Independent Age submission to the Health and Social Care Committee's inquiry into clearing the backlog caused by the pandemic

1. About Independent Age

1.1 Independent Age's mission is to ensure that as we grow older, we all have the opportunity to live well with dignity, choice and purpose. Founded over 150 years ago, we are an established voice for people in later life, their families and carers. We offer free and impartial advice and information and a strong campaigning voice, as well as providing connection services to improve wellbeing and reduce loneliness. 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 and summary

2.1 At Independent Age, we have heard from people in later life about the impact of severe delays when accessing NHS physical health treatment in England.

2.2 While waiting lists had already been increasing, the COVID-19 pandemic has placed the NHS under unprecedented strain. Despite the extraordinary efforts of health and care staff to deliver urgent and life-saving care throughout the pandemic, the suspension of elective activity, reduced hospital capacity, and workforce shortages have contributed to waiting lists rising to their highest level on record with over 5.45 million people waiting for treatment in June.

2.3 Severe delays in access to elective care have disproportionately impacted people aged 65 and above, who are more likely than any other age-group to have multiple conditions or require elective hospital care.

2.4 Protracted waits for the most common elective procedures for people in later life such as joint replacements and ophthalmic (eye) operations can have a profound impact on quality of life. Deconditioning can also negatively impact surgical outcomes, cause other conditions to worsen or in some cases result in permanent disability. Worse still, many people in later life lack basic information on how to manage their condition before their operation, resulting in further distress, frustration and anxiety.

2.5 In addition, our research suggests that many people in later life have experienced deteriorating mental health during the pandemic. We know that medical professionals have been struggling with increased workload, and some of the older people we spoke to felt they shouldn't contact their GP at this busy time. Or, if they did, some weren't able to get an appointment or speak to anyone. This has led to a significant disruption in access to GPs, hampering referrals for mental health services and professional bereavement support.

2.6 Now more than ever, it's crucial that the distinct needs of people in later life are central to NHS and government action to clear the backlog in elective care. Sustainable investment is needed not just to boost hospital capacity, but to strengthen community services and perioperative care to better support people in later life to "wait well". This holistic approach not only improves overall resilience among people in later life, but reduces pressures on primary care, hospital administration and A&E.

2.7 To tackle the scale and complexity of the backlog and its disparate impact on people in later life, we are calling on the NHS and Government to deliver:

- Appropriate and adequate support before, during and after surgery to improve patient experience and health outcomes, empowering people in later life to "wait well".
- Increased support for GPs to improve the identification of mental health needs in people in later life and offer a range of support including referral to the Improving Access to Psychological Therapies (IAPT) programme.
- Bereavement leads at NHS England and across Integrated Care Systems to improve strategic oversight, coordination and investment in bereavement support, coupled with improved mapping of need and gaps in the provision of bereavement services.
- Reform of the adult social care system including increased funding, a universal entitlement to care, and better conditions and training for the professional workforce.

2.8 We welcome the opportunity to respond to this inquiry and have limited our focus the questions where we feel we can add value and insight. We have included our recommendations at the end of this document. We would be pleased to share additional oral evidence with the committee from our upcoming report on older people's experience of accessing surgery and waiting for treatment, due to be published in late September 2021.

What is the anticipated size of the backlog and pent-up demand from patients for different healthcare services including, for example, elective surgery; mental health services; cancer services; GP services; and more widely across the healthcare system?

3. Increase in waiting times for surgery

3.1 Before the COVID-19 outbreak, the NHS was already struggling with long waiting times for routine treatment. Funding issues since 2010, together with growing demand for NHS services - only partly explained by our ageing population[1] and staffing shortages - led to deterioration in hospital performance and other services across the board.[2]

3.2 One of the most severe impacts of the pandemic on the health service has been the rapid rise in waiting lists and waiting times created by the suspension of non-urgent elective activity and the reduction in hospital capacity. In June 2021, the number of people waiting for hospital treatment had reached a record high of 5.45 million.[3]

3.3 Predictions about the size of the waiting list generally accept that it will get worse before it improves. Even optimistic scenarios suggest it could take between five and nine years to be fully addressed.[4] A recent report from the Institute for Fiscal Studies (IFS) outlined a best-case projection of 9 million people waiting for treatment next year, and a worst-case projection of 11 million people waiting within a year, rising to over 15 million by the end of 2025.[5]

3.4 The amount of time people are waiting for surgery is also an issue. Over 1.7 million (1,704,198, or 31%) of the patients on the waiting list had waited longer than the 18-week standard, with over 300,000 patients waiting 52 weeks or more. To give some context, prior to the pandemic, in February 2020, the number of patients waiting 52+

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[1] King's Fund, 2021. NHS waiting times: Our position. https://www.kingsfund.org.uk/projects/positions/nhs-waiting-times
[2] Health Foundation, 2020. The bigger picture: learning from two decades of changing NHS care in England. https://www.health.org.uk/publications/reports/the-bigger-picture
[3] NHS England, 2021. NHS referral to treatment (RTT) waiting times data June 2021. https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2021/08/RTT-statistical-press-notice-Jun21-PDF-410K-69343.pdf
[4] Institute for Fiscal Studies, 2021. Could NHS waiting lists really reach 13 million? https://ifs.org.uk/publications/15557
[5] Institute for Fiscal Studies, 2021. Could NHS waiting lists really reach 13 million? https://ifs.org.uk/publications/15557

weeks for treatment was 1,600. These longer waiting times have a significant impact on people in later life.

4. Disproportionate impact of waiting lists on people in later life

4.1 While NHS waiting times disaggregated by age are not available, severe delays in access to elective care are likely to have disproportionately impacted people aged 65 and above, who are more likely than any other age-group to have multiple conditions or require elective hospital care[6]. Through our research, people in later life told us their physical, emotional, and mental health has deteriorated while waiting for treatment. Some have reported experiences of long periods of avoidable pain, anxiety and depression, diminished mobility, and increased care needs.

4.2 Independent Age's forthcoming research, due for publication in late September, focuses specifically on improving the experience of people aged 65 and over in England waiting for common elective or non-urgent surgical procedures. The lower priority afforded to life enhancing surgeries such as joint replacements and ophthalmic (eye) operations has resulted in older patients facing longer waits during the pandemic with a profound impact on their quality of life. While age breakdowns are not available, it's likely that a large proportion of the 668,763 patients waiting for orthopaedic treatment in June 2021 were people in later life.[7]

4.3 Almost 5,000 people aged 65 and over responded to our Home Truths survey in 2021.[8] We asked about a range of challenges they might have experienced during the COVID-19 pandemic:

- 34% reported that their health had got a bit worse, and 9% reported it had got much worse
- 21% reported that their regular healthcare or treatment had been postponed or cancelled because of the pandemic
- 46% said reducing NHS waiting times was one of the most important things needed to protect the mental health of people in later life

5. Variation and inequalities in the backlog

5.1 Significant regional variation in the length of surgery waiting lists and post-surgery outcomes in England has created a "postcode lottery". Levelling up will require innovation to ensure equitable access to elective care and perioperative support wherever you live, not least for people in later life who may feel less able to access different hospitals or move to areas with better healthcare.

5.2 Across acute trusts the percentage of those for trauma and orthopaedics seen within 18 weeks varied from 28% to 100%.[9] Furthermore, the median wait for all treatments varies from 2.7 weeks to 18 weeks across Trusts whereas for trauma and orthopaedic it ranges from 2.6 weeks to 34 weeks on average across Trusts.[10]

5.3 While all regions experienced significant reductions in elective activity, the largest fall was in the North West, with 31% fewer total completed pathways in 2020 than in

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[6] Nuffield Trust, 2021. Elective (planned) treatment waiting times. https://www.nuffieldtrust.org.uk/resource/treatment-waiting-times
[7] Benzeval, M., Booker, C. L., Burton, J., Crossley, T. F., Jackle, A., Kumari, M. and Read, B. (2020), 'Briefing note COVID-19 survey: health and caring', Understanding Society Working Paper Series No. 2020-21. https://www.iser.essex.ac.uk/research/publications/workingpapers/understanding-society/2020-11
[8] Independent Age: 'Home Truths: Experiences of people in later life during Covid-19' 2021
[9] NHS England (2021) Consultant-led Referral to Treatment Waiting Times Data 2020-21. https://www.england.nhs.uk/statistics/statistical-work-areas/rtt-waiting-times/rtt-data-2020-21
[10] NHS England (2021) Consultant-led Referral to Treatment Waiting Times Data 2020-21. https://www.england.nhs.uk/statistics/statistical-work-areas/rtt-waiting-times/rtt-data-2020-21

2019. The smallest reduction was in the South West, which still recorded a 24% reduction compared with 2019. It is unlikely to be a coincidence that the South West and East of England, regions that came closest to restoring services to pre-pandemic levels prior to the second wave, generally had below average rates of the virus.[11]

5.4 Analysis by the Health Foundation found that in 2019 and 2020, the number of completed treatment pathways fell by 9,162 per 100,000 population in the most deprived areas of England, compared with a fall of 6,765 in the least deprived areas.[12]

6. Increased demand for community healthcare

6.1 In addition to demand for hospital care, the rising waiting list is likely to increase demand for general health management and community care. Community healthcare is a term that refers to care outside of hospital but separate from GP and other primary care services. It includes physiotherapy, rehabilitation, and exercise classes.

6.2 Delays to surgery will likely result in services that support prehabilitation and rehabilitation facing a high pent-up demand, which will impact deconditioning and deterioration in older people. Having good support, particularly prehabilitation, can help patients prepare properly for surgery. In addition, effective condition management can help patients 'wait well' and may help reduce the pain and anxiety that can arise while waiting for surgery. While such services exist, the NHS should think further how to better integrate these services into patient care plans and ensure that this support is provided on a more consistent basis. Our research suggests that many people in later life are not receiving the support they want and need while they wait for treatment. Yet, when it is provided it can have significant impact on patient experience and wellbeing.

7.The demand for mental health services

7.1 The research and analysis we conducted for our Minds that Matter report produced in 2020 confirmed that many people aged 65 and over experience mental health problems such as anxiety and depression. Conversations we've had throughout the pandemic suggest that COVID-19 has exacerbated existing mental health conditions and caused mental health to deteriorate in people who previously did not have problems.

7.2 A September 2020 analysis of older people who were shielding found that 'there were markedly higher levels of depression and anxiety among the high risk [shielding] group compared with the remainder [of older people]. Severe depression and anxiety symptoms were twice as common among high-risk individuals who were socially isolating compared with average risk participants.[13] More recently, in an Independent Age survey of 3,083 people aged 65+ conducted between June and July 2021, 48% of respondents said the pandemic has made their mental health worse.[14] We therefore anticipate the pandemic will lead to an increased demand for access to mental health services among people in later life. This may particularly be the case where the effects are *persistent*, such as the impacts of complicated bereavement, chronic loneliness and ongoing physical deconditioning.

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[11] Health Foundation, 2021. Longer waits, missing patients and catching up: How is elective care in England coping with the continuing impact of COVID-19? https://www.health.org.uk/news-and-comment/charts-and-infographics/how-is-elective-care-coping-with-the-continuing-impact-of-COVID-19
[12] Health Foundation, 2021. Longer waits, missing patients and catching up: How is elective care in England coping with the continuing impact of COVID-19? https://www.health.org.uk/news-and-comment/charts-and-infographics/how-is-elective-care-coping-with-the-continuing-impact-of-COVID-19
[13] Steptoe and Steel, 2020. The experience of older people instructed to shield or self-isolate during the COVID-19 pandemic. Health: ELSA.
[14] Independent Age online survey, 2021.

7.3 Poor physical health also has an impact on people's mental health. Our research, and conversations with older people suggests that increased waits for surgery and general physical deconditioning due to the restrictions in place to cope with the pandemic have caused a deterioration in mental health.

7.4 Our 2020 research illustrated how long waits for mental health support can be difficult for people, with one survey respondent saying:

> *'I went to [the doctor] and he put me on a referral pathway for the cognitive behavioural therapy programme that the IAPT team was running. Well, first of all I had an assessment in February with a psychologist, which was very helpful. But then I was waiting and getting worse between February and November, when I had my first appointment.'*

7.5 We are concerned that due to the unprecedented pressure on GP practices, some older people have either been unable to get appointments to discuss their mental health or haven't wanted to book an appointment and take a slot away from someone who they believe might need it more than them. Alongside this, we know many people in later life have been reluctant to visit their GP due to anxiety around COVID-19 exposure. Due to these multiple factors, we are concerned that many people needing mental health support have not yet presented to their GP, creating a hidden waiting list.

7.6 GP surgeries have made much available online, which we know will have worked for people of all ages, but there are some in later life who are not online, or have poor internet connection, and will have been unable to engage with their surgeries and health professionals remotely.

8. Bereavement support

8.1 Independent Age estimates that up to 318,000 people aged 65+ in England and Wales lost their partner (by all causes of death) during the period between the first lockdown in March 2020 and the ending of many of the restrictions in May 2021[21]. Although many cope with a bereavement without the help of formal bereavement support services, we know these are vital for some. Normally just under 10% of the bereaved population go on to experience something called complicated grief, or prolonged grief disorder. This is where the normal grieving process is interrupted and people feel unable to move through their grief. We are concerned that the restrictions in place during the pandemic have caused great disruption to the grieving processes, increasing the likelihood of more people experiencing prolonged grief disorder, and therefore needing treatment.

8.2 We know some will not have sought help yet, while others may be left alone to cope with their grief while they sit on long waiting lists for support. Concerns about waiting times for bereavement support came through in an Independent Age survey on the impact of COVID 19, conducted in May 2021. Comments included:

> *"Told nothing available. On waiting list for months. Still suffering shock."*
>
> *"I was place on a list for bereavement support but I was never contacted."*
>
> *"My GP has referred me to a councillor, I've been waiting about 2 months so far."*

<u>What capacity is available within the NHS to deal with the current backlog? To what extent are the required resources in place, including the right number of staff with the right skills mix, to address the backlog?</u>

9.1 GPs play a crucial role in the provision of mental health support, prescribing effective medication and making referrals to IAPT or social prescribing services. They also assess and refer people on for further treatment and surgery for physical health issues such as knee replacements and cataract operations. We know GPs have faced unprecedented challenges during the pandemic and we are concerned that this could have limited the number of older people getting support being referred to the support they need for both their physical and mental health problems. Recent polling by the Richmond Group shows that people (of all ages) reported worse experiences of access to, and quality of, a GP in June 2021 compared to February 2021.[15]

9.2 Regarding IAPT services to support people with mental health problems, even prior to the pandemic, people aged 65+ consistently made up only around 6% of IAPT clients[16], well short of the 'expected rate' of 12% calculated by the Department of Health in 2011.[17] During the pandemic there has been a drop in referrals, from a high of 163,000 in January 2020 to a low of 58,000 in April 2020.[18] Referrals have not yet fully recovered to pre-pandemic levels. While the latest data suggests that IAPT services are currently largely meeting waiting times targets,[19] with 93% of all referrals for people aged 65+ in Q4 2020 starting treatment within 6 weeks, these figures don't fully reflect the impact of disruption in access to GPs, who are the primary source of referrals to IAPT,[20] and the resulting 'missing referrals'. As a result, we are concerned that there will be a large surge in referrals, potentially leading to increased waits for treatment. It's also crucial not just to look at waiting times between referral and first appointments. Previous research reveals that in the majority of CCGs in England, the average waiting time between a patient's first and second IAPT treatment was longer than the average initial wait for treatment.[21]

How much financial investment will be needed to tackle the backlog over the short, medium, and long-term; and how should such investment be distributed? To what extent is the financial investment received to date adequate to manage the backlog?

10. Long term investment to reduce waiting lists

10.1 Tackling the scale of the backlog will require political will and long-term investment. It's crucial that funding is directed towards strengthening NHS capacity and addressing workforce pressures, in combination with short term funding for community services to empower patients to "wait well".

10.2 This dual focus on patient experience alongside patient outcomes will help reduce pressure on hospitals, improve quality of life and resilience in patients waiting for treatment, and deliver longer term savings to the NHS and social services. Improving communication, preparation and support for patients on waiting lists will be pivotal to ensuring nobody is left behind in recovery efforts.

10.3 The British Medical Association has estimated that the cost of the backlog of non-COVID-19 services is at least £10.7 billion.[22] The Royal College of Surgeons of England

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[15] Richmond Group of Charities and Britain Thinks, 2021. Attitudes towards and experiences of the NHS during Covid-19: views from patients, professionals and the public.
[16] NHS Digital, 2020. Psychological Therapies, Annual report on the use of IAPT services 2019–20.
[17] Department of Health, 2011. Talking therapies: A four-year plan of action.
[18] Nuffield Trust, 2020. Improving Access to Psychological Therapies (IAPT) programme.
[19] NHS Digital, 2021. Psychological Therapies: reports on the use of IAPT services, Quarter 4 2020-21 data.
[20] Pettit, S., Qureshi, A., Lee, W., Stirzaker, A., Gibson, A., Henley, W., & Byng, R. (2016). Variation in referral and access to new psychological therapy services by age. *British Journal of General Practice*.
[21] House of Commons Library, 2020. Briefing Paper: Mental health statistics for England: prevalence, services and funding.
[22] British Medical Association, 2020. Spending review 2020. https://www.bma.org.uk/media/3567/spending-review-2020-member-briefing.pdf

has said the recovery fund cannot be a one-year commitment only and must be an annual commitment for at least six years.[23]

10.4 We support calls for the Department for Health and Social Care to produce annual independent projections of healthcare workforce needs, coupled with a workforce plan. In terms of infrastructure investment, greater use of surgical hubs[24] has the potential to reduce strain on services. However, careful consideration and acknowledgment of access constraints, particularly for those in later life, is required. Services need to be designed to account for people's circumstances such as difficulty travelling far from home and the anxiety of being in an unfamiliar hospital. This means reviewing and investing in patient transport services and other local community services that help people get to NHS sites.

What can the Department of Health & Social Care, national bodies and local systems do to facilitate innovation as services evolve to meet emerging challenges?

11.1 Social prescribing can be an important route to provide support for people in later life to stay well while they wait for surgery. Social prescribing enables health professionals to refer people to a range of local, non-clinical services, often focused on improving mental health and physical wellbeing. We welcome the Government's recent focus on social prescribing as part of a targeted NHSE&I initiative to use personalised care approaches to support elective waiting list management, but this must be implemented consistently across the country.

How might the organisation and work of the NHS and care services be reformed in order to effectively deal with the backlog, in the short-term, medium-term, and long-term?

12. More support for waiting well services (community services)

12.1 Demand for community healthcare is rising, primarily due to the shift in disease burden as people live longer with long-term conditions that cannot be cured by episodes of acute hospital treatment. Better support in the community can not only improve overall resilience and quality of life for patients while they wait, but also improve hospital outcomes and reduce the strain on primary care, hospital administration and A&E. However, current support is very poor for people in later life.

12.2 Our research suggests that a high proportion of people in later life do not receive additional treatment or information on managing their condition while waiting. Yet patients have told us this would have a big impact on their experience of waiting. Improving people's experience means improving supporting them to avoid deterioration and putting more focus on helping people manage their condition while they wait. It also means ensuring patients get the information and advice they want while they wait.

12.3 Research from National Voices highlighted key ways to support people living with long term conditions, including receiving continuity of care over time, being given relevant information, being treated as a partner in care, and support and advice being provided between appointments.[25]

[23] Royal College of Surgeons of England, 2021. A new deal for surgery. https://www.rcseng.ac.uk/about-the-rcs/government-relations-and-consultation/position-statements-and-reports/action-plan-for-england/
[24] Royal College of Surgeons of England, 2021. A new deal for surgery. https://www.rcseng.ac.uk/about-the-rcs/government-relations-and-consultation/position-statements-and-reports/action-plan-for-england/
[25] National Voices (2021) Ask How I Am: Supporting emotional health among people living with long-term conditions. https://www.nationalvoices.org.uk/publications/our-publications/ask-how-I-am

12.4 We believe there may be a gap in integrating community healthcare into wider patient care plans. We anticipate demand for community health care to increase significantly in line with projected increases in waiting lists.

13. Social care funding and reform

13.1 Investment in the NHS alone will not ensure that the people who rely on these systems get the help they need, when they need it. In order for the people to receive the care and support they need; it is essential that the Government reform and fund the social care system in England.

13.2 Significant cuts to social care budgets since 2010 have forced councils in England to effectively ration access to social care. Funding for social care was £700 million lower in 2017/18 than in 2010/11.[26] At the same time, demand has been increasing. In 2018/19 there were 1.9 million requests for social care, a rise of 3.8% on the previous year.[27] The consequence has been many more people going without the care they need or relying on family carers to fill the gaps. This situation creates huge anxiety for people in need of care and their families. It also prevents councils being able to invest in anything that is not about immediate crisis management, resulting in opportunities for early intervention being missed. The pandemic has exacerbated these funding issues for councils and left many older people without the care they need.

13.3 People need a fairer set of entitlements to care, and protection from the financial risks that come with developing care needs. For many of the people we speak to, it often comes as a shock to discover that they are liable for their social care costs. Many assume the state plays a much greater role, similar to the model of services free at the point of use in the NHS. The system has also become significantly less generous over time, with no change in the 'floor' of £23,250 for a decade. Currently one in ten people will face catastrophic care costs (of more than £100,000) which can see lifetime savings wiped out due to developing care needs. With no limit on how much people may need to pay, it is incredibly hard to plan ahead. There are currently no mechanisms for individuals to insure themselves against these financial risks. The Health Foundation's international review found that no country they studied has been able to make voluntary insurance work for social care.[28] The state must intervene to effectively share the burden of this risk with the individual.

13.4 It is vitally important that people have the chance to get to know and trust the individuals caring for them. This is undermined if carers change so frequently they feel like strangers. Endemic low pay, poor opportunities for career development and progression have made it extremely difficult to recruit and retain professional care workers in sufficient numbers. There are currently more than 112,000 vacancies in social care, and if the workforce is to grow in line with demographic changes then there will be an additional 480,000 social care roles to fill by 2035 - an increase of 29%.[29] In 2020, the national turnover rate in adult social care was 30.4%, equivalent to approximately 430,000 leavers in that year.[30] There are many reasons for this. While there have been some improvements in pay over the last decade, it is still the case that hospitality and retail jobs often pay equivalent or more for arguably less demanding work. More than

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[26] Kings Fund, Social Care 360, https://www. kingsfund.org.uk/publications/social-care-360/expenditure
[27] Ibid
[28] The Health Foundation, Identifying options for funding the NHS and social care in the UK: international evidence, July 2018 https://www.health.org.uk/sites/default/files/Social%20care%20funding%20-%20international%20evidence_web.pdf
[29] Skills for Care, https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/national-information/The-size-and-structure-of-the-adult-social-care-sector-and-workforce-in-England.aspx
[30] Skills for Care, The state of the adult social care sector and workforce in England, October 2020 https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/nationalinformation/The-state-of-the-adult-social-care-sector-and-workforce-in-England.aspx

half of care workers in domiciliary care are on zero-hour contracts, which while providing flexibility, also give little stability.[31] Pay progression is also poor: a care worker with five or more years of experience can expect to earn just 12 pence more per hour than a care worker with less a year of experience.[32] The impact of this for older people is they have very limited opportunity to build up a relationship with those who are assisting with intimate tasks such as washing and dressing. Older people also tell us their care can often feel rushed, and short visits mean the care they receive is very basic and transactional.

13.5 People should be supported to understand how they can access care and have the opportunity to challenge if they do not think the correct decisions have been made about their care. Awareness and understanding of how social care operates is very low. We know from calls to our Helpline that people find the system incredibly complicated to navigate and interpret.

13.6 In addition, we are concerned that it is difficult for people to effectively challenge decisions made about their care and support. In the majority of councils, people have to use a complaints procedure, which in Independent Age's view is not fit for purpose. Local authorities are required to respond to a complaint within six months, but in reality it can take much longer than this, creating significant stress and worry for older people and their families. The language of 'complaints' and its negative connotations can also be off putting. From calls to our Helpline, we know many older people are not comfortable with the idea of complaining. Many do not feel it is an appropriate response to wanting decisions about their care and support to be reviewed. Furthermore, the high proportion of complaints being upheld by the Local Government and Social Care Ombudsman suggests that issues are not being dealt with effectively through current complaints procedures. The Government has previously acknowledged the importance of a robust appeals system for adult social care and consulted on this in 2015, but no response to the consultation was ever published.

13.7 One in five older people in England are carers, and some do not recognise themselves as such and are not aware of the forms of support available. We know from speaking to people in later life, that it can be especially hard for older carers to prioritise their own well-being, and full-time older carers are at increased risk of low mental wellbeing compared to non-carers.[33] Older carers are more likely than non-carers to have physical health problems and are less likely to have had more than 10 visits to the GP in the past 12 months than non-carers.[34] There are also clear financial impacts – full-time carers are more likely to be in the lowest income quintile after housing costs than part-time carers and be unable to cover unexpected costs.[35]

14. Recommendations

14.1 Waiting well

Short term

- NHSE&I to mandate the development of a personalised care and management plan for all people waiting 6 months or longer for treatment. Such plans should be reviewed to adapt to changing needs, including fast referrals for any physical and mental health conditions that emerge as they wait.

[31] Ibid
[32] Ibid
[33] Independent Age, In Focus: experiences of being an older carers, https://independent-age-assets.s3.eu-west1.amazonaws.com/s3fs-public/factsheets/2020-03/IA-PI377_Carers_snapshot_v4.pdf?Q_zkx1vVmCSRlKBUCoGe99aswpIOEeWS
[34] Ibid
[35] Ibid

- NHSE&I should develop guidance on the involvement of health professionals with expertise in treating older patients in the clinical validation of patient waiting lists.
- NHSE&I should support the implementation of its guidance on 'Communicating with Patients Waiting for Care' by piloting different approaches to support these principles. Trials should include the creation of a single point of contact for waiting patients, and information about the Patient Advice and Liaison Service (PALS) in patient correspondence.
- The Prime Minister should establish a taskforce for managing the waiting list backlog with a requirement to publish annual progress reports. This should include detailed analysis of regional variations in performance, workforce and staffing levels and any health inequalities within the backlog.

Medium term

- NHSE&I should support ICSs to develop consistent and best practice perioperative pathways so that every patient has the best opportunity to prepare for their treatment and 'wait well'.
- DHSC should fund surgical hubs in each ICS, targeting high volume procedures such as knee and hip replacements. Funding must take account of the staffing requirements for these hubs and the expansion of wrap-around services, such as patient transport, to make sure these sites are easily accessible to all older patients.
- NHSE&I should work with charities, patient groups and other providers to provide clear signposting to local and national services that can provide practical or emotional support for those waiting for treatment

Long term

- NHSE&I should assess patient-facing administration processes such as hospital correspondence, switchboards and booking systems. It should use this information to help Trusts improve these services for people in later life.
- DHSC should develop a long-term plan for NHS recovery which maintains the healthy lives of older people at its centre. This must consider the impact of the pandemic on people in later life and related NHS health workstreams, and refresh commitments to improving the health and care of older people in light of these.
- DHSC should be required to produce annual independent projections of healthcare workforce needs and publish a new workforce plan. This should look at workforce needs to both reduce waiting times in hospitals and to help older patients 'wait well' by increasing the allied healthcare workforce.
- NHSE&I and NHS Digital should support Trusts to publish more granular data to identify differences in the waiting experiences of particular groups, especially different groups in later life.

14.2 Discharge to Assess

- With current funding expiring, renewed investment in discharge to assess is urgently needed to improve health outcomes among people in later life and reduce strain on the NHS by enabling patients to swiftly transition from inpatient hospital care to community care and support.

14.3 Mental Health Services

We are calling for increased support for GPs to enable them to improve the identification of mental health needs among people in later life and to provide a choice of support, including referrals to Improving Access to Psychological Therapies (IAPT) services.

- The Government and the NHS should monitor the age profile of GP and IAPT service users and take action where needed to ensure older people have equitable access to support.
- Public awareness campaigns should target older people to raise their awareness of IAPT.
- GPs and IAPT services should continue to give older people a choice of channel for appointments (e.g., online, telephone, face-to-face), ensuring that everyone can access services in a way that suits their needs and circumstances.
- GPs, when looking at physical health issues with older people, should use short screening tools to help identify anxiety and depression where appropriate.

14.4 Bereavement Support

Bereavement is currently a somewhat neglected area at both national and local levels. To address waiting times for, and increase access to, bereavement support, we would like to see a greater clarification of responsibilities for this key service.

At the local level we would like to see a named bereavement lead within each ICS structure who is responsible for:

- Mapping the level of need in the population with a particular focus on lesser heard communities.
- Mapping existing provision of both informal and formal bereavement support and who this currently reaches in order to identify gaps in provision.
- Coordinating information sharing between existing groups working to support bereaved people and feeding in local information to create accurate, up-to-date national databases of support options.
- Developing strategies for what the right touchpoints are for more consistent signposting from both professionals within health and social care but also within community settings.
- Although this set of tasks cannot be achieved by any one individual and will require partnership working between all parts of the system, we think a named lead would provide greater focus and accountability for these activities.

This should be complemented at the national level with a named bereavement lead within NHS England to drive a more strategic approach and champion the need for investment in bereavement services, including those provided by the voluntary and community sector. While improvements in bereavement services will happen at the local level, this national leadership could make a real difference to engagement and investment in bereavement services. This role could sit within the existing briefs of mental health or end of life care, but it is important that responsibility is clearly attributed.

14.5 Social care reform

The social care system in England is in need of wholescale reform and significant financial investment. To improve the experience of people in later life and their families, Independent Age recommends:

- The Government bring forward a funding plan which ends the cycles of crisis and lastminute cash injections that have characterised the social care sector in recent years. This is the fundamental building block of all future reform.
- The Government introduce a universal entitlement to social care free at the point of use. This must include covering personal care costs, but we would welcome any policy that went further to include services that go beyond personal care.

- The Government establish a mechanism to protect people from catastrophic costs. However, it is crucial that any policy to cap these costs forms just one part of a package of wide-reaching reforms.
- The Government publish a comprehensive workforce strategy, akin to the People Plan for the NHS. Wages must be increased to reflect the complex and demanding work that professional carers do. There must also be pay parity between the NHS and social care for equivalent roles. Professionalisation of the care sector which should include establishing a registration model to bring England in to line with Scotland, Wales and Northern Ireland. Government and care providers also need to work together to develop clear career pathways in social care, including a system of portable, accredited training.
- The Government bring forward an immigration system that will enable a route for care workers from overseas, as it is unlikely we can fill gaps with domestic recruitment alone.
- Local authorities take steps to actively promote the entitlement to carer's assessments and increase the number of assessments they conduct to ensure that the safety and wellbeing – including mental wellbeing – of unpaid carers is protected. This must be adequately resourced to make sure that local authorities are supported to implement this work.
- Local authorities ensure all family carers are aware of the options open to them for respite and how to access these.
- Local Authorities provide clear, actionable information and advice to everyone who needs it, including self-funders, as stated in the Care Act.
- The Government implement a statutory appeals process for adult social care, as already outlined in the Care Act. As a first step, they should re-open the consultation on an appeals process for adult social care.