

Written evidence from Independent Age (COV0214)

1. About Independent Age

1.1 We offer regular contact, a strong campaigning voice, and free, impartial advice on the issues that matter to older people: care and support, money and benefits, health and mobility. Our vision is that we can all live a happy, connected and purposeful later life. Our mission is to ensure that as we grow older, we all have the opportunity to live well with dignity, choice and purpose. For more information, visit www.independentage.org. Registered charity number 210729.

1.2 For more information about this submission contact public.affairs@independentage.org

2. Introduction

2.1 At Independent Age, we have seen how the COVID-19 virus outbreak has significantly impacted people in later life, due to both the effect the virus has on them physically, alongside the impact of the measures put in place to tackle it.

2.2 There have been positive efforts in response to the outbreak, at both a national and local level. However, we are concerned that a number of human rights issues have arisen for people in later life and these have been exacerbated by existing inequalities and ageism in the health and social care sector.

2.3 In addition to the high numbers of deaths, people in later life have been disproportionately affected by a number of issues. They include:

- Blanket decisions about care.
- Being moved from NHS settings into care homes without appropriate testing for COVID-19.
- Access to social care services and changes to the Care Act.
- Poor communication and lack of clarity of Government guidance.

2.4 While there have been some positive changes and good responses from local and national Government to some of these issues, it is now crucial that these are embedded into future learnings as COVID-19 continues and as we face local lockdowns and potential future waves.

2.5 We welcome the opportunity to respond to this inquiry. We particularly want to contribute evidence to the third question; which groups have been disproportionately affected by the measures taken by Government to address the pandemic.

3. Blanket decisions about care

3.1 Everyone in later life should be treated fairly and equally. However, at the start of the COVID-19 pandemic, Independent Age was concerned about troubling narratives regarding the treatment and care of people in later life. There were reports of arbitrary decisions about intensive care treatment disadvantaging older people, alongside blanket Do Not Attempt CPR (DNACPR) orders being placed on people's records.¹

¹ UK healthcare regulator brands resuscitation strategy unacceptable, The Guardian, <https://www.theguardian.com/world/2020/apr/01/uk-healthcare-regulator-brands-resuscitation-strategy-unacceptable> published 1 April 2020, last accessed 15 July 2020.

- 3.2 There were also reported cases in the media of individuals feeling pressurised into signing DNACPR forms resulting in those affected feeling fearful and anxious that their wishes and lives do not matter.²
- 3.3 We were pleased to see NHS England reiterate to GPs and healthcare professionals that ‘blanket’ policies on clinical decisions are inappropriate, whether due to medical condition, disability or age, especially with regards to DNACPR forms³, and that new national guidance on applying DNACPRs is to be produced.⁴ It is crucial that the fundamental principles underlying the NHS Constitution continue to be applied during the pandemic, including in any future waves or lockdowns.
- 3.4 We also believe that age played too large a part when decisions were being made about critical care treatment. In April, a draft NHS COVID-19 critical care decision support tool was reported in the media as having been circulated to healthcare professionals. In this tool, age was given undue weight in decision making.⁵ This tool contradicted the National Institute of Health and Care Excellence (NICE) published guidance for use during the pandemic. NICE states the need to assess someone’s frailty alongside several other factors to assess the likelihood of critical care treatment achieving the desired outcome.⁶ Rather than assessing age alone as a risk factor and counting it in addition to frailty scores.
- 3.5 It is unacceptable to make blanket treatment decisions based on age alone, or where a person’s age is given undue weighting against other factors, such as their usual state of health, fitness to treat and ability to benefit from treatment. Chronological age is a poor proxy for a person’s health status and resilience and using it alone to determine treatment decisions could be considered ageist and may breach an individual’s human rights.

4. Moving older people from NHS settings to care homes without appropriate testing for COVID-19

- 4.1 We are very concerned about the decisions made early on in the pandemic to discharge older people from NHS hospitals to care homes without testing them for COVID-19. This disproportionately impacted the health of people in later life.⁷ The National Audit Office estimates around 25,000 people were moved from hospitals to care homes from mid-March to mid-April without COVID-19 testing. This took place before a policy was introduced to test everyone in hospital before they were moved to their care homes.⁸ Since the beginning of the pandemic there have been 66,112 deaths of care home residents, almost 20,000 of whom tested positive for COVID-19. Between the start of January 2020 to 1st May 2020 there were 46% (23,136) more deaths in care homes than in the same period in 2019.⁹ The very high rate of deaths in care homes is unacceptable. People being discharged from hospital without being

² Examples of older and vulnerable people pressured into signing Do Not Resuscitate forms, <https://www.itv.com/news/wales/2020-04-06/shocking-examples-of-older-and-vulnerable-people-pressured-into-signing-do-not-resuscitate-forms/> Published 6 April 2020. Last accessed 15 July 2020.

³ <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/maintaining-standards-quality-of-care-pressurised-circumstances-7-april-2020.pdf>

⁴ <https://www.leighday.co.uk/News/Press-releases-2020/July-2020/Government-agrees-to-issue-guidance-to-ensure-pati>

⁵ NHS, [COVID-19 decision support tool](#), last accessed 15 July 2020.

⁶ NICE, Critical care in adults [NG159], Published 20 March 2020.

⁷ NHS England, <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/urgent-next-steps-on-nhs-response-to-covid-19-letter-simon-stevens.pdf>

⁸ BMJ, 2020, 369:m2375, <https://www.bmj.com/content/369/bmj.m2375>

⁹ ONS; Number of deaths in care homes notified to the Care Quality Commission, England, accessed 15 July 2020,

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglandandwales/deathsoccurringupto12june2020andregisteredupto20june2020provisional>

tested suggests that early plans to increase capacity in hospitals failed to fully consider the health of care home residents. We believe releasing someone infected with COVID-19 from hospital, into a residential care or nursing home, may have breached the rights of the infected individual, and the human rights of the other older care home residents. We welcome the potential investigation by the Equality and Human Rights Commission into the discharge of these patients, exploring whether their human rights have been affected.¹⁰

5. Access to social care and changes to the Care Act

5.1 The changes to social care provision during the pandemic, and as a result of the Coronavirus Act 2020, were intended to help the care sector cope with an uncertain time of high demand. However, we are concerned that while the NHS was rightly given significant additional funding to tackle the pandemic, the support people could expect from the social care system was cut back. The official Care Act easements enable local authorities to temporarily stop or reduce the amount of support someone is receiving. Though only a small minority of local authorities turned these on officially, and all have now turned them off, we are concerned that some local authorities who have been stretched to breaking point may have reduced their service offer unofficially. This means many older people could be left without support for day-to-day tasks like washing or dressing, which could lead to a huge amount of anxiety, stress and pain.

5.2 A small but increasing number of our service users have raised that they experienced difficulty accessing formal domiciliary care services. They shared with us that they had not heard back from their local authority when contacting them, or they had experienced delays to necessary assessments.

6. Lack of communication and clarity of relevant guidance for older people

6.1 We do not believe the Government properly considered people in later life when developing plans to communicate the guidance on social distancing. Any person aged 70 and over who didn't fall into the clinically extremely vulnerable group (those shielding) by default was classed as 'clinically vulnerable' due to being 70 or over. This group had specific guidance which advised them to stay at home as much as possible and "take particular care" when social distancing. However, in April our research showed that 43% of UK adults over-65 incorrectly believed that the Government had instructed over-70s without any underlying health conditions to shield themselves entirely and not leave the house at all. Only 30% were able to identify the correct advice for over-70s without underlying health conditions.¹¹ We appreciate that many people over 70, who were not advised to shield, may still live with serious long-term health conditions and disabilities and for some they may have felt safer staying at home. However, for healthy over 70s, we do not feel enough clear information was communicated to empower them to understand their options and decide for themselves what they felt safe to do. This lack of clarity disproportionately affected older people as all over 70s were in one of the two clinically vulnerable groups.

¹⁰ <https://www.telegraph.co.uk/news/2020/05/14/equalities-watchdog-considers-whether-sending-patients-hospitals/>

¹¹ Independent Age, this survey of 483 people aged 65 and over was carried out online between 15.05.2020 – 18.05.2020 by Opinionium, for Independent Age, <https://www.independentage.org/news-media/press-releases/independent-age-calls-for-clarity-governments-covid-19-messaging-to-over>

- 6.2 Most of the information and guidance for the clinically vulnerable group is only available online. However, many older people lack access to digital information - 869,000 people between 65 and 74 years old and almost 2.5 million people over 75 have never used the internet.¹² In addition, advertising about social distancing on television, radio and in newspapers is aimed at the general public, without explaining the specific guidance for those in the clinically vulnerable group and what they should do differently. One older person in her early 70s and without any underlying health conditions that rang our advice line told us that she was not sure if the rules allowed her to go and visit her friend, in a similar situation, for a socially distanced meet up to keep each other company.
- 6.3 We are concerned that the lack of targeted messages and clear communication of guidance means that many people in later life may not have known what options they had under the guidance. We know some people later in life may have shielded themselves believing this was what they were being instructed to do and lived in isolation for a significant period. This put them at unnecessary and increased risk of loneliness and related mental health problems and meant many had difficulties accessing food because they didn't think they could go to the supermarket. As we move through the pandemic, and second waves approach, the Government must ensure it clearly communicates any new guidance to both the clinical extremely vulnerable group and the clinically vulnerable group, so they know what action to take to minimise their risk of catching COVID-19.

7. Future decisions

- 7.1 Independent Age believe that there are several principles that should be included in decision making in the future in order to maintain and not diminish older people's human rights. They are:
- Ensure guidance and decisions about treatment are based on health and fitness to treat rather than chronological age.
 - Older people are not disproportionately affected by changes in services as a result of coronavirus.
 - Ensure people in later life are involved and informed about decisions about their care and wellbeing.
 - Ensure that people in later life are involved in the development of guidance and that such guidance fully accounts for their circumstances.
 - Collect a wide range of data to monitor the impact of COVID-19 on older people for the duration of the pandemic.

22/07/2020

¹²ONS, Internet users, UK: 2019, <https://www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/bulletins/internetusers/2019#:~:text=In%202019%2C%20within%20the%20UK,%25%20being%20recent%20internet%20users.&text=Recent%20internet%20use%20by%20retired,in%20the%20older%20age%20groups>