# M1/AGEUK/01: Module 1 of the UK Covid-19 Public Inquiry ("the Inquiry") Response to request for Evidence under Rule 9 of the Inquiry Rules 2006

## Statement of truth: Paul Farmer, Chief Executive, Age UK

## About Age UK

- '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. This statement is prefaced with the acknowledgement that the events under investigation by the Inquiry predate my tenure as CEO of Age UK. I have therefore consulted widely across the Age UK network to inform this response. I can confirm this statement is based on what I have been told and is true to the best of my knowledge and understanding.
- 2. The Age UK network as a whole comprises 130 independently registered charities that operate under a brand agreement which provides a framework for cooperation and collective endeavour. This includes 'Age UK' and 120 local Age UKs working across England and our partners in each of the nations including Age Cymru and 5 local Age Cymru partners, Age NI, Age Scotland and Age Scotland Orkney. In addition Age International works to support older people in more than 40 countries worldwide.
- 3. Across the UK, the charities reach around one million older people each year, seeking to ensure older people have enough money; are socially connected; receive high quality health and care; are comfortable, safe and secure at home; and feel valued and able to participate in society. Together we: research, advocate and campaign; provide information and advice (online, by phone, face to face and printed materials); deliver public information campaigns, direct services and support; and work to drive improvement and innovation in provision across the private and public sector. Collectively we also provide a wide range of health and social care related and NHS or local authority commissioned services.
- 4. This statement offers the perspectives of 'Age UK' on behalf of the wider group and the overarching themes I draw on here are consistent across the nations. However, it is important to note that local jurisdictions undertook different levels of engagement around emergency preparedness and approaches to that engagement. I have included examples below where I feel it is important to make a distinction or highlight differences

in approach and have done so in good faith and to the best of my ability within the permitted response timeframe.

### Older people are a high-risk group

Age UK does not believe that older people and their needs were adequately considered or understood when decisions about emergency planning, preparedness and resilience were taken by the UK Government. In any type of scenario planning for a national emergency, and particularly when planning and preparing for a health emergency, it is inevitable that older people will be at greater than average risk and have unique needs and vulnerabilities. The older population carries a greater overall risk from infectious disease due to a range of physical and social factors including a higher burden of morbidity, complex multimorbidity and age-related reduction in immune system response. This is well-established and reflected in UK vaccination policy for infectious diseases such as flu. For example, analysis of influenza related hospital admissions and deaths in England estimated that people aged over 65 were three times as likely to be hospitalised and 15 times as likely to die following admission compared to those aged 45-64. Amongst those with clinical risk factors, older people were nearly five times as likely to be admitted compared to adults aged 45-64 and nearly three times as likely to die.<sup>i</sup> Furthermore the burden of risk falls hardest on the least advantaged older people, with those living in the most disadvantaged circumstances experiencing multimorbidity 10 to 15 years earlier that those in the most affluent areas.<sup>ii</sup>

- 5. Older people at greatest health associated risk are also amongst the most likely to live in communal settings such as care homes and to rely on hands on personal care support, either in residential establishments or their own homes. Furthermore, older people are subject to particular social risk factors deriving from the greater likelihood of living with physical, cognitive or sensory disabilities that make it much more challenging to manage in a crisis or when their usual routines and networks are disrupted. For instance 16% of people aged 65-74 have difficulty undertaking at least one essential everyday task (activities of daily living), rising to 23% of those aged 74-84 and 46% of those aged over 85.<sup>III</sup> Therefore, there is no excuse for any government administration to have overlooked the specific and predicable risk a national emergency would pose to older people, particularly in planning for an infectious disease pandemic.
- 6. Sadly, it appears that to the extent pandemic planning and preparation did take place, the UK Government did not give any specific consideration to older people's needs. In

the event of a pandemic, robust planning and preparedness measures will always need to include consideration of the following: 1) immediate response of the health and care system; 2) management of interim non-pharmaceutical interventions; and 3) public communications. Age UK believe that the Government's failure to consider the older population in respect of each of these three key planning principles was responsible for some of the worst policy failures towards older people at the height of the pandemic.

- 7. Government priorities appeared to reflect embedded ageist and ableist attitudes towards older and disabled people. This resulted in a lack of understanding of the needs of older people, a lack of consideration towards unintended or indirect consequences of policy measures on older people, particularly with regards to non-pharmaceutical interventions (NPIs) and inadequate communications strategies. Government planning also failed to account for the need to sustain the underlying resilience of the older population, and the services and support on which many of them rely.
- 8. Examples of how serious failures to anticipate and plan for the needs of older people in a pandemic played out in practice include non-conveyance of older people to hospital, use of blanket restrictions, restricted access to intensive and critical care and palliative medications, inappropriate use of anti-psychotic drugs in some care settings, imposition of Do Not Attempt Cardiopulmonary Resuscitation orders and failures of end-of-life care protocols. These are serious breaches of accepted practice. Planning failures were also reflected in the design and implementation of non-pharmaceutical interventions, including shielding and social distancing measures, that failed to adequately mitigate the predictable consequences for older people's health and wellbeing. Later, the government's Living with Covid strategy failed to recognise the unequal impact of the virus on different groups, including older people, those living with chronic illness or disability and those from minoritised ethnicities. This lack of planning for older people forms at least part of the explanation for excess deaths.
- 9. We fully recognise that the Government had to make complex judgements in highly pressurised circumstances and in respect of a novel disease about which initially, they knew very little. However, it is wrong to describe the events of the pandemic as wholly unforeseen. The National Audit Office examined the preparedness of Government for the pandemic and found that since 2008 the National Risk Register identified an influenza pandemic as the UK's top non-malicious risk<sup>iv</sup>. The UK Government also carried out Exercise Cygnus in 2016, a simulation of an influenza outbreak to test response readiness. To the best of our knowledge, planning failures were evident in the simulation

exercises which neglected to look at social care and care home settings in the necessary detail, and consequently the needs of older people were not effectively considered as part of that exercise.

10. Age UK has extensive domestic and international expertise in emergency and humanitarian support for older people and would have relevant insight to offer Government in preparation for an event of this type. However, we can find no record of Age UK having been consulted at any point on pandemic preparedness or asked to provide evidence on potential impacts on older people. Insofar as planning efforts were made, we believe they were narrowly focused around clinical and academic expertise and did not appear 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.

## National government engagement with Age UK prior to January 2020

- 11. Age UK plays a role in communicating the views and experiences of older people to the UK government and advocating for policies and service provision that improve experiences of later life. Age UK has extensive engagement with the Government and statutory bodies at both national and local level and is regularly called on for input and advice in other instances. Yet despite prior engagement on a range of other subjects, Age UK was not directly engaged in pandemic planning prior to January 2020. To the extent that Age UK did engage with government at national level prior to January 2020 regarding emergency preparedness and resilience planning, our primary points of contact related to national consultation responses, parliamentary and policy briefings and the sharing of research findings as part of routine engagement with government and Parliamentary business.
- 12. Examples of Age UK responses to broader emergency and disaster planning initiatives include the topics of supporting older people in the case of flooding [PF1<sup>v</sup>] and policies for extreme weather events [PF2<sup>vi</sup>], including raising awareness of fuel poverty and the increased risks of stroke and heart attack for older people in colder weather. A number of recommendations within these briefings were applicable in the context of the pandemic. Perhaps the most relevant expertise Age UK held related to the challenge of getting older people vaccinated. Age UK was already running an extensive winter campaign including flu vaccination uptake in the older population, underpinned by a programme of insight and research and toolkits [PF3<sup>vii</sup>]. As soon as the vaccine race began it was

evident that mass vaccination was the government's core objective –yet despite its' specific and unique organisational knowledge, and strong track record of delivery, Age UK was not systematically engaged to support the vaccination effort.

- 13. Age UK has also produced public-facing guidance to support older people at risk in emergencies across a range of topics. Again, the advice identified in these responses is highly relevant to the Covid-19 scenario and coping with NPI's. For example, Age UK's guidance document "Staying safe at home, out and about and when you're online" [PF4<sup>viii</sup>] was published in 2016. It was not written with the Covid-19 pandemic in mind yet outlines recommendations that apply equally well to support older people in this context. For example, this guidance offers tips for older people to overcome challenges shopping and banking online safely, both of which became vital life skills many older people had to rapidly acquire during the pandemic. Age UK has expertise in communication to older people, as do many other health and care charities vis a vis their beneficiaries, and has invested a considerable amount of time and effort to understand how best to communicate with them.
- 14. There was a lack of recognition of the scale and scope of Age UK's offer and reach to both older people and systems leaders as a trusted source of information. Age UK has a long history of articulating the risks and mitigations for issues that impact older people in times of crisis, and communicating with older people and professionals to influence behaviours. Unfortunately, connections do not seem to have been made in national scenario planning to this pre-existing insight, knowledge and experience. 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.
- 15. Even though access to food, banking and essential products and services for people who were shielding or otherwise vulnerable was a predictable issue, the Government's response was initially confused and continued to be desperately slow, again highlighting the lack of planning of preparedness for a national emergency. Age UK and others pressed the Department for Environment, Food and Rural Affairs to join up services and coordinate efforts to ensure support in getting food reached those who needed it most, especially those who were isolated and not online. We spent many hours in meetings

with DEFRA officials but ultimately the outcomes were disappointing. Age UK did work to directly refer people to priority shopping delivery as well operating a range of shopping and food delivery schemes across the country. Age UK also contacted the financial regulators, the banks and the Post Office to seek solutions to the problems accessing cash facing older people that became apparent in getting support to those in need.

16. National Government guidance says: 'Where appropriate, organisations should consider at an early stage in planning whether voluntary organisations may have capabilities which could assist in responding to an emergency." Age UK feels that the sector's potential roles and skills were not engaged early enough, despite Age UK responding to the pandemic with a range of practical and psycho-social support for older people. For example, it did not seem that the Government tested its own communications function with older audiences and neither did it work consistently or effectively with Age UK, who have a longestablished and successful approach to methods of engagement with older people. The information on the Age UK website was widely seen as a trusted source of information from Google with our content often ranking in the top three, if not top, of the search results on key topic including lockdown information, with advice sought from multiple audiences including older people themselves, carers, journalists and other communications professionals. The lack of pre-planned coordination between the Government and the VCSE in both the planning phases and during the height of the pandemic meant that efforts were not as coordinated and strategic as they could have been.

## Local government engagement with Age UK services prior to January 2020

- 17. We believe that the Government should have taken steps to access the expertise held within local services prior to January 2022. Local Age UKs play an essential role to support people in a crisis. Age UKs are located throughout the country including in rural areas and are trusted by older people. The support Age UKs provide is often quite informal, relying on staff and volunteers' willingness to give up their time, 'get stuck in', and use their own resources, such as cars.
- 18. Historically, some Age UKs have worked with local authorities and other agencies to coordinate efforts in an emergency. Age UK Herefordshire & Worcestershire, for example, is involved in the local emergency/disaster group with the council, police, fire service, health services and Environment Agency. In these forums Age UKs – and the wider

<sup>&</sup>lt;sup>1</sup> https://www.gov.uk/guidance/preparation-and-planning-for-emergencies-responsibilities-of-responder-agencies-and-others

voluntary sector – are a valuable partner, able to support older people during and after a crisis, reaching isolated people and providing personal support. For example, during the 2013/14 floods, Age UK Herefordshire & Worcestershire staff took part in volunteer schemes using '4x4' vehicles and bicycles to reach isolated homes to deliver medication and take people to hospital.

19. These types of local networks were activated and proved invaluable during the pandemic. Small community groups have a vital role in doing the kind of detailed, targeted support work that emergency services cannot and as such the voluntary sector should have a key role in emergency planning. However, local Age UK partners describe inconsistent engagement and collaboration with different branches of government. For example, Age UK Solihull were engaged by their Local Authority during the first lockdown but would have liked to have been involved much earlier on. Overall, the local picture was variable with some engagement in some places some of the time, but no overall strategic approach.

## Perspectives of Age International

- 20. Internationally, the Sendai Framework for Disaster Risk Reduction<sup>2</sup>, agreed in 2015, commits national governments to taking concrete steps to address older people's needs as part of wider efforts to minimise the impact of national emergencies.
- 21. Age International, as part of the Age UK group, focuses on responding to the needs and rights of older people in low and middle-income countries. They do this as part of the Disasters Emergency Committee (DEC) and as the UK member of the HelpAge International global network. Age International engagement with the UK Government in the international response to the COVID-19 pandemic also took place through its membership of Bond, the UK umbrella body of non-governmental organisations working on international development and humanitarian response.
- 22. Age International does not believe that the Government was prepared to respond to the emerging international humanitarian crisis that was created by the pandemic, nor did the Government understand how to take into consideration the needs and rights of older people as part of its response. The then Department for International Development

https://www.preventionweb.net/files/43291\_sendalframeworkfordrren.pdf?\_ql=1\*1vzh4wd\*\_ga\*NiczMDA2OD0xLiE2NzM2MDq4MDk.\*\_ga\_D8G5WXP6YM\* MTY3MzYwODgwOS4xLiAuMTY3MzYwODgwOS4wLiAuMA..

(DFID) took lead responsibility for the Government's international response to COVID-19. During initial meetings with the DFID teams responsible for leading the response, the view was expressed that older people could not be singled out as a priority group as this would undermine the humanitarian principles of neutrality. The UK was not alone in taking this view, as the UN's first Humanitarian Response Plan in March 2020 did not identify older people as a priority group most at risk from COVID-19, despite overwhelming epidemiological evidence to the contrary.

23. Prior to the pandemic, the Government paid little attention to the needs and rights of vulnerable older adults in developing countries. It is Age International's view that the Government did not take full advantage of opportunities to benefit from the expertise and experience of organisations like Age International. A regular meeting was established between a select number of international development organisations, including Age International, and DFID staff (occasionally with Ministers). However, these meetings did not focus sufficiently on operational matters, nor did their purpose appear to be about mobilizing and resourcing a more effective civil society response.

## Perspectives of Age Northern Ireland

- 24. The changing and complex communications around COVID-19 were further compounded by people in Northern Ireland accessing public health messages aimed at people living in England and Ireland as well as Northern Ireland.
- 25. In Northern Ireland the Department for Communities established an Emergencies Leadership Group to co-ordinate government and sector response to COVID-19, for example on food, volunteering, wellbeing, community advice helpline and financial help for charities. Membership of this group included the Commissioner for Older People. Age NI was not a member of the Emergencies Leadership Group but fed in issues and concerns through a communications and engagement subgroup. Direct engagement with age sector groups on the ground were stronger in places where relationships had already been developed.
- 26. In 2021, the Department for Communities and Public Health Agency provided funding for an Age NI programme, *Good Vibrations*, which aimed to deliver information, inspiration and activities to help older people stay well and connected, address loneliness and isolation, and promote the physical and mental wellbeing of older people across Northern Ireland.

## Perspectives of Age Scotland

- 27. Age Scotland were proactively approached by the Scottish Government in March 2020 with a view to providing specific resourcing to scale up helpline services for older people in Scotland, which demonstrates some recognition from the Scottish Government of both the need for improved and dedicated advice and information dissemination for older people regarding the developing pandemic; and of the existing reach and status of Age Scotland as an established and trusted source of information, advice and support. Age Scotland feel this was made possible due to Scottish Government access to Coronavirus-related funding from the UK Government.
- 28. Following this, there was often a lag between Government announcements and publication of associated information, in which time Age Scotland would receive calls from older people seeking clarification which they were not able to easily provide, due to the delays – often of several hours. This could have been avoided by a more streamlined flow of information.

## Absence of planning in social care settings

- 29. As early as 10 March 2020, Caroline Abrahams, Charity Director at Age UK, publicly warned 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" [PF5]. Sadly, this absence of preparation is writ large in the mortality and morbidity outcomes: Covid-19 has had a disproportionate impact on older people's health with particularly devastating results in care homes and where people were receiving domiciliary care.
- 30. Despite the unwavering efforts on the part of those working in the care sector, the tragic result of so many outbreaks of the virus across care homes has meant that in England and Wales 45% of deaths involving Covid-19 of people aged 70+ were care home residents [PF6<sup>ix</sup>]. 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<sup>x</sup>. In addition to a high number of deaths, there has been a marked deterioration amongst older people with care needs as

well as declines 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.

- 31. In our evidence submission to Module 2 of the Inquiry we provide more detailed analysis of the reasons why older people in social care settings were failed so badly [PF7]. Reasons include the historic weaknesses in the approach and understanding of some government departments and organisations of the challenges facing older people, ageist assumptions embedded deep into policy, and a lack of representation of older people's needs within government and key advisory bodies. 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.
- 32. For example, it would not have come as a surprise that most care home buildings were deliberately designed as communal spaces, limiting the practical capacity to implement isolation measures in these settings. Similarly, we could have avoided the unrealistic expectations placed on frontline care workers, volunteers and unpaid carers who were pitched into managing a major health crisis without adequate guidance, support or access to Personal Protective Equipment or daily testing. Residential care staff did not have the right resources, training, experience or skills to undertake the tasks expected of them in delivering complex medications and treatment.
- 33. Specific challenges were also identified in home care, supported living and extra care housing, all of which received even less governmental attention. There also 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, the extent to which it was routine for staff to work in multiple settings and how reliant large numbers were on keeping working to survive financially.
- 34. By definition those older people reliant on social care are typically living with severe frailty, and are some of the most unwell and most vulnerable of all of the population. Those in communal settings were at enormous risk because these were ideal conditions for an infection to spread. Older people are reliant on intimate personal care that precludes meaningful quarantine and isolation policies, and therefore requires

meticulous forethought for safeguarding. The contradictions evident in policies that allowed staff to work between homes, but denied visitation rights for residents, revealed that decision makers did not know how these settings operated in practice. It also disastrously underestimated the crucial importance to health and wellbeing of contact with loved ones for care home residents, many of them living with dementia. This amounts to wilful ignorance, bordering on negligence – if government had taken the time to understand social care and those it helps, they would have known it would be in no position to safeguard people living in these circumstances. As it was the Government took no steps to strengthen resources to place the sector in a better position in case of such an emergency.

35. Government should have understood its own systems, their extremely limited purchase on our highly fragmented system of social care, and the difficulties that would result from this in the event of a pandemic emergency. Unfortunately, this critical lack of understanding was a significant flaw in advisory models and predictions as well as impeding effective decision making and resource allocation.

#### National communications

- 36. In the event of a massive emergency the idea that you will need to communicate is not an unforeseeable prospect. Despite this, government pursued very ad hoc engagement with Age UK. As stated, organisations like ours have significant communications expertise for older audiences and Age UK supported NHS England extensively in some of their communications, when our advice was sought. Other branches of Government either did not seek or were resistant to taking on board our expertise. As referenced, we had done a lot of work pre-pandemic on vaccination uptake amongst older people and could have shared the learning and insight prior to the onset of the pandemic, or during the early months of vaccination development. Shielding was another area where our advice was rejected.
- 37. Lack of preparedness was evident in the quality of government communication of key public health messages and communication of legislation changes which often appeared hurried, opaque and confusing. For example, the lack of clarity and consistency over social distancing rules and regulations caused many services and forms of support to close down or withdraw in the first phase of the pandemic, including many of our own day centres, support groups and other home-based visiting services. This extended beyond professional settings with non-resident family, neighbours, carers and friends

being unclear on what was allowed and afraid of breaking the rules. The consequences were that many older people were completely unable to take care of their own wellbeing, the burden on resident family members and carers increased significantly, and many older people were left to cope alone in very difficult circumstances.

- 38. The consequences of communications failures had knock on effects as the pandemic progressed, exacerbating a tidal wave of misinformation (the 'infodemic'). Public health measures tended towards the reactive, with certain social distancing measures, including school and border closures, applied and revoked in haste and seemingly without assessment of the impact on older people. At the same time, other measures such as the banning of mass gatherings seemed to be implemented much too late, with an unreasonably high threshold of evidence required for their enactment, at odds with the much cited 'precautionary principle' towards vulnerable groups. This was a missed opportunity to collaborate with the voluntary and community sector to ensure practical support and public health messages reached those communities most in need. As it was, many older people felt anxious, abandoned and mistrustful of government. The low rates of vaccine uptake amongst some groups of older people demonstrate one particularly negative impact of this communications failure. As a result, Age UK expended considerable energy clarifying rules and guidance, explaining and communicating the evidence, providing reassurance and supporting older people to make safe decisions. For example, in the early phases of the pandemic Age UK received a large number of gueries from older people and families seeking clarification as to whether the guidance allowed cleaners to work in people's homes and information on how to do so safely. This reflected the hugely important role that informal or low-level support plays in enabling older people 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.
- 39. The other consequence of this lack of clarity around legal changes made undertaking a balanced risk assessment and appropriate mitigation extremely challenging for local services. It was very difficult for local services to get the balance right in evaluating the trade-offs between protecting beneficiaries from the harm of Covid-19 infection on the one hand, and protecting them from the physical and mental health costs of extended periods of social isolation on the other. The risks to people's health go beyond the risks of the virus. Age UK tracked the impact on older people's health and wellbeing over the course of the pandemic, our research has found nearly 1 in 3 older people report loss of

mobility during this period, 1 in 4 report that they now live in more pain and 1 in 5 have experienced symptoms of cognitive decline.<sup>xi</sup> Unfortunately, as it borne out by our ongoing research, many older people will not fully recover or regain lost function. Keeping 'lifeline' services running for older people as far as possible must be the goal in planning for future emergencies of this type.

#### Lack of planning evident in essential supply chains

40. A generalised lack of preparedness was evident in other parts of the system too. For example, it did not seem that effective mechanisms were in place for ensuring there were adequate essential food, medical and other supplies, with widespread shortages of Personal Protective Equipment being a clear example of this issue. The consequence of this was to put many older people's lives at risk, along with those frontline workers across health, social care and voluntary sector services who were caring for them. There was also a lack of business continuity planning, as Government plans did not seem to anticipate the impact of Covid-19 staff sickness on essential non-Covid related core health services, social care or the provision of other forms of support, including through the voluntary sector. There was a failure to consider how these would be delivered with significant numbers of personnel being unavailable for work.

#### Failure to anticipate indirect impacts on older people

- 41. The other clear example of planning inadequacy was the failure to anticipate a range of secondary consequences for older people resulting from national policy decisions on non-pharmaceutical interventions. Lack of preparation was revealed time and again as decisions were made with little understanding or consideration of the impact they would have on lives of older people and the entirely predictable harm they would cause. For example, lockdowns and shielding policy had a disproportionate impact on older people's physical and mental health, with many older people reporting anxiety and depression, loss of mobility (balance and falls), deconditioning through reduced physical activity and an increase in social isolation and loneliness. Mitigation measures, in so far as it was possible, should clearly have been factored into the planning process.
- 42. Another issue that had a huge impact on older people was reduced access to the day-today health and care services that are imperative for older people to manage pre-existing health conditions and access essential services and support vital to their welfare. As we age our immune system weakens and the likelihood of having a health condition

increases. Withdrawal or suspension of these services had the negative impact of lowering general resilience so that older people were left in worse shape to recover from COVID or other adverse health events and, at population level, the task of managing overall demand on the health and care system was made more difficult.

- 43. This was particularly felt for 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 the expert advice of geriatricians sought at the early stages of the pandemic. Many older people are finding they are unable to return to previous levels of fitness and resilience, especially people living with frailty.
- 44. Planning and preparedness should not just cover the acute phase of the pandemic but should also take into account the recovery phase. Even if certain measures were unavoidable impacts at the time, it is our view that government should have anticipated and planned for the fact people would need on-going support to recover. In reality, we have seen any such support withdrawn, with little planning for the long-term recovery of those most impacted. Planning guidance suggests that people with life-threatening and chronic disease, due to their particular needs, should be included in the design of policies and plans to manage their risks before, during and after disasters. We detail these challenges in our consultation response [PF4<sup>xii</sup>] to the Department for Health and Social Care Coronavirus: Lessons Learnt.

#### Lack of accurate data across key services

45. Data deficiencies were exposed over the course of the pandemic with significant gaps in data collection across key services for older people. For example, there were large gaps in social care data; there was no central database that identified the care homes that had the capacity to isolate infected residents and the ones that did not. The Care Quality Commission turned out to be 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 direct. 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.

46. Age UK has long argued that improvements must be made to data collection and analytical methods in order to fully understand diverse experiences across the older population, particularly those of minoritised groups. Too often data on older people is presented in the category 'over 65/65+' with no further breakdowns beyond that age cut-off. We have called for the enactment of the dual discrimination duty under Section 14 of the Equality Act 2010, in recognition of the fact that discrimination can be compounded when experienced through more than one protected characteristic. Resolutions focused on a single protected characteristic may not be as effective in cases of dual discrimination where multiple factors may need to considered. The UK and devolved governments were aware of such data deficiencies before the pandemic.

## National engagement with Age UK from January 2020

- 47. In response to the Covid-19 pandemic specifically, Age UK operated across a range of functions in relation to health care systems. 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 other senior stakeholders. We also worked directly with NHS and social care organisations including providers and commissioners bodies 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 to feedback to 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.
- 48. Productive engagement and collaboration throughout the pandemic worked where we had pre-existing relationships or with those who were already experienced in the benefits of partnership working. In other cases the process of engagement and collaboration was much more challenging. However, overall it was clear there was no structured approach to working with external partners, as well as historic weaknesses in the approach and understanding of some departments and organisations.

- 49. We would like to draw out one particular aspect of the engagement and collaboration challenges set out above. It was often apparent that 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 not from those expert in older people while little if any weight or consideration was given to other sources. 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.
- 50. We recognise that establishing engagement can be operationally challenging in a crisis, which only serves to underline the importance of involving organisations such as ours in pre-planning and preparedness as well as establishing protocols for collaboration as part of that planning. In future, planning should consider approaches to gathering and interpreting evidence and insight which recognise the value of a broader range of sources, including those from outside Government or academic sources. The use of local knowledge, practices and context, as appropriate, should complement scientific knowledge in risk assessment. These relationships should be developed and tested in 'peacetime' so that systems are already established and functional when emergencies strike.
- 51. We recommend that in future Government planning goes further than simply identifying population groups likely to be at greater risk of infection. They should explicitly consider the impact of living with a high level of risk in vulnerable population groups, as well as identify those groups who may experience specific challenges in the event of implementation of non- pharmaceutical interventions. Furthermore, we recommend Government maintains an up to date understanding of those populations and sources of specialist expertise and advice that can be drawn on as required. The tragedy is that many of the consequences of the pandemic for older people were largely avoidable.

### Invest in older people's health, wellbeing and resilience

52. Age UK runs a Building Resilience programme [PF<sup>xiii</sup>] that is delivered by 8 local Age UKs through holistic, person-centred advice sessions with older people. The programme specifically targets people who are experiencing a significant life event or coping with a life change, by providing one-on-one sessions aimed at supporting the person to resolve their situation and helping them to achieve what it is that matters to them. Doing all we can to make sure older people are able to stay well, active and engaged in their

communities is the best way to reduce the need for care in hospital and improve general resilience. It is Age UK's view that investing in the health and resilience of the nation, including older people, is the best investment any Government can make in terms of emergency planning and preparedness.

53. Each and every day we hear from people who cannot access the right diagnosis, treatment and support and are suffering avoidable harm or severely impaired quality of life as a result. To address the issue of resilience a more comprehensive offer in the community is urgently needed, both from GPs and community services, that can anticipate care needs and build a package of support around people to reduce the risk of deterioration. These principles were at the centre of NHS England's Ageing Well programme<sup>xiv</sup>. If the case was already clear before the crisis that these approaches are needed and that older people are the primary target for them, it is now inescapable.

#### Lessons learned for future pandemics

- 54. Age UK has made separate representations as to lessons learned in its consultation responses to both the Department for Health and Social Care and to this Inquiry [PF8, PF9<sup>xv</sup>]. Each highlights the need for government to engage support from voluntary and community sector organisations before crises hit, especially important as local authority budgets continue to fall, limiting what they can do directly. Government must address the root causes of ill health and invest in the social drivers that protect it.
- 55. We fully appreciate that in a time of crisis, when individual and institutional bandwidth is severely stretched, it can be difficult to find capacity to invest in collaboration and engagement. Yet ultimately it would have paid dividends. Government was always going to be unable to address the full scale of the challenges posed by the pandemic working alone. Greater investment in partnership working before the pandemic struck would have enabled Government to strengthen their response and allowed for more support at greater speed to those most in need. Investing in partnership building skills and on-going collaboration should be seen as a routine part of preparedness. Ultimately Age UK and our partners drew on our extensive experience and leveraged our reach to provide a huge range of services and support to older people and their families during this time of crisis, as well as working hard to bring real time insight and our expertise to government and other national bodies. However, valuable time and energy was lost due to a lack of joined up working across government and an established framework for engaging with external partners.

## Need for a rights-based framework and approach

- 56. As detailed above, the pandemic has highlighted and exacerbated pre-existing discrimination towards older people. When there were difficult trade-offs to be made or a balance to be struck between different aspects of managing the pandemic, we saw little evidence that the rights of older people influenced the decision-making process, either in planning or implementation.
- 57. Age UK believe that the Government should consider equalities and the protection of human rights as a fundamental tenet of all its work related to emergency planning and preparedness (including scenario planning for application and enactment of those principles in times of crisis). However, a system that does not properly protect the rights of older people outside of an emergency, will inevitably fail to give sufficient regard to those rights in emergency planning and preparedness. Therefore, strengthening the baseline from which the existing framework of rights are enacted, to ensure that older people are better protected both inside and outside of times of crisis, is a vital first step.
- 58. Age UK contend that the Government should have been alert to the fact that certain groups of people, including older and disabled people, were going to be especially vulnerable in a pandemic. As we set out earlier in this statement, these are predictable and well understood risks. In recognition of this fact, Government should have assessed any risk mitigation strategies through the lens of existing human rights legislation to uphold and protect older people's fundamental rights in this context. This would have included steps to engage with the organisations and experts who could advise on policies and approaches to balance risks and trade-offs and consider a range of appropriate mitigation strategies. This should be part of the routine planning process and such strategies embedded into national and local plans.

## Embedding equalities and human rights into pre-planned and prepardness

- 59. There are a number of practical steps Age UK believes are necessary to ensure systems uphold and protect the rights of older people in emergency planning.
- 60. As a first step Government must invest in strengthening the underlying platform for human rights protections and more consciously apply the appropriate mechanisms to consider them in all aspects of government business. There is existing legislation to build

on; and while imperfect, The Human Rights Act 1998 (HRA) and The Equality Act 2010 provide a framework through which older people's rights can be protected and enforced in their day-to-day interactions with public services, including protection of the rights of care home residents.

- 61. It is important to recognise that no single measure will deliver a surefire approach, instead a range of measures and mechanisms need to be established and enacted to create a safety net for human rights that will not fail at times of emergency. However, Age UK believes that the establishment of an Older People's Commissioner for England to champion the rights of older people and the support of Government for an International Convention on the Rights of Older People (that could be reflected in domestic policy and provision) would both provide important safeguards.
- 62. Furthermore, we believe that more preparedness work is needed in the following specific areas, to strengthen the underlying platform of rights for older people:
- 63. A review of guidance in respect of the Civil Contingencies Act (CCA) and Local Resilience Forums (LRFs) is overdue in the light of the Covid-19 pandemic. The CCA needs strengthening to ensure that it doesn't fail to give regard specifically to the rights of older people, such as by making explicit references to upholding human rights. Further, membership of LRFs should be revised to better reflect a wider range of partnership working and to ensure that the voices of partners with relevant expertise are heard at a local planning stage. Currently there is no comprehensive register of the vulnerable settings where people are likely to be drawing on support, above and beyond those already known to a Local Authority. Vulnerable people may be known to voluntary and community services, energy suppliers, GP services, faith leaders and others. But while we hope that greater integration between NHS and Local Authority services will eventually help bridge the divide, there is currently no failsafe mechanism to join the dots between services to ensure that people are not falling through the gaps. As a first step however, and as a minimum requirement, we recommend that a register of all vulnerable settings should be maintained at LRF and place level for use in an emergency.
- 64. The pandemic also brutally expose the lack of existing rights, protections and means of redress in for older and disabled people in vulnerable settings and receipt of care services. During the pandemic, the cessation of in-person CQC inspections, visits from health professionals and restrictions on visits from family members undoubtedly contributed to the development of closed cultures and the failure to uphold the rights of

vulnerable older people. Emergency planning specifically must take account of how inperson external oversight can be safely preserved in all settings where older people could be at risk.

65. Similarly, 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. More broadly, significant reforms are needed to enable the sector to meet the rapid increase in care needs, whilst respecting the human rights of older people in care settings. For example, it is important that redress mechanisms are in place for those receiving social care, including those who pay and arrange their own care (who cannot currently make a claim under the Human Rights Act). Rights and dignity must be at the core of adult social care reform.

## Upholding rights during an emergency

- 66. An effective human rights-based framework must be able to translate human rights concepts and protections into practice at times of crisis. Yet during the pandemic, Age UK saw little evidence that decisions were being considered in respect to the human rights framework, nor that Government was routinely applying the lens of the Equality Act 2010 to guide their actions and seeking to mitigate or compensate for the disproportionate impact on some groups. It is our view that in the absence of clear guidance supporting application in practice, Government did not consistently or meaningfully engage these human-rights principles to guide decision-making, bringing into question the proportionality of its response on a range of issues already described in this witness statement.
- 67. A powerful example of this was the ways in which 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. Effective emergency planning should have been able to identify adequately resourced contingency discharge facilities. Another clear example of failure to account for older people's rights was the decision-making around Do Not Attempt Cardiopulmonary Resuscitation orders and failures of end-of-life care protocols. Age alone should never justify the application of a DNACPR or be used as a proxy for health status. The effective implementation of human rights-based frameworks when these

decisions were made would have guarded against this type of inappropriate policymaking.

- 68. Some of the questions concerning complex rights trade-offs were very finely balanced with less clear-cut evidence for decision-making. For example, considering such difficult questions as appropriate allocation of healthcare resources or decisions about maintaining rights to family life particularly for vulnerable people in care settings. Even more reason, then, for preparedness planning to be informed by a rights-based framework designed to avoid unlawful discrimination and tackle complexity. Meaningful preparedness must address difficult ethical challenges that require a balancing of rights issues (such as who is admitted to hospital or what treatment they are able to access in any setting) and provide a rights-based framework which reflects a shared ethical consensus. We fully acknowledge that the Government faced many extremely difficult decisions where there were few 'good' options, but we would argue that it is therefore all the more important to make equality and protection of people's rights with particular reference to protected characteristics an explicit and visible part of decision making.
- 69. Any rights-based framework for decision making should be established and scrutinised well in advance, so that complex ethical debates and political decisions about risk, differential impact and possible trade-offs can be debated outside of the heat of emergency. This would require Government consulting widely on emergency scenario planning, engaging with those who have with a clear understanding of how things work on the frontline of service delivery to ensure policy can be implemented. Equality impact assessments should be far-reaching and comprehensive, analysing the potential of the policy to give rise to discrimination. For older people this would have surfaced a number of issues, for example, the tensions and trade-offs inherent in attempting to balance the goals of shielding policy against care home visitation rights.
- 70. Just as Government are able to access rapid expert advice relating to other matters during an emergency for example through Scientific Advisory Group for Emergencies Ministers and officials should have access to advice that takes an equalities and human rights perspective to be clear on how decisions may impact different groups of people. As a first step, Age UK believes Government should undertake a review of the membership and role of the Moral and Ethical Advicory Committee. This would help Government to be sure it is asking the right questions and making decisions in the full knowledge of the balance of rights to be weighed, bringing in a wider cadre of expertise and experience able to rapidly review and advise on decision-making. In emergency

preparedness and planning, as in all facets of good governance, it is a necessity that Government place a high priority on the protection of human rights and consciously take a human rights-based approach to their work. Tragically, we have seen how quickly human rights can be violated when they do not.

## Health inequities and older people

- 71. The need to apply a rights-based lens to planning and preparedness decision making is particularly stark when you look at the Covid-19 data as it relates to older people when indexed by other protected characteristics that created a greater cumulative vulnerability. Although age was the dominant risk factor, additional factors across the older population such as ethnicity, income, sex or disability appeared to go unrecognised. The disproportionate impacts of the pandemic on certain groups of people reveals the stark inequalities that exist in our society that maintain gaps in experience, access and outcomes. Inequalities in Covid-19 mortality persist with mortality rates 3 to 4 times higher in the most deprived areas. While people from black and minority ethnic backgrounds were at nearly three times the risk of dying of covid than their white counterparts, with the risk to black African men 3.8 times that of white men. Every effort must be made to reduce these unjust and avoidable differences in outcomes and the pursuance of this goal requires particular attention to equitable practices for service restoration and recovery.
- 72. Given the evidence that some groups of older people have been at greater risk –for example some members of black, Asian and minority ethnic communities, disabled people and those living in poverty this means that an intersectional approach to risk assessment is necessary to capture the complexity of overlapping needs. Approaches to planning and preparedness need to ensure that all issues are considered in relation to how they might negatively impact a particular group with unique vulnerabilities, and enable Government to put in place the necessary mitigations to protect against this. In practical terms, a minimum requirement would be to build routine equalities impact assessments into all phases of emergency planning and preparedness.

#### The next crisis is already here

73. Finally, it must be acknowledged that at the time of writing we find ourselves already in the midst of another crisis across health and social care services that threatens consequences of a similar order of magnitude for older people. Many challenges were entrenched long before the onset of Covid-19. The pandemic exposed existing frailties within systems and infrastructure that were not able to cope with the added pressure. The NHS is much leaner and 'runs hot' compared to many of its European neighbours, with little slack in the system to respond in times of crisis. To address current health threats, and to prepare for future crises, longer-term contributory factors must be reckoned with: the case for a comprehensive workforce strategy, investment in fit-for-purpose premises and systems, and measures to resolve the on-going crisis in social care is well made and must be urgently addressed.

- 74. All this is happening in the context of an ageing population the number of people over 75 is projected to double in the next 30 years – with 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. Effective public health measures require an increased and sustainable funding settlement to enable local authorities and others to plan and deliver safe and effective services. However, cuts to the Public Health budget since 2015 have been at around 24%, undermining efforts to protect health<sup>3</sup>, with disproportionate cuts in the areas of highest need, exacerbating existing inequalities.
- 75. Coupled with this, 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. We need a new vision of local civic preparedness – a model that is seen by both national government and local authorities as an asset and used strategically to protect older people (and others) at risk.
- 76. 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 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

<sup>&</sup>lt;sup>3</sup> https://www.kingsfund.org.uk/projects/nhs-in-a-nutshell/spending-public-health

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.

- 77. In summary, Age UK believe that many of the catastrophic consequences for older people and other vulnerable groups could have been significantly mitigated with adequate forethought, preparedness and civil planning. The stark impacts of the pandemic on older people, particularly those from ethnic minority backgrounds, carers, those living with chronic health conditions such as dementia, those living with disability and those living in the most deprived and marginalised communities, speaks to the absence of such planning for an emergency of this kind - an emergency which whilst itself unprecedented, draws many parallels with previous emergencies and planning exercises from which lessons should have been learned and contingency plans made.
- 78. We want to share our learning to help the Government, health and care providers and others better understand older people's lives and strengthen the protection and support for them. Age UK hopes this statement will aid the Inquiry to understand the impact these leadership failures have had on the lives of many older people and their loved ones, and learn the necessary lessons, so that the nightmare scenarios we have seen play out for older people through the Covid-19 pandemic are never repeated. Older people were always going to be at the eye of this type of storm, a fact that the UK Government should have accounted for in planning, preparedness and resilience decisions.

Cromer D. et al. (2014) Journal of Infection: vol 68; issues 4: pp 363-371

ii https://www.kingsfund.org.uk/projects/time-think-differently/trends-disease-and-disability-long-term-conditions-multi-morbidity

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Hitos://www.nao.org.uk/reports/the-advernments-progradmess-for-the-covid-19-pandemic/
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xi Age UK (2021). Impact of Covid-19 on older people's mental and physical health: one year on

x<sup>ii</sup> Department for Health and Social Care Coronavirus: Lessons Learnt. https://www.ageuk.org.uk/globalassets/age-uk/documents/programmes/building-resilience/fair-processing-notice-building-resilience-programme.pdf

<sup>\*\*\* &</sup>lt;u>https://www.longtermplan.nhs.uk/areas-of-work/ageing-well/</u>
\*\* Department for Health and Social Care Coronavirus: Lessons Learnt; Age UK formal response to Module 2 Rule 9 request

Witness Name: Mr Paul Farmer Statement No.: M1/AGEUK/01 Exhibits: Dated: 17 February 2023

## **UK COVID-19 INQUIRY**

## WITNESS STATEMENT OF PAUL FARMER, CEO, Age UK

I, Paul Farmer will say as follows: -

Please see enclosed response

## Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.



Dated: 17 February 2023