding concerns about the health and well-being of older people as Covid-19 lock-down restrictions lift across the country, dated 15/07/2020.	INQ000508510
CA4/08	See CA4/04	Email from Rhianon Steeds (Campaigns and Public Affairs Support Officer, Age UK) to Baroness Bryan of Patrick, regarding Age UK Briefing - Support for over 60's who have to work during the COVID-19 pandemic, dated 09/10/2020.	INQ000508526
CA4/09	See CA4/04	Letter from Rhianon Steeds (Campaigns and Public Affairs Support Officer, Age UK) to MP's, regarding Care home visits, undated.	INQ000508527
CA4/10	See CA4/04	Email from Rhianon Steeds (Campaigns and Public Affairs Support Officer, Age UK) to Richard Drax MP, regarding Westminster Hall debate - Effectiveness of the Government response to Covid-19 in Care, dated 10/11/2020.	INQ000508528
CA4/11	See CA4/04	Email from Rhianon Steeds (Campaigns and Public Affairs Support Officer, Age UK) to Joy Morrissey MP, regarding Westminster Hall debate - Family visit access in health and social care settings, dated 09/11/2020.	INQ000508529
CA4/12	See CA4/04	Letter from Rhianon Steeds (Campaigns and Public Affairs Support Officer, Age UK) to Mr Shannon, regarding Westminster Hall debate - The effect of the covid-19 outbreak on people affected by dementia, dated 10/11/2020.	INQ000508530
CA4/13	See CA4/04	Letter from Rhianon Steeds (Campaigns and Public Affairs Support Officer, Age UK) to Jim Shannon, Fiona Bruce and David Linden, regarding Westminster Hall debate - The effect of the Covid-19 pandemic on Freedom of Religion or Belief, dated 23/11/2020.	INQ000508531

CA4/14	See CA4/04	Letter from Rhianon Steeds (Campaigns and Public Affairs Support Officer, Age UK) to Joy Morrissey MP, regarding Westminster Hall debate - Family visit access in health and social care settings, dated 09/11/2020.	INQ000508532
CA4/15	See CA4/04	Briefing from Age UK for UK Parliament titled Post budget briefing social care, dated 08/03/2021.	INQ000508507
CA4/16	See CA4/04	Briefing from Age UK titled Care Workers, dated November 2020.	INQ000508533
CA4/17	See CA4/04	Briefing from Age UK titled Social Care Reform, dated June 2020.	INQ000508534
CA4/18	See CA4/04	Joint Letter from disabled, older people's, unpaid carers', health and food charities to Rt Hon George Eustice MP (Secretary of State, DEFRA), regarding food access and inventions for vulnerable people during the COVID-19 crisis, dated 08/07/2020.	INQ000508535
CA4/19	See CA4/04	Letter from Vicky Foxcroft MP (Shadow Minister for Disabled People) to Rishi Sunak (Chancellor of the Exchequer), regarding Lack of support available to allow high-risk people safely return to work for 1 August when shielding programme ends, dated 10/07/2020.	INQ000508536
CA4/20	See CA4/04	Briefing from Age UK titled Joint statement on the rights of older people in the UK to treatment during this pandemic, dated 30/03/2020.	INQ000508511
CA4/21	See CA4/04	Briefing from Age UK titled Age UK response to DNR forms during Covid-19 crisis, dated 07/04/2020.	INQ000508512
CA4/22	See CA4/04	Briefing from Independent Age titled Joint Statement: Focus on protecting older people's rights, dated 20/11/2020.	INQ000508513
CA4/23	See CA4/04	Document from Age UK titled Consultation Response: Delivering Core NHS and Care services during the Pandemic and Beyond , dated 08/05/2020.	INQ000508514
CA4/24	See CA4/04	Report from Age Uk titled Additional Age UK Evidence to the Treasury Select Committee: Inquiry into economic impact of coronavirus (COVID-19), dated 24/06/2020.	INQ000508515

CA4/25	See CA4/04	Document from Age UK titled Consultation Response - Social Care: Funding and workforce, dated 05/06/2020.	INQ000508516
CA4/26	See CA4/04	Document titled Treasury Select Committee Inquiry Response on Fraud, undated.	INQ000508517
CA4/27	See CA4/04	Report from Age UK titled Joint Committee on Human Rights - Covid-19: human rights implications for older people, dated May 2020.	INQ000508518
CA4/28	See CA4/04	Report from Age UK titled Women and Equalities Committee - COVID-19 and older BAME people, dated 10/07/2020.	INQ000508519
CA4/29	See CA4/04	Document from Age UK titled Covid status certification review: Call for Evidence, dated 29/03/2021.	INQ000508520
CA4/30	See CA4/04	Report by Age UK, titled The Impact of Covid-19 to date on older people's mental and physical health, dated 09/10/2020. [Publicly Available].	INQ000176650
CA4/31	See CA4/04	Report by Age UK, titled Impact of Covid-19 on older people's mental and physical health: one year on, dated 11/02/2021. [Publicly Available]	INQ000176634
CA4/32	20	Paper from Age UK titled Social Care Assessment and Eligibility (England), dated 01/05/2019 [Publicly Available].	INQ000502185
CA4/33	23	Paper from Age UK titled Social Care Reform and Funding (England), dated May 2019 [Publicly Available].	INQ000502187
CA4/34	24	Paper from Incisive Health titled Care deserts: the impact of a dysfunctional market in adult social care provision, dated 16/05/2019 [Publicly Available].	INQ000502188
CA4/35	25	Report from Association of Directors of Adult Social Services, titled ADASS Budget Survey 2018, undated [Publicly Available]	INQ000080753
CA4/36	32	Evidence Submission from Age UK titled Age UK evidence to the Health Committee and Communities and Local Government Committee joint Inquiry on long term funding of adult social care, dated March 2018 [Publicly Available].	INQ000502190

CA4/37	29	Exhibit KB/25: Skills for Care report on the state of the adult social care sector and workforce dated September 2019 [Publicly Available]	INQ000103564
CA4/38	35	Briefing by Age UK, titled Joint Committee on Human Rights COVID-19 - human rights implications for older people, dated 08/05/2020 [Publicly Available].	INQ000176646
CA4/39	38	Report from DHSC and NHS titled Novel coronavirus (COVID-19) standard operating procedure Running a medicines re-use scheme in a care home or hospice setting, dated 23/04/2020.	INQ000509354
CA4/40	49	Report from Nuffield Trust titled Deaths at home during the Covid-19 pandemic and implications for patients and services, dated 05/04/2023 [Publicly Available].	INQ000502192
CA4/41	52	Report from Age UK titled More Harm than Good: Why more isn't always better with older people's medicines, dated 19/08/2019 [Publicly Available].	INQ000502193
CA4/42	56	Report from Department of Health and Social Care titled Good for you, good for us, good for everybody: A plan to reduce over prescribing to make patient care better and safer, support the NHS, and reduce carbon emissions, dated 22/09/2021. [Publicly Available]	INQ000217383
CA4/43	58	Report from Age UK, titled Ethnic disparities and inequality in the UK: call for evidence, dated 30/11/2020. [Publicly Available]	INQ000217401
CA4/44	62	Report from Age UK titled Parliamentary Briefing Social Care Reform, dated June 2020 [Publicly available]	INQ000101412
CA4/45	62	Report from Age UK, titled Consultation Response Department for Health and Social Care Coronavirus: Lessons Learnt, dated 24/11/2020.	INQ000104086
CA4/46	66	Article from Health and Social Care, and Science and Technology Committees titled Coronavirus: lessons learned to date, dated 12/10/2021.	INQ000509355

CA4/47	88	Emails between Charlotte Augst (Chief Executive, National Voices), Professor Helen Strokes-Lampard (University of Birmingham), and Junior DHSC Official, regarding National Voices members feedback, dated between 25/03/2020 and 27/03/2020.	INQ000508521
CA4/48	87	Emails between Caroline Abrahams (AGE UK), and Professor Helen Strokes-Lampard (University of Birmingham), regarding March Update on Decision Support tool, dated 28/03/2020.	INQ000508522
CA4/49	87	Emails between Caroline Abrahams (AGE UK), and Professor Helen Strokes-Lampard (University of Birmingham), regarding Decision Support Aid, dated 28/03/2020.	INQ000508523
CA4/50	87	Emails between Caroline Abrahams (AGE UK), and Professor Helen Strokes-Lampard (University of Birmingham), regarding Decision Support Tool, dated between 28/03/2020 and 29/03/2020.	INQ000508524
CA4/51	87	Emails between Caroline Abrahams (AGE UK), Steph Harland (AGE UK), Helena Her-Klots (Older People's Wales), and Donald Macaskill (Scottish Care), regarding Update on Decision Support Tool in England, dated between 28/03/2020 and 29/03/2020.	INQ000508525
CA4/52	94	Report from Age Cymru titled Tell me more, dated December 2021.[Publicly Available]	INQ000509356
CA4/53	100	Tweet from Matt Hancock (Minister fro Health, DHSC), regarding Easing of Shielding protection, reduction in inflection rates, dated 31/05/2020.	INQ000509357
CA4/54	68	Report from Age UK titled Visiting in care homes: where now, undated.	INQ000509358
CA4/55	108	Report from Office for Statistics Regulation titled Adult Social Care Statistics in England, dated January 2020 [Publicly Available].	INQ000502199
CA4/56	115	Report from Age UK titled The Failing Safety Net, dated September 2018. [Publicly Available]	INQ000217400