Attachment 1.

Questionnaire response
UK COVID-19 Inquiry: Module 2 - Rule 9 Request to Age UK
Reference: M2/R9R/AGEUK/TJS

Please provide the following information:

1. A brief overview of the history, legal status and aims of the organisation or body. Please explain whether the work of the organisation or body is UK wide, or is instead confined to England, Scotland, Wales or Northern Ireland only.

'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 133 independently registered charities that operate under a brand agreement which provides a framework for cooperation and collective endeavour. This includes 'Age UK' and 123 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. The network is supported by the commercial activities of AgeCo, a community interest company providing paid for services and products that benefit people in later life and generates income for our charitable work.

Across the UK, the charities reach millions of 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.

This response was collated by 'Age UK' on behalf of the group. The overarching themes of our narrative and response are consistent. However, it is important to note that local jurisdictions experienced different challenges and took different approaches. To reflect this, we have appended a separate responses to question 6 from Age UK, Age Scotland, Age Cymru and Age NI to capture these nuances (see attachments 4,4a,4b,4c).

2. A brief description of the group(s) which the organisation or body supports or represents.

Age UK and its partners works on behalf of the older population and advocate for long term improvement in experiences of later life. However, there is no single way to define what it means to be an 'older' person and individual aspects of our work will be context specific.

Financial and legal entitlements are commonly based on chronological age – either age 65 or equivalent to entitlement to the state pension. In employment 'older workers' are defined as those over the age of 50.

However 'ageing' is a physiological process with wide variation in experiences and impact on life expectancy and healthy life expectancy across different communities and parts of the

country. Therefore in other aspects of our work we take a life course approach focusing on those experiencing the challenges and forms of exclusion, disabilities, health conditions or care needs that are typically associated with older age and the ageing.

Throughout our work we also seek to ensure that the voices and experiences of minoritised older people and those experiencing social exclusion are fully represented.

To quantify the scope of our work, there are nearly 25.5 million people aged over 50 in the UK – representing 38% of the total population. Of which more than 12.5 million are aged over 65 (19% of the population) and 5.8 million people aged over 75 (9% of the population). For the reasons set out above, while most of our efforts are directed towards those aged 65 and over, in some areas of policy and in less advantaged communities we have reach to those in their 50s and early 60s.

3. A brief overview of the work of the organisation or body in supporting or representing the relevant group(s) between January 2020 and Spring 2022 as it relates to the response to Covid-19 of (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive.

Age UK plays a vital role in communicating the views and experiences of older people to the UK government, advocating for policies and service provision that improve experiences of later life. Between January 2020 and Spring 2022 we had sustained engagement with a number of relevant government departments and representatives as they developed their response to Covid-19.

In this questionnaire and in the attachments provided, we have provided an overview of that engagement and the challenges that emerged for older people as they sought to navigate the pandemic. We have done so in good faith and to the best of our recollection.

As stated, Age UK is a national charity that works with a network of partners, including Age Scotland, Age Cymru, Age NI and local Age UKs across England. This response was collated by Age UK on behalf of the group. The overarching themes of our narrative and response are consistent. However, it is important to note that local jurisdictions experienced different challenges and took different approaches as reflected in attachments 4,4a,4b,4c.

4. A list of any articles or reports the organisation or body has published or contributed to, and/or evidence it has given (for example to Parliamentary Select Committees) regarding the impact on the group(s) which the organisation or body supports or represents of the response to Covid-19 by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive. Please include links to those documents where possible.

Please see Attachment 2 for a list of articles, reports and evidence submissions Age UK has made regarding the impact of the pandemic on older people, with relevant links provided.

Please see attachments 4a, 4b and 4c for information specific to the devolved administrations.

5. The view of the organisation or body as to whether the group(s) it supports or represents was adequately considered when decisions about the response to Covid-19 were made by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive. Please also explain the reasons for the view expressed by the organisation or body in this respect.

Age UK does not believe that older people and their needs were adequately considered or understood when decisions about the response to Covid-19 were made by the UK Government. Please see Attachment 3 ('Narrative response') for more detail on the reasons for this assessment. Please see attachments 4a, 4b and 4c for information specific to the devolved administrations.

6. Whether the organisation or body raised any concerns about the consideration being given to the group(s) which it supports or represents with (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive, when the Government(s) and/or Executive were making decisions about their response to Covid-19. Please provide a list of any such correspondence or meetings with the UK Government, Scottish Government, Welsh Government and/or the Northern Ireland Executive, including the dates on which the body or organisation wrote or such meetings were held, to whom the correspondence was addressed or with whom the meeting was held, and any response received from the UK Government, Scottish Government, Welsh Government and/or Northern Ireland Executive addressing such concerns.

Please see Attachment 4 ('Table of concerns') for a list of concerns raised to the UK Government. Please see attachments 4a, 4b and 4c for information specific to the devolved administrations.

7. A brief summary of the views of the organisation or body as to any lessons, if any, that can be learned from any consideration which was given to the group(s) that the organisation or body supports or represents by (a) the UK Government; (b) the Scottish Government; (c) the Welsh Government; and/or (d) the Northern Ireland Executive when they were making decisions about their response to Covid-19.

In response to this request we have set out a wide range of issues and challenges experienced by older people over the course of the pandemic. We hope this will aid the Inquiry to understand the unique and enduring impact this period has had on the lives of many older people and their loved ones. We have also set out our overall conclusions relating to the Government's conduct throughout the pandemic and summarised the lessons that should be drawn out and taken into consideration for the future. Please see attachments 4a, 4b and 4c for information specific to the devolved administrations.

See: Age UK Consultation Response Department for Health and Social Care Coronavirus: Lessons Learnt

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

One of the most substantial barriers to effective strategic and operational decision making over this period of time was the lack of knowledge and understanding of the older population or of the essential services and support that are vital to their welfare – most notably social care. We engage specifically with challenges relating to Government's approach to the social care sector below; however it is important to recognise that this was part of a bigger 'blind spot' across multiple parts of Government and those advising them.

As we have made clear in attachment 3 to this submission, the challenges facing older people were wide ranging. While some were common experiences across the population, many were either a facet of the particularly high risk posed by Covid-19 to older people or the way in which measures to combat the pandemic intersected with pre-existing vulnerabilities or underlying challenges and prejudices. However as attachment 3 also makes clear a common theme emerges: from the start there was both (1) a lack of effective

analysis of how the risk of infection and implementation of non-pharmaceuticals would impact older people; and (2) the sufficient insight to enable Government to design rules and guidance, services and support to mitigate against predictable and preventable harm.

It should have been apparent from the very beginning that older people would be at the eye of the storm. Age was identified early on as a major risk factor for critical illness and mortality; the risk of living with a pre-existing health conditions, disability or care need rises directly in line with age, including the majority of people advised they were clinical or extremely clinically vulnerable; older people have greater likelihood of social isolation and digital exclusion; older carers are more likely to be providing intensive informal care; and there was a predictably high risk of losing (and not regaining) mobility, cognitive function, strength and balance or cardiovascular fitness amongst older people. In addition, the experiences of other countries that were ahead of us during the pandemic, such as Italy, demonstrated the vulnerability of older people, especially those living in residential settings.

In future we recommend 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 they maintain an up to date understanding of those populations and sources of specialist expertise and advice that can be drawn on as required.

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

The lack of understanding or effective management of the challenges facing the social care sector warrants particular attention, given the seriousness of its impact on older and disabled people.

Again, from the beginning it was clear that older people in need of care and support, either in their own home or living in a care home, would be at extremely vulnerable to Covid-19. The nature of personal care means close and regular physical contact with others is inevitable and unavoidable, and by definition those individuals are likely to be at high risk of critical illness in the event of contracting the virus or any associated reduction in access to health care services.

However, we believe there were three critical factors in why older people in receipt of social care were exposed to a major avoidable harm in ways that amounted to a failure to respect their human rights:

1. *We believe there was a clear sense of fatalism. The underlying assumption was that older people with care needs would be unlikely to survive and therefore there was a limited amount to be done if someone contracted the virus, or in the event of an outbreak in a care home. This attitude, we believe, 'wrote older people off' and underpinned both the failure to properly consider the care sector as a whole, as well as instances of care recipients being denied adequate access to clinical care.*

2. *At the outset government and those advising them had little if any knowledge about the realities of the care sector. There were unrealistic expectations about the skills and capabilities of staff and the operational capacities and resources of providers. There was a lack of understanding of the workforce, notably its reliance on low paid staff with poor terms and conditions (including adequate sick pay or protections), and the extent to which it was common for staff to work in multiple settings. Indeed in the early days of the pandemic, Government collected no routine data about the sector and had no means of communicating with providers, relying on CQC registration lists. Unfortunately, this critical lack of understanding was a significant flaw in advisory*

models and predictions, as well as impeding effective decision making and resource allocation.

3. *Throughout the pandemic we noted a resistance on the part of government to intervene in or provide strategic support to services which are predominantly provided by the private or voluntary sector. This led to repeated delays and hesitation. The challenges of an 'orphaned' sector delivering an essential public service were brutally exposed. Local authorities have responsibility for commissioning services, but only for those who meet strict needs and financial eligibility criteria, and for sustainable functioning of a local care market. Individual service users, carers and families must make their own arrangements under other circumstances. National bodies take responsibility for setting and registering against minimum standards of quality and safety. The NHS has responsibility for provision of healthcare services, but discharge some of this responsibility through the funding nursing contribution, with providers of residential care with nursing responsible for employing nursing staff.*

In summary, this patchwork of responsibility coupled with lack of knowledge and a seeming fear of opening the flood gates to demands from providers, the workforce and service users meant the Government's response to the first wave was deeply inadequate. In our view it led to avoidable suffering and harm. Subsequent waves were better managed as Government recruited new leadership and finally engaged with external sources of advice, but it remains our view that despite the best efforts of those championing the needs of the sector and those who rely on it, Government decision making failed to deliver a response fully commensurate with the scale and severity of the challenge at any stage.

In this respect it is difficult to make a future recommendation as many challenges in the pandemic response were due to deep pre-exiting and continuing flaws in the social care system as a whole. However, it is clear that better knowledge of and engagement with the care sector from the outset, acknowledging and responding to its strategic importance in protecting lives and delivering an effective pandemic response would have made a significant difference. It could have saved many lives and safeguarded service users, families and staff from deeply traumatic experience.

Ingrained ageism and lack of consideration of the rights of older people.

Sadly, it did not escape the notice of older people that the value of their lives came into question over the course of the pandemic. Indeed, we heard strongly from many that the consistent expressions of ageism in the public discourse and ageist assumptions embedded deep into policy, delivery and decision making had a profound effect on their mental and physical health.

It is also not, in our view, an overstatement to say that this ingrained ageism and lack of consideration of the rights of older people cost some their lives and will have caused irreparable damage to others. The challenges we set out above in respect of the care sector are, at least in part, rooted in such attitudes and perspectives. However, as we set out in our overall submission, time and again decisions were made with little understanding or consideration of the impact they would have on lives of older people and the entirely predictable, harm they would cause. An overriding fatalism about their chances of survival, coupled with lower value placed on safeguarding older people's lives and health, led to an inappropriate reliance on chronological age in policymaking, as well as blanket application of policies to older people. Lastly, as we set out below, when there were difficult trade-offs to be made or a balance to be struck between different aspects of managing the pandemic, we saw little evidence that the rights of older people influenced the decision-making process.

While only some of this critique can be directly attributed to Government actions and decisions, we would like to point out that national bodies and their leaders also have an important platform and responsibility to set the tone and influence implementation and practice. Government largely failed to do this, although we would like to note and commend some important exceptions to that observation.

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. Older people felt marginalised and devalued, which eroded the trust of many in Government and national institutions at a critical time. In future we recommend that the Government explicitly considers equalities and human rights in plans and preparations, as well as establishing a clear rights-based framework to guide decision making for officials and national bodies.

Lack of established frameworks to guide decisions that sought to balance risk-reduction and quality of life.

One particularly important aspect of the challenge of balancing rights came to fore in the question of managing the pandemic in residential settings. Early on measures were implemented to reduce the risk of families and visitors introducing the virus into settings and prevent contagion between residents. In practice this resulted in residents experiencing long periods of isolation which, as our narrative submission makes clear, had a profound impact on their mental and physical health. Older people in residential care described losing the will to carry on; people living with dementia lost their remaining memories and recognition of people in their lives; and thousands of people would go on to die without ever seeing their loved ones again. The impact on partners, families and friends should not be underestimated either and, as we have noted in our evidence, many have reported experiences of trauma and traumatic bereavement as a result.

While efforts to safeguard residents from infection were vital, swiftly imposed inflexible rules that failed to take in account individual circumstances and settings cause huge irreparable harm. Despite repeated representations by organisations advocating for residents and their families and advice from the care sector, Government largely failed to respond to the evidence of wider harm. In our view Government was highly sensitive to the criticism that it had failed to safeguard care homes in the initial wave of the pandemic and adopted a highly risk adverse position on visiting. Yet at the same time Government failed to deliver an adequate, sustained response to the management of Covid in care homes. Many families and residents felt their quality of life and relationships were sacrificed to maintain the appearance of a tough approach.

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 by any means, and the balance of risk was continually shifting as more information emerged and the pandemic evolved. However 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 made it near impossible for residents and their families to challenge decision makers. We recommend that government address this fundamental lack of rights for residents in order to ensure that in future decisions can be made with reference to an established body of rights that have been developed in consultation with providers, staff and residents and their families and loved ones.

Inconsistent engagement and collaboration with partners outside of government, including the voluntary and community sector.

There was an inconsistent approach to communication, meaningful engagement and collaboration between different branches of Government and potential external partners,

including the voluntary and community sector. In our view this meant a number of valuable opportunities were missed to use the insight and expertise of external organisations to improve Government decision making, processes and communications; as well as opportunities to collaborate to ensure practical support and public health messages reached communities most in need.

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. 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.

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 alone. Greater partnership working would have enabled Government to strengthen their response and allowed for more support at greater speed to those most in need.

In future we recommend that Government involve relevant external stakeholders in contingency planning and explicitly consider the role of potential partners, particularly the voluntary and community sector, in effective delivery of those plans. Investing in partnership building skills and on-going collaboration should be seen as a routine part of preparedness.

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

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, while lesser weight or consideration was given to other sources. It meant data and advice was drawn from a comparatively narrow perspective and often biased against those bringing information or insight grounded in real-time experience and data collection. As a result Government was often slow to recognise or respond to emerging problems and challenges or made less effective decisions.

Again, we recognise that establishing engagement can be operationally challenging in a crisis. However future planning should consider approaches to gathering and interpreting evidence and insight which recognise the value of a broader range of sources, including those from outside Government or academic sources. This is of particular importance in fast evolving and novel situation where traditional models of evidence gathering may be too slow or fail to capture relevant data and insight.

Summary of recommendations:

1. ***Importance of agreed ethical frameworks:** If older people's human rights had been more expansive, better defined and properly communicated and understood, we believe the 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.*

2. ***Addressing 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. There is a compelling case for a Minister for Older People and an Older People's Commissioner too.

3. ***Active support and protection for the vulnerable:*** *the lives and health of people who rely on essential services, including people living in care homes or receiving home care, informal carers and those in receipt of regular healthcare, must be actively protected from the enhanced risk engendered by their circumstances.*

4. ***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.*

5. ***At no time should blanket policies based on age be applied*** *to individual decision making about treatment, care or access to services. Age should not be used as a proxy for the health status or vulnerability of any individual.*

6. ***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 affects the financial wellbeing, physical and mental health of older people.*

7. ***Meaningful engagement and partnership with the voluntary and community sector*** *should be built into long-term pandemic recovery plans and recognised as an essential building-block for the holistic support of older people (and of other groups too).*

8. ***Governmental responsibility for social care must be made explicit*** *as an essential public service on which hundreds of thousands of people depend. The State's responsibility must be made clear for current and future governments.*

9. ***Maintaining an appropriate balance between keeping people physically safe, ensuring their wellbeing and quality of life, and respecting individual preferences,*** *should be a guiding principle for policy-making.*

10. ***Longer-term contributory factors must be addressed:*** *Long-standing NHS estates issues; workforce crises across the NHS and social care, austerity measures and cuts to public health budgets all worsened the impact of the pandemic and place older people at risk in the event of future crises.*

Appendix of attachments

Attachment	Description	Question	Nations
ATT 1	Age UK questionnaire response	ALL	
ATT 2	Age UK publications	Q4	Module 2
ATT 3	Age UK narrative response	Q5	Module 2
ATT 4	Age UK Concerns table	Q6	Module 2
ATT 4a	Age Scotland	ALL	Module 2a
ATT 4b	Age Cymru	Q6	Module 2b
ATT 4c	Age NI	Q6	Module 2c