



**Independent  
Age**

# Patiently waiting

Older people's experiences  
of waiting for surgery

# Contents

Foreword	2	4. Supporting people to avoid decline and helping to prepare for surgery	30
Acknowledgements	4	4.1 Helping patients prepare for surgery	31
Recommendations	5	4.2 Improving condition management	32
1. Introduction	7	4.3 Recommendations	34
1.1 Scope of this report	8	5. Patient communications	35
1.2 Methodology	9	5.1 Engagement while on the waiting list	36
1.3 Surgery in later life	10	5.2 A point of contact	39
2. Waiting times and the impact of COVID-19	12	5.3 Recommendations	41
2.1 Waiting times before the pandemic	13	6 What needs to happen now	42
2.2 The impact of COVID-19 on waiting times	14	6.1 Recommendations	44
2.3 Prioritisation of surgery	16	7 Conclusion	45
2.4 The 'missing patients'	17	Endnotes	47
2.5 The postcode lottery remains	18		
2.6 Financial insecurity and health	19		
2.7 Current plans for recovery	20		
3. The impact of waiting on older patients	21		
3.1 Deterioration while waiting	22		
3.2 Waiting in pain	23		
3.3 Declining mental health and wellbeing	25		
3.4 Loss of purpose	28		
3.5 Recommendations	29		

# Foreword



*We have spent the past year learning how surgery can help people in later life and what their experiences have been before and after treatment.*

**The fact that many of us are lucky enough to be living longer should be celebrated, but we also need to be realistic about what this means. For some, ageing can come with a range of long-term conditions, disabilities and short-term illnesses. These can be hard to cope with, and often have a severe impact on someone's physical and mental health.**

For those where an operation would help, having surgery can be a truly transformative experience. Whether it's something lifesaving like having a cancerous tumour removed, or something life-enhancing such as a knee replacement, surgery can change someone's experience of life and their outlook.

At Independent Age, we have spent the past year learning how surgery can help people in later life and what their experiences have been before and after treatment.

It's no surprise to those of us who work in, work with or use the NHS that it has been struggling in recent years to meet demand for its services. However, COVID-19 has pushed it, and those working in it, to the brink, with many services unable to continue as normal.

Non-urgent procedures have been put on hold as everything was done to reduce the pressure on hospitals, so they could continue providing urgent and lifesaving treatment during a truly difficult time.

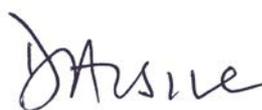
This has had an inevitable impact on waiting lists for other treatments. As I write this, there are more than 5.6 million people waiting for hospital treatment across the country. Worryingly, that number doesn't include the millions who haven't come forward for treatment yet, including those who may have stayed away from health services for fear of catching COVID-19 or because they didn't want to create more work for the already hard-pushed staff in the NHS. A large proportion of the people waiting are older and many are living in pain every day, as they wait for treatment for their hips, knees and other procedures that could significantly improve their quality of life.

Through our research we heard from people in later life who are struggling with day-to-day tasks like preparing food, brushing their teeth or going for walks. Their wait for surgery is affecting their mood and wellbeing, and many have told us they feel frustrated and forgotten. We spoke to one woman, for example, who waited almost two years for a joint-replacement operation. This was well before the pandemic began. Her health deteriorated so much during the wait that she was unsure whether she was physically able to have the operation at all. To compound the situation, she received little information from the hospital, and no guidance on how to stay well while she waited. That can't be right.

We know that it will be a long road to recovery for the NHS. It will take sustained investment and political will to get us back to achieving the elective waiting times standard. And while we agree this must be a priority for our government and NHS, there are actions we can take right now to improve the experience of the millions of people aged 65 and over waiting for surgery.

We know that people in later life need good communication, preparation and support to 'wait well' and feel empowered, informed and involved in decisions about their treatment.

At Independent Age, we are ready and willing to play our part to ensure solutions to improve people's experience when accessing surgery are identified and implemented. We look forward to working with others across national and local governments, and with the NHS, to make this a reality.



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**Deborah Alsina, MBE**  
Chief Executive

# Acknowledgements

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# Recommendations

## Enable everyone to 'wait well'



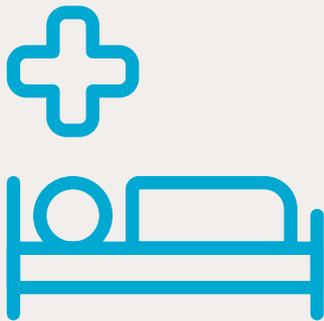
1. NHS England and Improvement (NHSEI) to mandate developing a personalised care and management plan for all people waiting six months or longer for treatment. Such plans should be reviewed to adapt to changing needs, including fast referrals for any physical and mental health conditions that emerge as they wait.
2. NHSEI should develop guidance on involving health professionals with expertise in treating older patients in the clinical validation of patient waiting lists.
3. NHSEI to support integrated care systems (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.
4. NHSEI to 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.

## Improve patient involvement and engagement



5. NHSEI should support implementing its guidance *Good communications with patients waiting for care* by piloting different approaches to support these principles. Trials should include creating a single point of contact for waiting patients, and information about the Patient Advice and Liaison Service (PALS) in patient correspondence.
6. NHSEI to assess patient-facing administration processes such as hospital correspondence, switchboards and booking systems. It should use this information to help NHS trusts improve these services for people in later life.

## Increase NHS capacity



7. The Department for Health and Social Care (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.
8. 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.

## Provide leadership and accountability



9. 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 analyses of regional variations in performance, workforce and staffing levels and any health inequalities within the backlog.
10. DHSC, alongside the prime minister's new taskforce, should develop a long-term plan for NHS recovery that 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.
11. NHSEI 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.

# 1. Introduction



## 1. Introduction

**Waiting times for routine NHS physical health treatment in England have increased in the past five years. Accessing treatment in a timely manner was a challenge before the outbreak of COVID-19 in March 2020, and the pandemic has made the problem much worse.**

At Independent Age, we want to ensure that as we grow older, we all have the opportunity to live well with dignity, purpose and choice. This is currently not the case. Many people in later life across the country have told us that, as they wait for surgery, their condition is getting worse, they face daily pain and they often lack basic information on how to manage their condition before their operation.

The issue of waiting for treatment is not unique to people aged over 65. In England, however, this group is a greater user of elective hospital care than any other age group. Common circumstances like living alone or having multiple conditions can also make managing a condition and preparing for surgery more complex.<sup>1</sup> So, it is crucial that the health system, national and local governments and the third sector recognise the distinct needs of this group when it comes to access to treatment.

The NHS has been under unprecedented pressure since the start of the pandemic and the recovery from that will be a long process. There is no one solution to rebuilding the NHS for a post-COVID world, but this report contributes to the debate by adding the voices of people aged 65 and over. Reducing the backlog of elective care will take several years, but it is possible to immediately improve the experience of those waiting for treatment by rethinking the support we give to them.

In sharing the experiences of people in later life, this report intends to draw attention to the importance of maintaining the quality of life of those waiting for treatment, why good perioperative care and support are vital, and the value of good communication to patient wellbeing. Independent Age hopes to reframe the waiting times debate so that national and local plans do not just focus on achieving targets but also improve the everyday experience of those in later life who are waiting to be treated.

### 1.1 Scope of this report

Older people's experience of hospital and surgical treatments is a complicated topic covering a range of issues across the treatment pathway. In this report, we focus on the experience of people aged 65 and over in England waiting for common elective or non-urgent surgical procedures. We do not focus on any one health condition, but instead look at commonalities across different conditions and circumstances of people in later life. We review the impact of waiting on older people's mental, emotional and physical health. And we identify what older patients want in terms of support and information as they wait for surgery.

This report does not attempt to summarise or assess the different clinical approaches that can be applied to people in later life, including the initial assessments on the suitability of surgical treatment; nor does it intend to recommend different clinical approaches for perioperative care.

## 1. Introduction

In this report, we:

- examine the issues affecting older people's access to surgery, both pre- and post-pandemic
- look at how longer waiting times affect people in later life
- explore what people in this group say about their experience of waiting for surgery
- consider what changes could make this experience better.

### 1.2 Methodology

Our research began in spring 2021. The data was collected during a period when the NHS was beginning to resume non-urgent services and address the backlog created during the COVID-19 pandemic.

For our research, we:

- conducted a literature review using a snowball methodology to assess the impact of waiting times on quality-of-life outcomes
- interviewed 26 people in later life across England about their experience of waiting for surgery
- surveyed almost 3,000 older people in England about the impact of the pandemic on their physical health and their access to healthcare
- commissioned an online, nationally representative YouGov survey of about 8,000 people aged over 50, and another poll of about 4,000 adults aged over 18 in Great Britain, asking questions about people's experience, needs and priorities when waiting for treatment on the NHS.<sup>2</sup>

Our recommendations and analysis of this data were informed by discussions with other charities, experts and clinicians, as well as Independent Age colleagues and campaigners. We wish to thank everyone involved in this research project.



## 1. Introduction

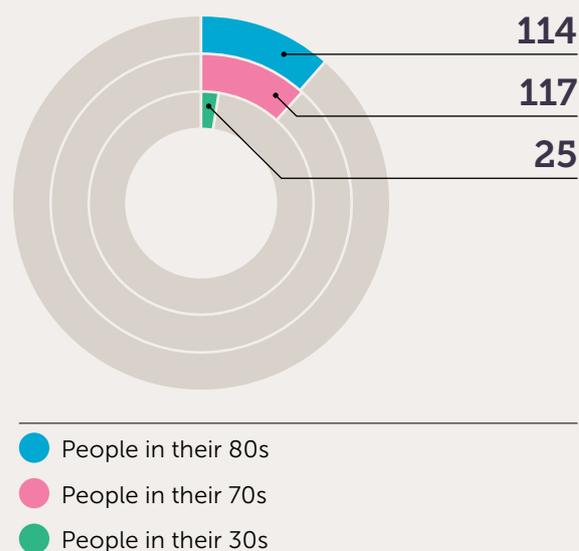
### 1.3 Surgery in later life

People aged 65 and over in England generally access health services more regularly than younger people, broadly reflecting the increased likelihood that they will have multiple health conditions. This trend has increased in recent years, with the number of primary care consultations, and the length of these consultations, rising significantly in line with age in later life.<sup>3</sup> In December 2019, prior to the pandemic, there were more than 3.3 million hospital admissions for people aged 65 and over, which made up more than a third of all admissions in that month.<sup>4</sup>

People in later life are also greater users of elective hospital care than any other age group. Common types of elective procedures for people aged 65 and over include joint replacements and ophthalmic (eye) operations. Analysis by the Institute for Fiscal Studies (IFS) found that, in 2017, there were 117 elective hospital admissions per 1,000 people in their 70s, and 114 for those in their 80s. This compares with 25 for every 1,000 people in their 30s.<sup>5</sup> This implies that any delays to elective care are likely to have a bigger effect on the older population.

However, it is worth noting that rates of elective care are lower for those aged 90 and over. This reflects that surgery for the 'oldest old' in our society is often seen as a last resort, reflecting the typically higher levels of frailty seen among those who make up this group. In addition, the increase in comorbidities – living with multiple conditions – among those in later life has made judgements harder when considering if surgery is a suitable treatment.

#### Elective hospital admissions per 1,000 people



## 1. Introduction

There has been growing medical recognition that biological age matters more than chronological age when assessing fitness to treat people with surgery. In addition, the nature of ageing and being able to age well has begun to change perspectives among patients. Older patients are now more likely to expect a higher standard of wellbeing in later life and have higher expectations of independence, quality of life and managing chronic conditions.

There are multiple factors involved when considering what treatment an individual should receive. Importantly, these judgements cannot be generalised across patients or age groups. It appears progress has been made to ensure more consistent access to surgery for those in later life. However, less focus has been put into ensuring that older patients do not deteriorate as they wait for surgery or into reviewing what good support for this group looks like.



## 2. Waiting times and the impact of COVID-19



## 2. Waiting times and the impact of COVID-19

### Waiting times were rising before the pandemic but have now risen to unprecedented levels.

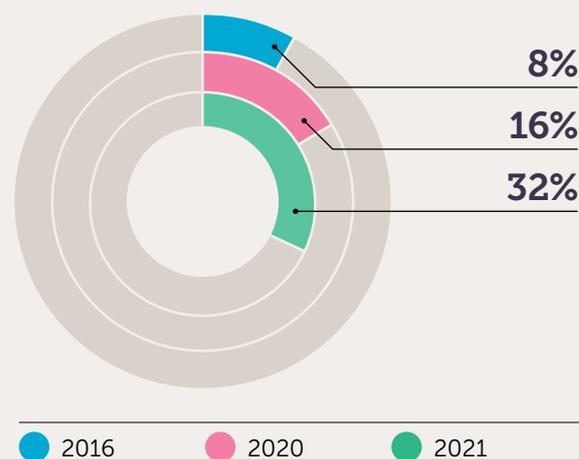
COVID-19 pressures have meant patients have been categorised based on the surgery they require, with those requiring life-enhancing surgeries, like joint replacements, typically being lower priority. As a result, older patients requiring these surgeries are facing longer waits, with a large number waiting more than 12 months. While the NHS is all too aware of these problems, the current plans are insufficient to tackle the backlog and, in particular, address the needs of people in later life waiting for surgery.

### 2.1 Waiting times before the pandemic

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 care and staffing shortages, led to deterioration in hospital performance and other services across the board.<sup>6</sup> Our ageing population has been a factor in rising demand, but this only explains part of the rise in demand for NHS services since 2000.<sup>7</sup>

In February 2016 there were more than 3.3 million patients on the waiting list, of whom nearly 270,000 had waited more than 18 weeks.<sup>8</sup> By January 2020, before the full impact of COVID-19, a total of 4.4 million patients were on the waiting list, with almost 1 in 6 of these (approximately 730,000) waiting more than 18 weeks.

### Patients waiting more than 18 weeks



**The number of people waiting for hospital treatment reached a record high of 5.6 million in July 2021**

## 2. Waiting times and the impact of COVID-19

### 2.2 The impact of COVID-19 on waiting times

The COVID-19 pandemic has provided a dramatic shock to the NHS at all levels. In the early months of the pandemic, NHS operational plans and resources were redirected to managing the outbreak, treating those infected with the virus and preventing the health service from being overwhelmed.

Eighteen months on from the initial outbreak, the NHS continues to struggle to return to business as usual. Leading reasons for this include being advised to postpone all non-urgent treatment in England, public fear around the safety of health settings leading to non-presentation for treatment (worsening health in many cases), and the increased burden of infection control on service delivery and staffing levels.

These impacts have not been consistent on all populations and groups: for example, the beginning of the pandemic saw many people discharged early to clear beds for incoming COVID-19 patients, which particularly affected older patients. A YouGov survey commissioned by the Resolution Foundation also found that people with long-term conditions, women and people aged over 55 saw the biggest reduction in use of health services during the peak of the pandemic.<sup>9</sup>

One of the biggest impacts of the pandemic on the health service has been the rapid rise in waiting lists and waiting times created by suspending non-urgent elective activity, and the reduction in hospital capacity.

The number of people waiting for hospital treatment reached a record high of 5.6 million in July 2021.<sup>10</sup> More than 1.7 million (32%) of the patients on the waiting list had waited longer than the 18-week standard, with almost 300,000 waiting 52 weeks or more (293,102 patients). To give some context, prior to the pandemic, in February 2020, the number of patients waiting more than 52 weeks for treatment was 1,600.

### The waiting time standard

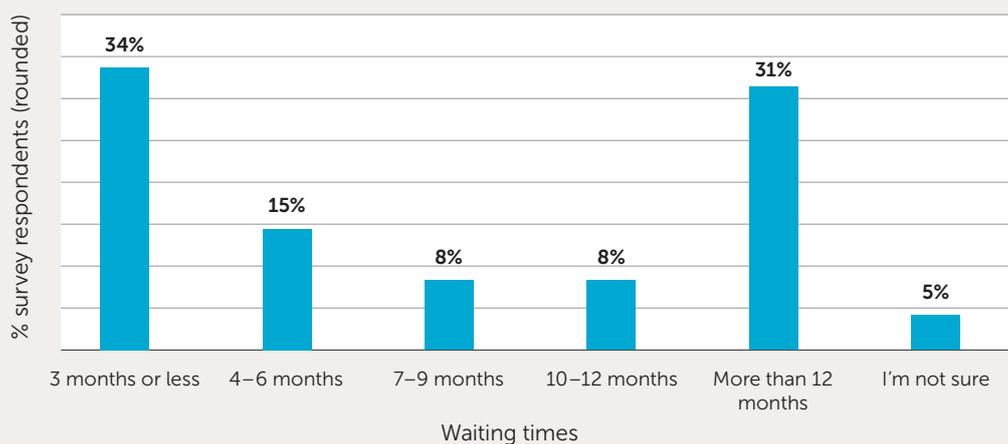
NHS waiting times standards set out the maximum amount of time most patients should have to wait to access specific services, such as planned hospital care and accident and emergency services.

In 2004 the Department of Health introduced new guidelines outlining that NHS patients should wait a maximum of 18 weeks from GP referral to initial consultant-led treatment in hospital. The NHS waiting time standard states that at least 92% of patients should wait no longer than 18 weeks for referral to routine hospital treatment. There is also a zero-tolerance policy on patients waiting longer than 52 weeks.

A review of NHS access standards began in 2019. The interim report proposed a new target of 'average wait' for people on the waiting list as a potential alternative to the current 18-week threshold target. Pilots of this approach began in 12 hospital trusts in August 2019, but publication of the review's recommendations has been delayed because of the pandemic.<sup>11</sup>

## 2. Waiting times and the impact of COVID-19

### How long have you been waiting?



\*Survey of 528 people waiting for surgery.

NHS waiting times disaggregated by age are not available; however, data collected in May 2020, as part of the Understanding Society COVID-19 study, suggests that 24% of participants aged over 50 had hospital treatment planned in the month before their interview. Of these, 57% who had treatment booked either experienced a cancellation or postponed their treatment themselves.<sup>12</sup>

In our Independent Age survey about the impact of the pandemic, 19% of respondents said they were waiting for a surgical operation or treatment.<sup>13</sup> Most of these had been waiting for three months or less (34%), but this was closely followed by people waiting a year or more (31%). In our interviews, people had generally been waiting between three months and three years for treatment.

*"I've been waiting two years for [surgery on] this trigger finger, but it began to get worse recently. So, I was aware of the waiting lists for all the people with operations, but I went to my GP and explained it was turning blue...and it seems to be getting very painful, so I said, 'Could I get someone to have a look at it?' So, they did it over the phone, they didn't go and look at it. Then I got a letter to say on the 28th of this month I'm going to have the operation."* Declan, 74, waiting two years

*"Well, I was just waiting for them to get in touch because I don't think there's any point really, is there, because they don't seem to be doing anything, it's just the national COVID service at the minute, isn't it? They haven't got anything for anybody else."* Theresa, waiting nearly two years

## 2. Waiting times and the impact of COVID-19

Predictions about the size of the waiting list generally accept that it will get worse before it improves. Modelling of the scenarios suggests it could take between five and nine years to be fully addressed.<sup>14</sup> A recent report from the IFS outlined a best-case projection of nine million people waiting for treatment next year, and a worst-case projection of 11 million people waiting within a year, rising to more than 15 million by the end of 2025.<sup>15</sup>

While there is a need for action to bring down the waiting lists rapidly, a singular focus on figures could risk prioritising numerical targets above patient experience. So, instead of just focusing on reducing waiting lists, we should also consider using the waiting period as an opportunity for people to prepare for surgery and manage conditions. Developing plans that reduce waiting times and improve the experience of the wait would have the biggest impact on those in later life who, as we will show, often have long waits and very poor quality of life while waiting.



*So, I just looked at him and said, 'So, how long is the waiting list?' And he just looked at me. He said, 'What can I say? We've only just opened up the waiting list to ordinary surgeries because of COVID,' and he said, 'I really cannot tell you how long it will be.'*

**Ann, 79, waiting a year**

### 2.3 Prioritisation of surgery

In response to the pandemic, the Federation of Surgical Specialty Associations developed a Recovery Prioritisation Matrix.<sup>16</sup> The matrix provides guidance for patient priority categories for surgery, ranging from P1 (urgent cases to be treated within 24–72 hours) to P4 (routine procedures to be treated in more than three months) categories. While people in later life are represented across all priority categories, many of the surgeries that are more common in later life, such as joint replacements, are categorised as P4.

In October 2020 NHS England published a framework for a national review and clinical validation of surgical waiting lists.<sup>17</sup> This outlined guidance to contact all patients awaiting surgery to reassess their needs and to prioritise the most urgent cases. It also introduced two additional patient priority categories of P5 and P6. These represent patients who wish to postpone a procedure because of COVID-19 or postpone for non-COVID reasons, respectively.

The validation framework outlines that clinicians should:

- check on a patient's condition and establish any additional risk factors
- establish the patient's wishes regarding treatment
- provide good communication between patient and carer and GP.

Information about the number of patients within each surgery priority category is not available; however, the routine surgery categories of P3 and P4 are likely to contain the greatest number of patients. In addition, certain specialities have been disproportionately affected by the pandemic. Orthopaedics (covering joint replacements) has consistently had the largest waiting list, with 681,190 patients waiting for treatment by July 2021.<sup>18</sup> Orthopaedics is also one of a small number of specialities where patients are waiting more than two years for treatment.

## 2. Waiting times and the impact of COVID-19

While age breakdowns are not available, it is likely that older people make up a large proportion of those waiting for orthopaedic treatment.

A recent Policy Exchange report on waiting times highlighted the issue of managing patients who are likely to be waiting much longer than the three-month timescale set as the cut-off for P3 priority patients.<sup>19</sup> It raised the question of what support will be necessary for patients waiting a long time who require re-prioritisation following their initial consultation. The report also indicated that some clinicians believe the re-validating process set out in October 2020 risks worsening health inequalities. The authors of that report propose that reforms are made to the waiting list so that patients are prioritised based on a combination of clinical need, but with higher weighting given for those living in disadvantaged areas, to reflect their overall greater health need.

It is unclear what criteria apply to prioritising those on the waiting lists (aside from those waiting the longest), including how a person's physical condition and frailty is assessed. The lack of clarity around this, especially the role of frailty, makes it difficult to determine whether people could be advantaged or disadvantaged as they age when it comes to prioritising those waiting.

### 2.4 The 'missing patients'

The current record waiting list of 5.6 million patients must also be viewed in the context of the possible millions of missing patients not yet presenting or being referred to treatment. The potential high volume of missing patients may mean that, over time, the waiting lists rise further.

A key factor determining the size of the waiting list is the rate at which new treatment pathways are started and patients are added to the waiting list. This usually happens via a referral made following a GP appointment. In 2020 there was a sharp fall in the number of people starting new treatment pathways: only 14 million, six million (29%) fewer than in 2019.<sup>20</sup>

Projections by the Health Foundation's REAL Centre suggest that if 75% of missing patients are belatedly referred to specialist care, the waiting list could reach 9.7 million by March 2024, with fewer than half of patients treated within 18 weeks.<sup>21</sup>

Whether, when and how these missing patients will be added to the actual waiting list remains the single biggest unknown in planning to address the elective care backlog.<sup>22</sup> However, the Secretary of State for Health and Social Care, Sajid Javid, indicated that waiting lists could reach 13 million people.<sup>23</sup> Given the high proportion of people aged 65 and over who were shielding, and the concerns this group has expressed about not putting pressure on the NHS, it is highly likely that a large proportion of these missing patients are those in later life.

## 2. Waiting times and the impact of COVID-19

### 2.5 The postcode lottery remains

Local and regional variations in the length of surgery waiting lists and post-surgery outcomes have been a feature of the NHS since its creation. Prior to the pandemic, research had already indicated that a postcode lottery remained.<sup>24</sup> Now, COVID-19 has not only increased waits across the board but increased the local variation among providers. This level of variation is a problem for all patients but is particularly acute for those in later life, who may feel less able to access different hospitals or move to areas with better healthcare.

Every national or local surge in COVID-19 cases and hospitalisations had consequences for elective care. However, there were regional differences in the extent of the slowdown in completed treatment pathways and the speed of progress in restoring services. All regions experienced significant reductions in elective activity, but the largest fall was in North West England, with 31% fewer total completed pathways in 2020 than in 2019. The smallest reduction was in South West England, which still recorded a 24% reduction compared with 2019. South West England, along with the East of England, came closest to restoring services to pre-pandemic levels prior to the second wave. That both regions generally had below-average rates of COVID-19 could be a contributing factor.<sup>25</sup>

We can also see significant variation from the waiting list data. In July 2021 the median wait for all treatments, regardless of condition, varied from three weeks to 21 weeks across trusts in England. But this variation was greater for trauma and orthopaedic treatments, where the range was between three weeks to just over 35 weeks across trusts.<sup>26</sup>

This regional variation may also be a product of existing inequalities. 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.<sup>27</sup>



*I'm actually going private because I know the orthopaedic NHS waiting list is horrendous.*

**Susan, 70**

## 2. Waiting times and the impact of COVID-19

### 2.6 Financial insecurity and health

Many of those we interviewed talked about considering private healthcare as they found the wait for surgery intolerable. But a rise in private healthcare use could exacerbate or entrench existing health inequalities particularly among those in later life.

Most of our interviewees told us this was beyond their reach, either because of a lack of health insurance and/or the cost being prohibitive.

In our YouGov survey only 20% of respondents felt that private healthcare was affordable.<sup>28</sup> But this survey also found that 31% of people in later life have considered private healthcare for the operation they are waiting for. In addition, since the start of the pandemic, 18% of those waiting for treatment had paid for some form of healthcare; and, of those who had paid for private healthcare during the pandemic, 51% said it was their first time doing so. Of those who had paid for some form of healthcare during COVID-19, 13% paid for it either through a loan, mortgage or with support from friends and family.<sup>29</sup> This suggests that people may be going into debt to get the healthcare they need. Additionally, 54% said they paid for it out of savings, which may affect their long-term financial security.



**3 in 10 people in later life have considered private healthcare for the operation they are waiting for**



*I did look into the prospect of private for my knee, however, as a pensioner, it was unrealistic because we were talking about, I think it was £15,000 was the cheapest I could find.*

**Kate, 73, waited 18 months**

## 2. Waiting times and the impact of COVID-19

### 2.7 Current plans for recovery

We are now seeing a gradual recovery from the pandemic, but the near-term capacity of the NHS remains uncertain. Fluctuating COVID-19 cases in some areas have slowed down the recovery of elective care, and there remains uncertainty as to how the NHS will manage the combined pressures of the pandemic, flu and winter. As the biggest users of the NHS, any delay in returning to full capacity is likely to be significantly felt by people in later life, which is why greater attention is needed to manage their health outside hospital while they wait for treatment.

Since 2020 the NHS has introduced several measures and directives to return to pre-pandemic levels of service. In March 2021 NHS England published its elective recovery framework. This set out a series of national activity targets for elective treatment, measured against baseline 2019–20 activity. To support recovery, the government has committed £2 billion to tackling the elective backlog up to April 2022.<sup>30</sup> In addition, the recently announced Health and Social Care Levy is expected to raise more than £8 billion a year for elective activity for the three years from 2022–23 to 2024–25.<sup>31</sup> Sector reactions to these announcements suggest that these amounts may still not be sufficient, and also highlight the lack of detail around allocation of the funding. Previous estimates from the British Medical Association put the cost of the backlog at £10.7 billion. And recent estimates from the Health Foundation REAL Centre indicate that to meet the 18-week standard by 2024–25 would have required closer to £17 billion over this parliament.<sup>32</sup>

As well as the recovery framework, NHS England announced a series of pilot initiatives as part of a £160-million 'elective accelerator' programme in May 2021.<sup>33</sup> In this programme, 12 pilot sites will be offered £10–20 million to devise plans to exceed pre-COVID activity. It remains too soon to say what impact this accelerator programme will have on waiting times and patient experience.

The actions taken by government and NHS England are welcome but are not yet sufficient, given the scale of the problems facing the NHS post-COVID. It is important we recognise the scale of this backlog and invest in the long-term capacity of the NHS to get waiting lists down. We should also ensure that recovery plans improve the support for those waiting for treatment so that everyone waiting can do so with dignity.

# 3. The impact of waiting on older patients



## 3. The impact of waiting on older patients

### 3.1 Deterioration while waiting

As waiting times rise and the number of patients waiting 12 months stays at high levels, the risks of patient deterioration, or a loss of conditioning, can increase. A deterioration in a person's condition can put at risk their surgical outcomes, and severe deterioration or deconditioning can place doubt on their suitability for surgery. Deteriorating conditions can also have a greater impact on a person's life through greater pain and discomfort, and the knock-on effects on mental health and quality of life. These risks are particularly great for those in later life requiring life-enhancing surgeries, because they may have both long waits and could be vulnerable to rapid deterioration.

There is also a dearth of evidence on how older people's waiting times for surgery affect their recovery and the impact of waiting on their quality of life. There is some limited evidence, however, to suggest that longer waiting times can negatively impact post-operative outcomes: for example, for those seeking joint replacements, deconditioning contributed to a loss of muscle mass and impeded recovery.<sup>34,35</sup> One person we interviewed spoke about their experience of waiting and their belief that the long wait led to an unsuccessful outcome.

It is also unclear whether the physical deterioration caused by long waits is short term and reversible when the individual receives surgery, or whether the consequences of waiting persist beyond treatment. A limitation of much of the existing research is that it tends to focus on waits of less than 12 months. However, as we have shown, many of those waiting for surgery in later life appear to be waiting more than 12 months.

The full implications of the pandemic on overall health are yet to be known. But the combination of deterioration and deconditioning, because of shielding and lockdowns, has resulted in some people's overall health and wellbeing declining sharply. All four aspects of physical fitness – strength, stamina, suppleness and skill – can be affected by months of reduced physical activity.<sup>36</sup> Among those people we interviewed, many spoke about how, during the pandemic, they had felt weaker or had new sources of pain, which they believed were because of a reduction in their physical activity.

This was also borne out in our survey, which found that 71% of those waiting for treatment said their health had become worse during the pandemic. Among those not waiting for treatment, the figure was 49%. This may suggest that deconditioning because of the pandemic is contributing to a deterioration of older people's health.



*Because I've waited so long,  
I'm becoming ill and my  
muscles are becoming weak.*

**Gilly, 82, waiting three years**

### 3. The impact of waiting on older patients

Those we interviewed also shared how one health problem was creating another: for example, people shared that the deterioration of a knee joint affected their hip, or that one bad hip affected the other, so creating new health needs.

*"It's just things at home are really difficult, and I think what I have done, though, is, in wanting to do things at home, I have, probably, damaged the other hip. It is very difficult to not bend down, not do this, and I think I can feel the other hip, I can hear the grating of it."*  
Anonymous, 69

#### 3.2 Waiting in pain

Deterioration of a condition can lead to worsening symptoms, including pain. We know that pain is subjective and can vary depending on the health condition, a person's circumstances and the length of time they are waiting. Many people in later life waiting for surgery now say that they are frequently in pain. While some may develop coping mechanisms for their condition, delaying surgical treatment to these patients may reduce the efficacy of these attempts.

Many of those we interviewed and surveyed for this research described regular experiences of pain.

*"I'm getting a lot of pain in the legs, pins and needles. Sometimes my right leg, particularly in the morning when I get out of bed, just refuses to work. Sometimes I end up on the floor in a heap."* Steve, 65–69, waiting nine months



*I'm completely dominated by pain.*

**Sue**



**7 in 10 of those waiting for treatment said their health had become worse during the pandemic**



*I was told that the outcome of my operation wasn't successful...or as successful as it should have been because of the time that I'd been waiting to actually be referred and get the operation done.*

**Kate, 73, waited 18 months**

### 3. The impact of waiting on older patients

For some, pain wasn't constant but, when it appeared, could be debilitating.

*"The pain isn't 24/7 but sometimes it's almost like a wave of pain. It reaches a crescendo and then drops away again and does spread around the rest of the hand. Some days are good, some days are bad."* Charles, 70, waiting three months

One study of those waiting for joint replacements found that patients with delayed surgeries had greater pain and difficulty with functional activities than those with shorter waiting times.<sup>37</sup> It is no surprise, then, that, with rising waiting lists, we have found a high proportion of people saying they are in pain. In our Independent Age survey, 84% of people waiting for treatment said that they were in pain most or some of the time. Our YouGov survey of people aged over 50 also found that 52% of those waiting said they were in daily pain.<sup>38</sup>

Experiences of pain do not appear to be distributed equally. In a recent Versus Arthritis report looking at chronic pain in England, 18% of people aged 16–34 reported living with chronic pain, compared with 53% of those aged over 75.<sup>39</sup> Gender may also play a part, with women more likely to say they were in pain than men in our Independent Age survey. This generally reflects findings from other research, suggesting that older women are more likely to report pain caused by various health conditions and that chronic pain is more common among women, regardless of where the pain is felt.<sup>40,41,42</sup>



**More than half of those waiting said they were in daily pain, according to our survey of people aged over 50**



*I found that I'd wake up in the night, look at the clock and think, 'Oh, I can't take any more painkillers for another two hours.' Because you're looking at them every four hours and it was excruciating at times.*  
**Ann, 79, waiting one year**

### 3. The impact of waiting on older patients

Many older people told us they relied on taking painkillers to cope while they waited for surgery. Attitudes towards and experiences of this were mixed. Some struggled with the side effects of pain medication but found these more tolerable than the pain itself. Others did not want to rely on medication and found other ways of coping.

*"I went through a stage of being really, really down about it. I'm feeling a bit better now. My emotions are better, but the medication didn't seem to be suiting me very well and it made me very lethargic. I didn't want to go out, didn't want to do anything, when I am normally quite an active person, knee allowing." Anne, waiting six months*

Some who relied on medication for pain relief shared how they felt they were experiencing less benefit over time.

*"I think my body has got used to the medication because I've noticed the pain is getting worse. Whether it's the condition getting worse or the fact that my body is accustomed to the medication or a combination of the two, I don't know." Steve, 60–69, waiting nine months*

“

*I'm also taking 40mg of Citalopram for depression, which the doctor believes is linked to the physical condition.*

**Steve, 60–69,  
waiting nine months**

#### 3.3 Declining mental health and wellbeing

Mental and physical health are closely intertwined. Research has shown that people who live with long-term physical conditions are twice as likely to have mental health problems as those who do not.<sup>43</sup> A report by Versus Arthritis highlighted that anxiety, depression and distress are risk factors for developing some types of chronic pain, and that living with chronic pain can itself lead to depression and anxiety.<sup>44</sup> This can result in a cycle where people's pain and low mood exacerbate each other, leading some people to withdraw and isolate themselves, which in turn can reduce their ability to cope with the pain.

A recent report that Independent Age contributed to, led by National Voices and the Centre for Mental Health, explored the mental health consequences of having one or more long-term health conditions. The research outlined the different ways a physical health condition can affect people's mental health, including coming to terms with the illness and its effects, living with it day to day over many years, the burden of having to go through repeated appointments, treatments and procedures, and the effects on people's relationships. These findings were echoed by some of the people we spoke to. They shared how the ongoing uncertainty of when they would receive their treatment affected their ability to plan future activities, which had a negative impact on them. Others told us that the severity of the pain of their condition made them feel hopeless and unable to enjoy things that previously brought them happiness.

*"I have noticed that if I'm anxious, if I'm worried, or something like that, I feel that my problem starts, I get so tensed up and I start getting these chest pains. ...they suggested to me to be relaxed and not to worry about things." Anonymous, 71, waiting three months*

### 3. The impact of waiting on older patients

*"Feel it's never going to happen. Feel at a loose end waiting for some information knowing full well that that's not going to happen. Feel forgotten at the bottom of a list. Am I even still on the list? Feel as if tomorrow might come too late for me. Feel helpless as if I've lost all sense of feeling." Anonymous*

It is no surprise that long waits for treatment, coupled with daily pain in many cases, can significantly impact someone's mental health. A study on mental wellbeing while waiting for surgery found that some patients experienced an increase in anxiety and depression while waiting, which then decreased following their surgery.<sup>45</sup> Another study found that high or very high psychological distress was more prevalent in those waiting for joint replacement surgery compared with the general population.<sup>46</sup>

Our Independent Age survey added to these findings. Some 47% of those waiting for treatment said that the wait had made their mental wellbeing worse. Women and people living alone were more likely to report a negative impact on their mental wellbeing.

Loneliness was also a common consequence of the mental and physical health deterioration that people experienced while waiting for surgery. In our Independent Age survey, 46% of people waiting for treatment said their condition made them feel lonely often or some of the time, increasing to 62% of those who were living alone.

*"I feel depressed, I've suffered from depression, scared to go out and feel lonely... you do have people who are very, very lonely." Anonymous, 71, waiting three months*

*"Yes, I think the lockdown has impacted on all of my health, not just the arthritis. I have to be honest, this week I've come to the state where I feel a little bit depressed and isolated at home, because it has already been going on for two years and now this recent accident [a broken bone in her foot] I've had has pushed me back to square one again." Kate, 73, waited 18 months*

Research also suggests that depression is four times more common among people living with chronic pain than among those without.<sup>47</sup> Concerningly, few of our interviewees spoke about seeking support to improve their mental health. Many seemed to accept their circumstances or didn't think there was much that could be done for the problem. This is reflected in some nationally representative polling we conducted for our *Minds that matter* report in 2020, which told us that one in four people believe poor mental health is a normal part of getting older.<sup>48</sup>



*It's completely changed my life from a happy-go-lucky person to an extremely depressed person who is nervous about everything.*

**Maggie**

### 3. The impact of waiting on older patients

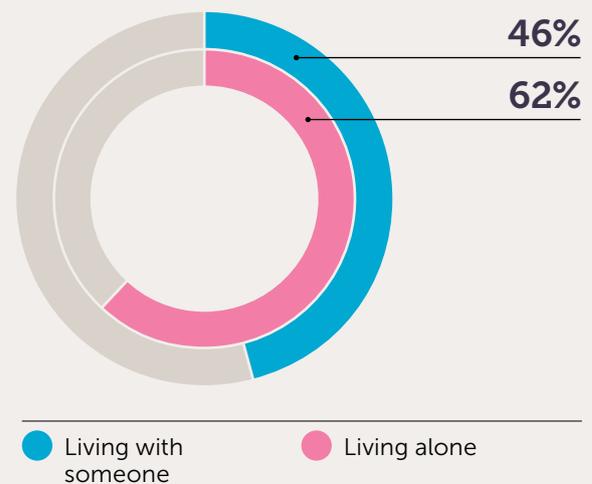
For those respondents who did want professional support and advice to tackle their low mood, anxiety or depression, some shared the difficulty of getting a medical appointment to discuss their mental health concerns. Research has shown that the older you are, the less likely you are to be offered a choice of mental health treatment compared with someone younger.<sup>49</sup> People in later life are also less likely to be referred to talking therapy than other age groups, with referrals of people aged 65 and over making up only 6% of all NHS talking therapy referrals in England, based on the last annual pre-pandemic figures. This is despite evidence that psychological therapy for common mental health issues can be highly effective for older people. The reasons for low referrals are complex but our research highlighted stigma, a lack of awareness among older people of support options available, and some assumptions made by some health professionals about older people's treatment preferences.<sup>50</sup>

As well as referral to support services such as talking therapy, research has found benefits from other dedicated support programmes, such as mental health resilience courses for people with long-term conditions. A study about one such course found significant gains in perceived resilience specifically among older patients after a six-week course, with peer support found to be key to the effectiveness of the approach.<sup>51</sup>



**Almost half of those waiting for treatment said that the wait had made their mental wellbeing worse**

**People waiting for treatment feeling lonely often or some of the time**



### 3. The impact of waiting on older patients

#### 3.4 Loss of purpose

For those in later life surgery is often the final recourse, meaning they could have been in pain or discomfort for months or years before this point. So for people aged 65 and over, longer waiting times can mean prolonged pain and a significant reduction in their quality of life, as daily activities and pleasures move out of reach.

The relationship between quality of life and waiting times is not straightforward because it depends on several factors, including the condition being treated, the impact of other health conditions, and other factors that can affect a person's enjoyment of life, such as financial security and levels of loneliness. It is important to recognise the limitations of these and to understand that a person's quality of life has multiple variables and can be hard to assess. However, our analysis suggests that living in pain for long periods is having a negative impact on quality of life among those in later life.

As we have explored, long waits can increase experiences of frequent pain. Several studies have analysed the effect of chronic pain on patient's lives, highlighting the strong correlation between pain and reduced physical activity.<sup>52,53</sup> One study in Canada found that a wait for knee or hip surgery longer than six months was associated with a clinically significant deterioration in patient quality of life.<sup>54</sup> The intensity and duration of pain can influence a person's physical health, diminish their physical activity and even cause disability, all of which can affect other aspects of their daily life.<sup>55</sup>



**More than half of people aged over 50 waiting for treatment reported that they have some difficulty with day-to-day activities**



**4 in 10 of all GP appointments involve mental health**



*Hugely anxious how I will manage surgery as [am] 24-hour carer for 93-year-old parent with dementia. Also knee pain is preventing me sleeping, making life intolerable.*

**Anonymous**

### 3. The impact of waiting on older patients

In our YouGov survey, 55% of people aged over 50 waiting for treatment reported that they have some difficulty with day-to-day activities.<sup>56</sup> Daily difficulty was significantly higher for women (63% compared with 47% among men). In our interviews, people spoke about how their health conditions and the wait for treatment often significantly impacted their ability to go about daily life. Reasons for this ranged from high pain levels, mobility issues caused by their health condition, the loss of key coping activities during lockdown, and the impact of the pandemic on their confidence to do certain activities. Sometimes a combination of all these factors impacted their ability to go about daily life.

*"Hugely anxious how I will manage surgery as [am] 24-hour carer for 93-year-old parent with dementia. Also knee pain is preventing me sleeping, making life intolerable." Anonymous*

*"I've completely stopped travelling underground. I was thinking if the pain starts, what will happen if I am in the train and the train is unable to stop?" Anonymous, 71, waiting three months*



*Arthritis is difficult to deal with anytime, but coping strategies are harder with no idea of when things will work out.*

**Anonymous**

For some, the impact of their condition affects their whole sense of self and purpose. Among those interviewed, some talked about how the pain and loss of mobility had reduced their ability to enjoy their hobbies and pastimes. Activities like walking, playing cricket, exercise and gardening were often cited as those activities that were integral to their lives and were now not possible.

Our evidence shows that currently people in later life who are waiting for surgery are showing signs of deterioration, frequent pain and a corresponding decline in quality of life. While the specific experiences of those waiting will differ, our research indicates that there may be a growing pain epidemic emerging as a result of the long waiting lists. As the NHS recovers and addresses the backlog, patient care needs to be rethought to ensure that everyone has an opportunity to wait well and minimise avoidable pain and anxiety.

#### 3.5 Recommendations

1. NHSEI to mandate developing a personalised care and management plan for all people waiting six 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.
2. NHSEI should develop guidance on involving health professionals with expertise in treating older patients in the clinical validation of patient waiting lists.

# 4. Supporting people to avoid decline and helping to prepare for surgery



## 4. Supporting people to avoid decline and helping to prepare for surgery

**Appropriate and adequate support before, during and after surgery can make a huge difference to someone's experience and outcomes. A key action in the NHS's Elective Care Transformation programme is to improve a patient's ability for self-care.<sup>57</sup>**

But from our interviews and surveys we found that this support was patchy and inconsistent. Given the risk of deterioration, deconditioning, regular pain and their effect on quality of life, there needs to be better support provided, particularly for longer waiters. Our interviews suggest that when this support is provided it can have a meaningful impact on a person's experience even if they are having a long wait.

### 4.1 Helping patients prepare for surgery

There is increasing consensus that the experience of waiting should be rethought. Research by National Voices has shown that those waiting wish to be more involved in decisions and planning around their care and treatment.<sup>58</sup> The think tank Policy Exchange has also suggested that the time spent waiting for a procedure should be seen as an "opportunity to bring clarity to both the patient and practitioner over any forthcoming procedure through shared decision-making which can play a significant role in reducing readmission". They also say that good prehabilitation services, such as peer support and self-management, are an important part of patients being able to wait well for elective surgeries.<sup>59</sup>

*"I actually got an appointment to attend a physio meeting to actually outline everything that happened in the operation procedure... It's very good and you get to meet some of the people that might be coming in and having their operation at the same time as you as well. And you do actually meet the staff that'll be dealing with you when you come in, and I thought all of that was good." Kate, 73, waited 18 months*

Unfortunately, current provision of both prehabilitation and preoperative care services is patchy and there is not one consistent approach across the country.<sup>60</sup> From our interviews, we heard that some people felt unprepared for surgery.

*"It's really worrying because I thought, I don't want to go in for this operation on Wednesday morning and that's the first time that I'll be told what kind of hip replacement I'm actually going to have." Anonymous, 69, waiting almost 12 months*

The 'elective accelerator' programme includes prehabilitation among the types of innovation being trialled.<sup>61</sup> While innovating such services should be encouraged, more consideration needs to be given to providing a consistent level of support across England.

### What is perioperative care, prehabilitation and preoperative care?

Perioperative care covers all stages of the surgery pathway from the time people are booked for surgery until they are discharged. As part of the perioperative pathway, thorough preparation is recommended. Preparation typically includes prehabilitation and preoperative care. Definitions for prehabilitation vary but are consistent in stating that it is a

pre-emptive preparation to reduce risks and enhance recovery after a stressful event like surgery. It may include access to information and support, exercise, nutrition, self-management and access to healthcare professionals. Preoperative care is often used interchangeably with prehabilitation but can include other actions such as preoperative assessments.

## 4. Supporting people to avoid decline and helping to prepare for surgery

### 4.2 Improving condition management

Good preparation for surgery should include support to wait well. This is especially important with waiting lists so high and people waiting longer. People in later life need both practical and emotional support while they wait for their procedure. They need to be helped to maintain good health, manage pain and deal with the impact their condition has on their day-to-day life. Support while waiting can be provided by health services, hospitals, GPs, nurses, social prescribing link workers, and non-health support services like online forums, peer support, friends and family, or voluntary and community sector (VCS) organisations.

Despite the value of such support, our research suggests many people in later life are not receiving the support they need. In our Independent Age survey, 84% of people waiting for surgery had not received any additional treatment for their condition while waiting, and 61% of people waiting had not received any information from their doctor about how to manage their condition.<sup>62</sup>

In addition, our YouGov survey found only 15% of people waiting received information about how to manage their pain and symptoms. This is especially concerning when 24% of older people waiting said information about how to manage their condition would improve their experience the most.<sup>63</sup>



*The only advice I've been given is to take paracetamol, no other advice than that.*

**Charles, 70, waiting three months**



**84% of people waiting for surgery had not received any additional treatment for their condition**



**15% of people waiting received information about how to manage their pain and symptoms**



**24% of older people waiting said information about how to manage their condition would improve their experience the most**

## 4. Supporting people to avoid decline and helping to prepare for surgery

Research from National Voices highlighted some key ways to support people living with long-term conditions, including receiving continuity of care over time, being given relevant information, treated as a partner in care, support and advice being provided between appointments, and small gestures of care by healthcare professionals, such as asking people how they are feeling during a consultation.<sup>64</sup>

*"I've had to have a lot of discussions about what are you going to do at home, and the support worker in the OT physio section has been brilliant and very good communication skills." Anonymous, 69, waiting almost 12 months*

Community health care needs to play a key role in supporting people who are waiting for, or who have recently had, surgery. Community healthcare is a term that refers to care outside hospital but separate from GP and other primary care services. It includes physiotherapy, rehabilitation and exercise classes. Community healthcare is central to the NHS's long-term plan; however, very few people we interviewed were accessing these types of services. This suggests there may be a gap in integrating community healthcare into wider patient care plans.

Social prescribing can also be an important route to support that can help people in later life stay well while they wait for surgery. Social prescribing is a means of enabling health professionals to refer people to a range of local, non-clinical services. These services are designed to support people with a wide range of social, emotional or practical needs, and many schemes are focused on improving mental health and physical wellbeing. As part of primary care teams, social prescribing link workers are meant to help people waiting for treatment by connecting them to advice and support. The government has recently highlighted social prescribing as part of a targeted NHSEI initiative, where personalised care approaches are used to help manage elective waiting lists. Beginning with musculoskeletal pathways, the government intends for this work to be cascaded to all priority clinical programmes in 2021.<sup>65</sup> This is a positive development, but we need to ensure that this is implemented consistently across the country.

For many people waiting for elective treatment, VCS organisations also provide important support: for example, peer support groups have helped some people discuss their experiences and manage their condition while they waited for surgery. Many charities also provide high-quality information and advice on specific conditions, exercise tips and what to expect when having medical procedures.



*I've had to have a lot of discussions about what are you going to do at home, and the support worker in the OT physio section has been brilliant and very good communication skills.*

**Anonymous, 69,  
waiting almost 12 months**

## 4. Supporting people to avoid decline and helping to prepare for surgery

*"They were talking about you trying to do physical therapy yourself, using stretching plastics and such like. They provided illustrations of this and there were sites where you can actually see it happening." Mike, 75*

Being given tools to manage pain can provide people with much needed coping techniques. Some we spoke to had managed to find information about how to manage pain for their condition online, but this was often through proactively searching the internet themselves, a resource that is not available to all in later life.

*"I went to their website and looked up arthritis in the hand because that's what it is, and they've got good advice and guidance on how to try to keep the hand working. It's still not good, obviously, but it's something." Anonymous*

Our research suggests that lots of people are not receiving the support they want and need while they wait. Yet, when it is provided it can have a significant impact on patient experience and wellbeing. Having good support, particularly prehabilitation, can help patients prepare properly for surgery. And 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 harder about how to better integrate these services into patient care plans and ensure that this support is provided on a more consistent basis.

### 4.3 Recommendations

1. NHSEI to 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.
2. NHSEI to work with charities, patient groups and other providers to provide clear signposting to local and national services that can provide practical or emotional support to those waiting for treatment.



*I went for the treatment [but] because I did not have someone to be with me 24 hours after, I was sent home and the treatment was cancelled. This was not mentioned in the letter sent to me before the treatment.*

**Anonymous**

# 5. Patient communications



## 5. Patient communications

**Patient-centred healthcare has been a mantra for the NHS for more than a decade – but, to date, a lot of it has focused on the design of diagnostic and treatment services.**

Our analysis finds that patient communications, especially those outside consultation, are important and play a role in the overall wellbeing of patients waiting for treatment. As the NHS rethinks healthcare post-COVID, we believe it should take the opportunity to shift from communicating to patients, to engaging with patients.

Our research found that the experience of communicating and engaging with the NHS had a significant impact on people's experience of waiting. Poor communication is known to be a common topic of feedback for the NHS and has been raised as an issue of concern previously.<sup>66</sup> Our findings align with other research showing that better communication with patients can alleviate the negative impact of longer waiting times.<sup>67,68</sup> Our evidence also shows how the experience of poor communication affects people in later life and why current approaches may not be sufficient to empower them. Therefore, patient communications should not be considered an optional extra but as integral to managing waiting lists.

### 5.1 Engagement while on the waiting list

The biggest concerns raised with us about patient communications were the impact of limited or low-quality information on people's understanding of where they were in the pathway. A high proportion of people we spoke to said they were uncertain as to whether they had been referred for an operation, despite being advised that such an operation was necessary.



**Half of over 50s on a waiting list had not received a confirmation from the NHS**



*Sending you questionnaires to fill in, saying you've had your op when you haven't had it, that's unacceptable. To have that done three times is just an insult, it really is.*

**Gilly, 82**

## 5. Patient communications

Our YouGov survey found that, among people aged over 50, 10% reported that they were on a waiting list but half of them had not received a confirmation from the NHS.<sup>69</sup> Similar experiences emerged in our interviews, with some people unsure whether they were on the waiting list or how long their wait could be. The uncertainty of this experience contributed to low mood, anxiety and depression, and made them feel unsupported. It also suggests that more people may think they are waiting for treatment than official figures suggest.

People in later life also shared their frustration about patient communications from their hospital. Several of those interviewed had significant concerns with the letters they received. Issues ranged from receiving letters for appointments after the appointment date, to follow-up letters being sent to them despite not receiving any treatment.

*"I have had endless letters that are duplicates, that are arriving after appointments... their administrative system seems to be all over the place." Anonymous*

For some, this experience was not just frustrating but had a direct effect on their mental health. One interviewee said that the poor communication rather than the actual wait was the source of stress and anxiety.

*"I think it gives you quite a lot of stress... I do accept it [the waiting time] and I understand it and, in a way, that doesn't make me as anxious. What does make me anxious is the poor communication and these confusions of letters and things." Anonymous, 69, waiting almost 12 months*

Another person spoke of the impact of waiting to hear about a surgery date.

*"Every day the postman comes and he brings you your post and every day you think, 'Oh, that looks like a hospital letter.' So, you leave it until the end, as it might be an appointment. And, it never is. Disappointing, it really is, it's a loss of hope in a way." Gilly, 82, waiting three years*

These experiences suggest that it is not just long waits that are problematic, but also how information about a patient's waiting time and potential surgery date are communicated.

Research conducted by the Kings Fund found that there is a range of issues with patient-facing administration that cause poor performance.<sup>70</sup> Poor communication in hospital can also create demands elsewhere, particularly for GPs, because general practice becomes the next resort once patients fail to reach their consultant or relevant departmental staff.<sup>71</sup>

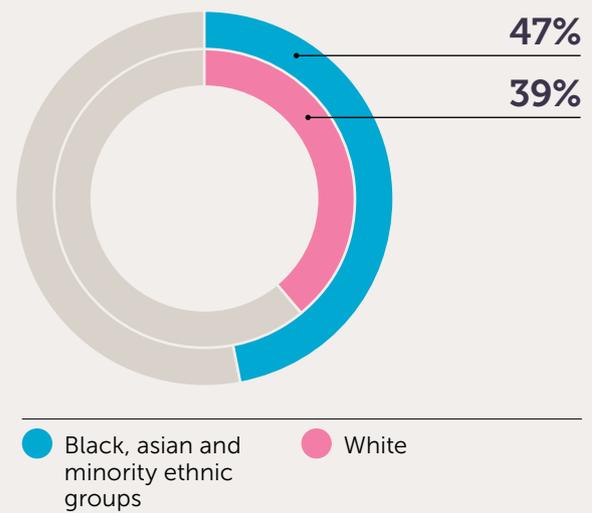
Our research also reaffirms existing evidence demonstrating that some people are better able to get faster or higher-quality service than others. Those who felt more informed, educated or had more experience of using the system, for example, felt more comfortable than others to challenge and proactively raise concerns. This aligns with previous research by academics into 'elbowing behaviour', which suggests that such activity is more common among the least deprived.<sup>72</sup>

## 5. Patient communications

While not intentional, the way the NHS works favours those who are best able to advocate for themselves. More socioeconomically advantaged patients are likely to have more information, networking skills, contacts and a consciousness of their rights, enabling them to exercise more effective pressure to get prioritised for treatment.<sup>73</sup> This seemed to be acknowledged by several of those who were interviewed who felt their improved experiences were directly linked to their tenacity.

Our YouGov survey also found that older people from black, Asian and minority ethnic groups were more likely to say their patient communications were bad (47%), compared with those who were not part of this group (39%).<sup>74</sup> This suggests that the experience of receiving good communication is not equitable and could be impacted by where you live in the country, language barriers or the way information is phrased. While multiple factors are likely to be the cause, the way the NHS communicates may be exacerbating existing social disadvantages.

### People finding NHS communications to be 'bad'



*It seems to me the more persistent you are, the quicker you'll get seen.*

**Anonymous, 70–74,  
waiting more than a year**

## 5. Patient communications

Age also plays a significant role in the level of people's confidence to ask questions, raise concerns and challenge decisions. Some of this age group felt that they could not make their case because of their age.

*"A lot of people haven't got verbal skills, they feel in an inferior position to doctors, nurses, receptionists... You do tend to worry that you can't make a fuss because you're old and I think if I had all this when I was younger, I would have been much more feisty."*  
Gilly, 82, waiting more than three years

These prevailing attitudes and assumptions could further entrench existing age inequalities and worsen both outcomes and experiences for those most in need or facing historical social disadvantage.

### 5.2 A point of contact

NICE guidance on perioperative care recommends that, when booking surgery, people should be given a point of contact within the perioperative care team who can be approached for information and support before and after their surgery.<sup>75</sup> Unfortunately, our research showed that very few people have this, even though, in our nationally representative polling, 33% of people waiting for surgery said that having a single point of contact would improve their experience most.<sup>76</sup>

Many of those we interviewed also raised concerns about how they could contact someone to discuss their operation, including booking an appointment and raising questions. Several of those noted that the pandemic had made reaching people even harder, with more administrative staff working at home yet the 'processes' only working if people were in their offices.



**1 in 3 people waiting for surgery said that having a single point of contact would improve their experience most**



*A lot of people haven't got verbal skills, they feel in an inferior position to doctors, nurses, receptionists... You do tend to worry that you can't make a fuss because you're old and I think if I had all this when I was younger, I would have been much more feisty.*

**Gilly, 82, waiting more than three years**

## 5. Patient communications

*"You just cannot, under any circumstance, get hold of them," Anonymous, 69, waiting almost 12 months*

Some of those interviewed also talked about protracted experiences navigating the switchboard at hospitals.

Positively, however, those who were directed to PALS spoke about how quickly they were able to get through to their consultant or the relevant appointments office. From our research, the use of PALS appeared to be primarily among those who had tried and failed to reach the relevant department by other means.

Many of those interviewed wanted a more personalised, patient-centred approach that treated them as an individual rather than just another patient. For most, this meant simple changes like easier direct access to the offices of their consultant and the relevant appointments office, as well as more timely communication from the hospital.



*Five consecutive days with the same recorded message, 'I'm sorry, I'm away from my desk at the moment, I'll get back to you such-and-such,' so I left a message, nothing came back.*

**Anonymous, 70–74,  
waiting more than a year**

It is important to note that there is significant variation in the experiences of communication from hospitals. While most people we spoke to had experienced problems on at least one occasion, others had positive and efficient experiences: for example, those we interviewed who had received a cancer diagnosis spoke passionately about the fantastic levels of engagement they received, and the value of cancer nurses in providing a direct line of communication for any questions or concerns.

*"They gave me a card that I could ring if I had any concerns in the night and I did have two or three times when my temperature shot up and I had to ring the Christie's hotline straight away." Anne, waiting one month*

Others spoke of having a good direct relationship with their consultant and being able to reach them with ease.

*"I can ring his office up any time if the condition gets worse and I find myself not being able to walk or I start falling over again. I have direct access to him which is good." Bob, 73, waiting two years*

Almost all talked positively about how well healthcare professionals, particularly consultants and nurses, provided information on the conditions they had during face-to-face appointments or over the phone. However, those we interviewed often felt that such engagement was driven by a healthcare professional's personal commitment – going above and beyond – rather than the hospital communication systems.

## 5. Patient communications

Changing how the NHS engages with its patients will require investment, practical guidance and strong leadership. The recent NHS guidance *Good communications with patients waiting for care* is a great example of practical guidance and templates.<sup>77</sup> But guidance alone is unlikely to be sufficient to change how these services are provided if it is not treated as a priority. For people in later life, good communication is an essential part of waiting well. While improving NHS engagement with patients is not an easy task, it is a challenge that the NHS should take on seriously as part of its approach to managing the waiting list backlog.

### 5.3 Recommendations

1. NHSEI should support implementing its guidance *Good communications with patients waiting for care* by piloting different approaches to support these principles. Trials should include creating a single point of contact for waiting patients, and information about PALS in patient correspondence.
2. NHSEI to 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.



## 6. What needs to happen now



## 6. What needs to happen now

**As the government and NHS consider how to respond to this unprecedented crisis, it is important that all voices are heard to ensure that the response does not leave anyone behind.**

The government should be ambitious in its plans to help the NHS out of this crisis and ensure that patients in later life get the care and support they need. A meaningful plan involves increasing hospital capacity, proper workforce planning and investment, and supporting the community services that are needed as patients wait.

The priority for the NHS should be considering how to expand its capacity to do more surgeries. Among the proposed ideas is that of surgical hubs. These are dedicated COVID-light sites to carry out surgical procedures. In their 2021 report, the Royal College of Surgeons England called on NHS England to consolidate COVID-light sites in every region and to ensure that at least one NHS hospital acts as a COVID-light site in each ICS, with additional sites in larger ICSs.<sup>78</sup>

Greater use of hubs has the potential to reduce strain on services, but carefully considering and acknowledging barriers to this for some people, particularly 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.

Increased physical infrastructure is important but not sufficient. The NHS capacity has been under strain because of a lack of long-term workforce planning and investment. Any action will be unsuccessful without considering the future workforce needs as it responds to an ageing population with multiple conditions. Meaningful workforce planning should not just focus on the hospital workforce but other specialities that are critical in the preparation, support and recovery of patients.

While NHS leaders will be determined to bring down waiting times, it is important that patient experience and quality of life do not come second to targets. We would like the government and NHS to show leadership by reimagining the waiting period as a time for management and preparation. It must invest in long-neglected parts of the system and ensure all parts of the NHS consider patient experience alongside patient outcomes. In practice, this means investing in community health services alongside hospital care, particularly ensuring that the workforce is in place to meet the rising demand for community healthcare. In taking this comprehensive approach, the NHS will be better able to help people maintain their health as they age, rather than just treat their ailments.

## 6. What needs to happen now

### 6.1 Recommendations

1. DHSC should fund specialist 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.
2. DHSC should be required to produce annual independent projections of healthcare workforce needs and a new workforce plan. This should look at workforce needs both to reduce waiting times in hospitals and to help older patients wait well by increasing the allied healthcare workforce.
3. 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 analyses of regional variations in performance, workforce and staffing levels, and any health inequalities within the backlog.
4. DHSC, alongside the prime minister's new taskforce, should develop a long-term plan for NHS recovery that 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.
5. NHSEI 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.

# 7. Conclusion



## 7. Conclusion

### **Hospital waiting lists are at record levels and are likely to get worse before they get better.**

As greater users of elective care than other age groups, people in later life will continue to be badly affected by long waiting times. As we have shown, many people in later life are facing deteriorating health, daily pain and a loss of joy as they wait. These findings will not surprise anyone in the NHS, but the scale of these problems is alarming.

People in later life have said they want better communication and information while they wait, greater support to manage their health, and more preparation and advice ahead of their treatment. Providing this support can help more of them regain their dignity and purpose.

We call on the government and the NHS to take urgent steps to tackle the growing backlog of hospital treatments and expanding waiting lists. In tandem, we urge the government and NHS to listen to older people's voices and take this opportunity to transform the waiting period from one of anxiety to one of patient empowerment, preparation and holistic support.



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