

July 2021

Attitudes towards and experiences of the NHS during Covid-19: views from patients, professionals and the public

Phase 3 (May – June 2021)

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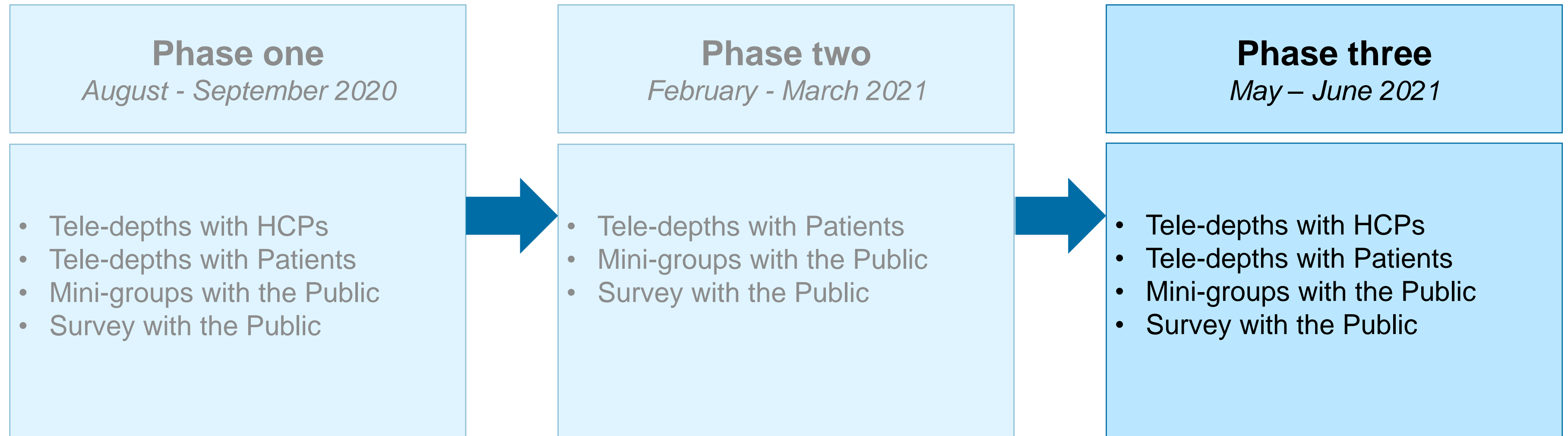
Future of the NHS

06

Key findings

01 Background and methodology

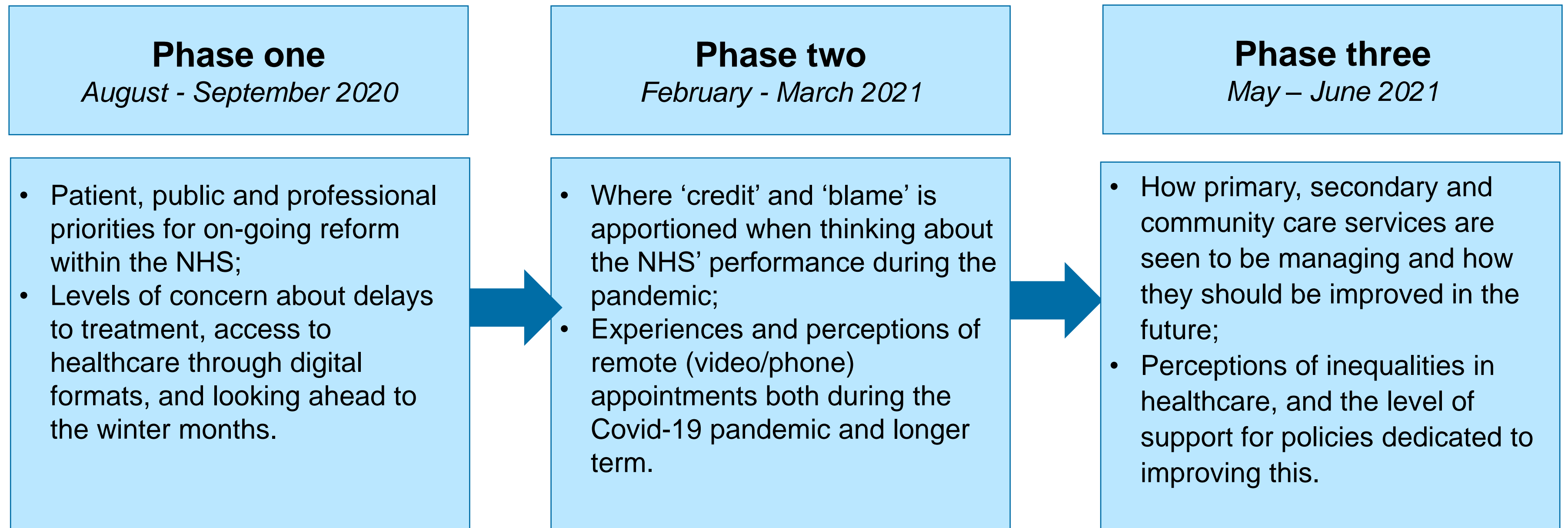
This is the final stage of an ongoing research study



Patients were re-recruited from Phase 1 and 2 to allow us to monitor their evolving experiences of and attitudes towards the NHS throughout the Covid-19 pandemic. New HCPs were interviewed in Phase 3 having been omitted in Phase 2 due to increased work pressures from Covid-19.

Research objectives

The core goal of this research was to understand how patient, public and professional attitudes towards the NHS have been shaped by the experience of Covid-19 and to explore expectations and priorities for the future. The research was designed to be iterative, with each phase building upon the last. Beyond this, each phase also had its own specific objectives:



Sample & methodology



8 x tele-depths with patients

- All have one or more long-term conditions, with a mixture of severity of conditions and in-service use.
- The conditions included*:
 - 5x patients with long-term health conditions
 - 2x patients with mental health conditions (ideally on waiting lists)
 - 1x cancer patient
 - 2x patient post-elective surgery

**Figures do not match total tele-depths conducted due to some participants having more than one condition.*



10 x tele-depths with health care professionals

- HCPs from a range of professions:
 - 3x GPs
 - 3x nurses
 - 1x diabetes nurse
 - 1x oncology nurse
 - 1x mental health nurse
 - 2x consultants
 - 1x oncologist
 - 1x chest physician
 - 2x AHPs (physio)
- Working in a range of locations across the country, serving a mix of urban, suburban and rural communities.



4 x mini-groups with the public

- 4x mini-groups with 5x participants in each
 - 10x 30–45-year-olds,
 - 10x over 50s.
- All participants were low-moderate service users.
- Participants from a range of locations across England, with a mixture of urban, suburban and rural areas.
- SEGs of C1C2.



Survey with 2000 members of the public

- Nationally representative survey with n=1723 members of the UK public aged 18+ online.
- The sample covered England only.
- Survey fieldwork took place between 11th – 13th June and was 6 questions long.

02 Key findings

Key findings

1

For the first time in this programme of work, there are indications that the Covid-19 ‘grace period’ is coming to an end.

- Whilst the public and patients continue to praise the NHS, there is a growing expectation of a return to ‘normal’ characterised as a return to face-to-face and improvements to waiting list times. This is accompanied by questions from a minority of those we spoke to about the commitment of those in the NHS to delivering this.

2

Overall, patients who have used primary care remain positive (68% rate the access as good, whilst 78% rate the quality of care they received as good).

- However, both scores are down from the previous wave, and 28% of those polled had to wait longer than 2 weeks for an appointment.
- Moreover, the qualitative research indicates that a growing gap between low expectations and generally positive experiences is leading to participants attributing these positive experiences to ‘luck’ – rather than to the system performing effectively.

3

Similarly, in secondary care whilst perceptions remain positive overall (75% rate the access as good, whilst 84% rate the quality of care they received as good), scores are down from the previous waves.

- Concerns in relation to secondary care coalesce around waiting lists; tackling waiting lists will be a key metric by which the NHS is judged moving forward.

Key findings

4

Spontaneous understanding of health inequalities amongst the public and patients is low, and tackling health inequalities is not widely seen as a priority for the NHS.

- Even amongst those HPCs and members of the public for whom this is seen as a more pressing issue, the complexity of health inequalities and the range of organisations involved leads to questions about whether the NHS has the funds or – on its own – the ability to resolve the challenge.

5

The public are more pessimistic about the standard of care that the NHS will be able to deliver moving forward than they were in February.

- In February, 21% of those polled expected the standard of care to get worse of the next 12 months; this has now risen to 32%.
- Pessimism is driven by an expectation that, even if we are able to move beyond the pandemic, pressures on the NHS (high patient demand, staff burnout, lack of funding) will continue.

6

HCPs are aware of patient concerns, particularly in relation to access, and are worried that they are seeing declining public support as a result.

- This is leading to calls for an open and honest conversation with the public about what they can expect from the NHS moving forward.

Similarities and differences between public, patients and professionals

	<i>Attitudes towards and experiences of the NHS</i>	<i>Support for NHS in addressing health inequalities</i>	<i>Future of NHS healthcare delivery</i>
Public	Although support remains strong on the surface, challenges in relation to access, concern about waiting lists and a view that the NHS should be 'returning to normal' is causing real frustration.	There are mixed levels of understanding of what the term 'health inequalities' means, even amongst HCPs. For most addressing health inequalities is not a priority when set against issues that are perceived to be more urgent e.g., waiting lists. There are also questions about whether the NHS has the funding to tackle health inequalities, and the extent to which it lies within its remit.	The public are less optimistic about the standard of care the NHS will be able to deliver moving forward than they were in February.
Patients			Patient and HCPs' views aligned with these concerns.
Professionals	HCPs are feeling pressure to deliver more services at pace and fear that the impact will lead to increased staff burnout. There is concern about the risk of losing public support.		

03

Attitudes towards the NHS and experiences of healthcare

- Impact of Covid-19 on perceptions and experiences of the NHS
- Patient deep dives

On the surface, support for NHS and frontline staff remains high and consistent with previous phases of research



What three words would you use to describe the NHS and social care system currently?

Although resourcing and funding issues are top of mind in discussions, there is **ongoing support for the work of frontline staff**, and **the NHS continues to be a source of national pride** for patients and the public.

“
To be honest I think they're brilliant the NHS... they're **doing a brilliant job**.
Patient, Surgery, Greater Manchester

“
I think the NHS is amazing but with that I mean **the doctors and nurses working hard**.
Public focus group, Greater Manchester”

However, cracks in these positive perceptions are beginning to emerge



What three words would you use to describe the NHS and social care system currently?

There is increasing frustration with the perceived failure of the NHS to **adapt to accommodate non-Covid-19 related illnesses.**

Whilst the majority of criticism remains focused on the Government, some of the public and patients are beginning to be **critical of frontline staff who they believe are using the pandemic as an ‘excuse’ for a reduced patient load.**

“*They need to open up. Shops, restaurants have opened up. People are in distress, in pain, they want to see doctors.*

Public focus group, Midlands”

“*The word ‘excuse’ comes to mind – Covid-19 is now just being used as an excuse.*

Public focus group, Greater Manchester”

And there is a growing expectation that ‘normal services’ should now be resuming

High vaccination rates are key to this growing pressure to resume ‘normal’ services, due to an assumption that this will have helped reduce pressure on the NHS.

Normality is characterised as...

A return to face-to-face appointments where either most appropriate for the appointment type or simply preferred by the patient.

“

I want to have a face-to-face appointment. In some ways, it doesn't feel like real treatment, I've never even met the psychiatrist I'm talking to.

Patient, Mental health, Sussex

”

Making meaningful progress in addressing waiting lists, and showing greater accommodation for non Covid-19 related illnesses.

“

*The challenge now is to catch up, and from what I have heard it is a big job. There **are lots of non-Covid-19 patients who need medical attention** that haven't received any in over a year.*

Public focus group, Greater Manchester

”

We looked at the NHS across three key areas

Primary care



Secondary care



Community care



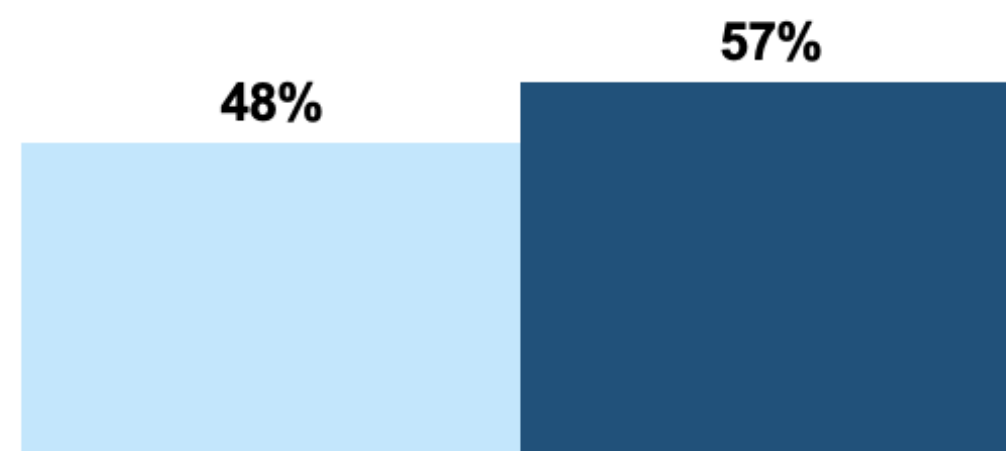
Primary care deep dive

An increase in the proportion of people who have used primary care since March 2021 has been accompanied by a decline in experiences of access and the quality of care

Have you used NHS services since the start of the pandemic in March 2020?

Showing % of respondents who selected each option

Phase 2 (Feb 2021)
Phase 3 (June 2021)

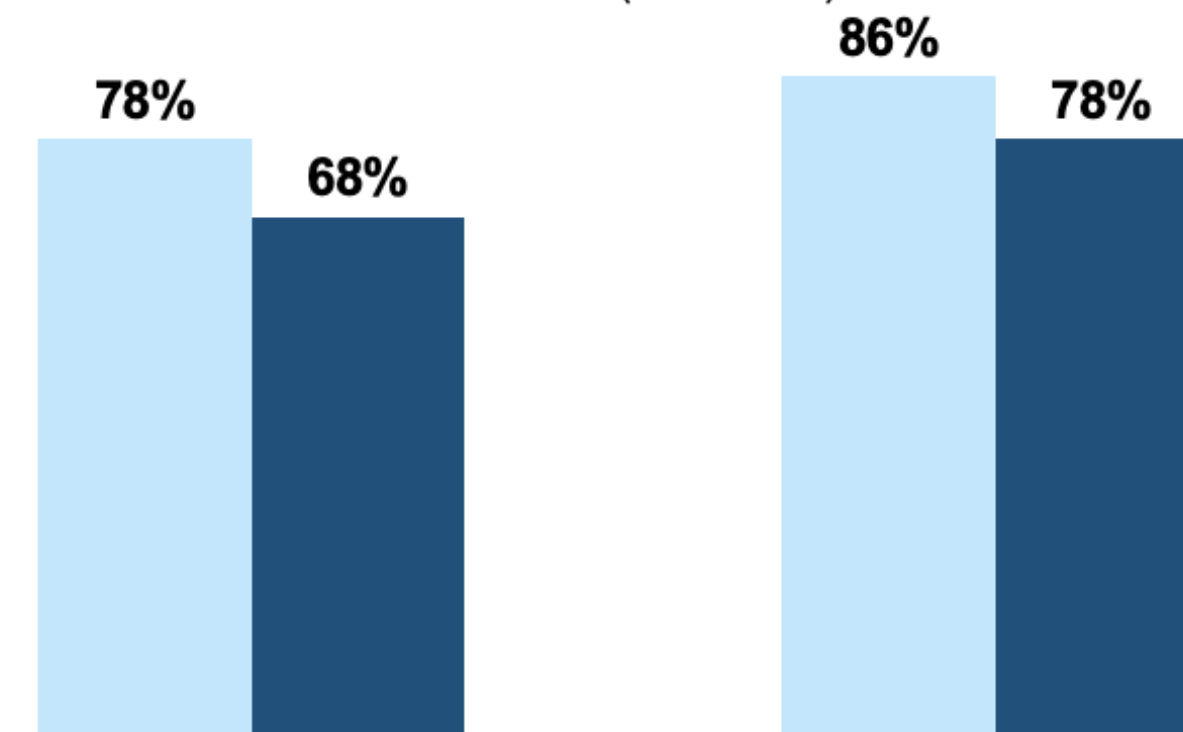


Yes, I have had an appointment with a doctor, nurse or other health professional at a GP practice

Have you rate the experience of accessing care / the quality of care you received?

Showing % of respondents who selected 'NET: good'

Phase 2 (Feb 2021)
Phase 3 (June 2021)



Access - Primary care

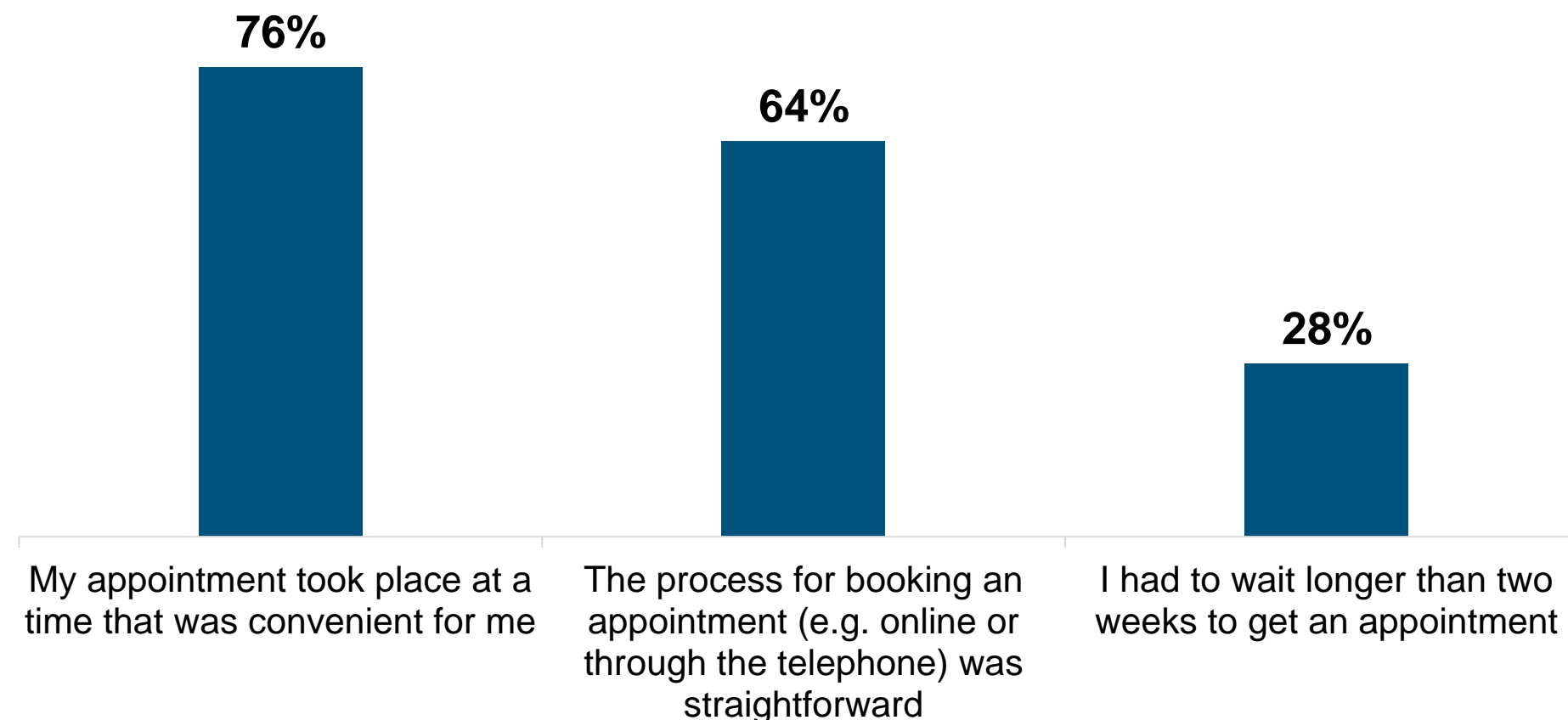
Quality of care - Primary care

Q. We'd like to understand your experiences of accessing NHS services since the first lockdown in March 2020. Have you used any NHS services since the start of the pandemic in March 2020? Base size: all respondents in Phase 2 Feb 2021 (n=2104) and Phase 3 June 2021 (n=1723).

Q. And thinking about your experience with doctors, nurses or other health professions at a GP practice, please tell us how you would rate: the experience of accessing care (e.g. making an appointment); the quality of care you received. Base size: all respondents who have had an appointment with a doctor, nurse, or other health professional at a GP practice in Phase 2 Feb 2021 (n=1011) and Phase 3 June 2021 (n=977).

While there are many positive access experiences, over a quarter (28%) report waiting more than two weeks for an appointment

Thinking about your experiences of using GP services, please tell us the extent to which you agree or disagree with the following statements
Showing % of NET Agree



Many focus group participants describe **getting an appointment as 'impossible'** and claim that **emergency or walk-in services are a better option for them should an issue arise.**

“

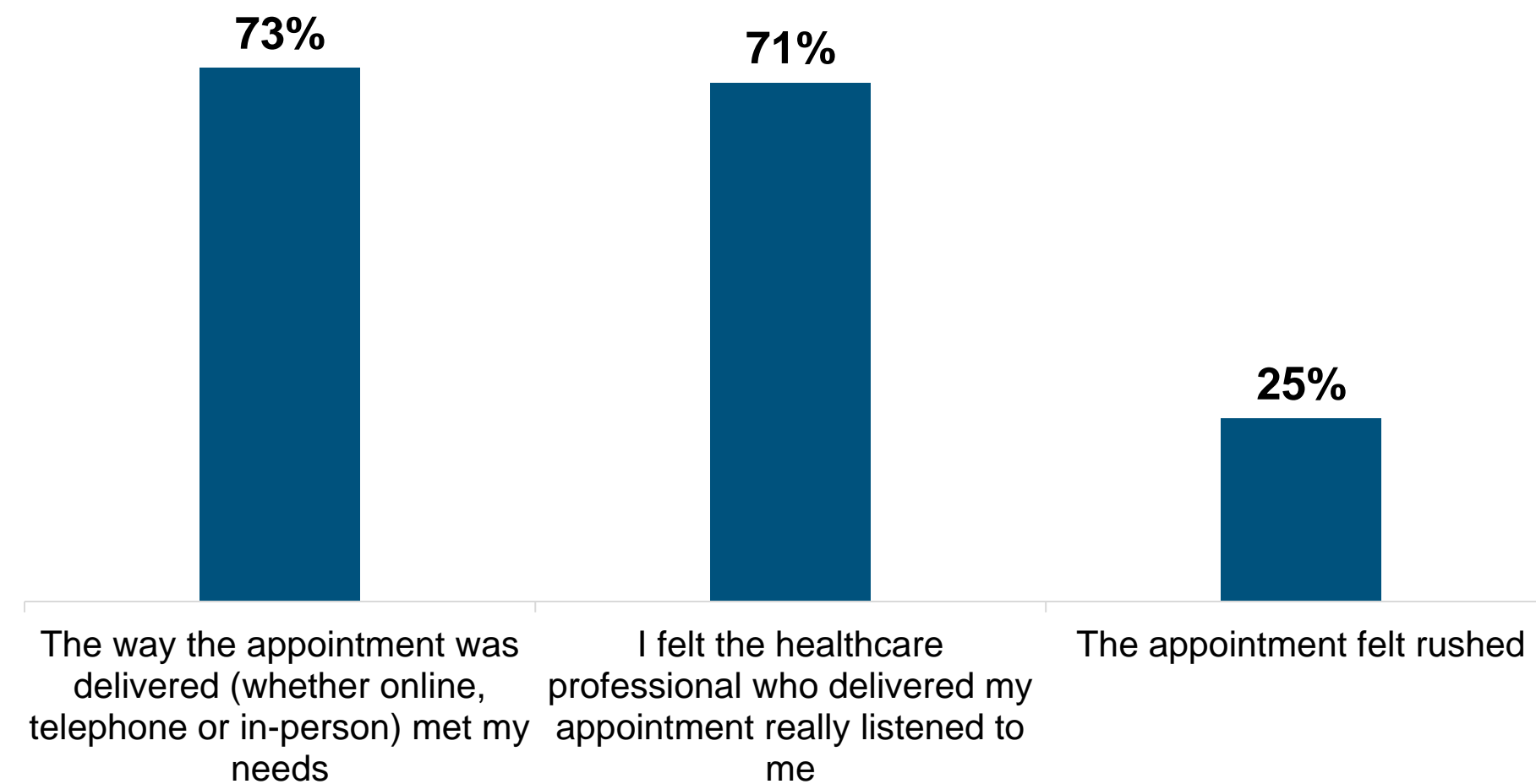
I called up at 7.59am and I was already 24th on the list. When I got through the morning appointments were all gone and I was told to call at 2pm again, even though I was in pain, and wanted to talk to a doctor.”

Public focus group, Midlands

”

Similarly, whilst perceptions of quality of care remain high, there are indications of a perception that doctors do not have the time to care

Thinking about your experiences of using GP services, please tell us the extent to which you agree or disagree with the following statements
Showing % of NET Agree



Focus group participants shared the view that **GPs do not always have sufficient time to address their concerns** and are seen to be ‘cutting corners’ by asking patients to send photos rather than examination for diagnosis.

“

*My son had a toe problem and they said to send a photo for them to have a look at it – **how can they really tell?***

Public focus group, Greater Manchester

”

The research suggests a gap between negative expectations and generally positive experiences – meaning that those positive experiences are often put down to luck

Overall, the majority of individuals have had positive experiences with their GPs since 2020

Quantitatively, **over half (54%)** of participants who have visited a GP surgery since March 2020 said that **‘overall, my experience was better than I expected’**, whilst only **16% disagreed** with this statement.

“*My doctors are pretty good. If I ring up at 8am I get an appointment, they are good like that. I think I am one of the lucky ones.*

Patient, Mental health and long-term condition, Greater Manchester”

However, these experiences are assumed to be in the minority

Qualitatively, **those that have positive experiences with their GPs say they feel they are the ‘exception to the rule’** due to widespread perceptions that primary care services are insufficient, even if this doesn’t align with their own experiences.

“*I have an amazing GP service. I’m probably the only person in the world. You can always get in touch, get an appointment. They’ve been doing phone appointments but you can also go in. 99.9% of population probably don’t have that.*

Public focus group, Greater Manchester”

Issues with access in particular are recognised by GPs, and attributed to significant workload pressures

The number of patients asking for help has increased, whilst remote appointments create pressure to see more patients each day.

Many GPs are bringing down their hours to part-time to avoid burnout, reducing the overall capacity of GP practices.

GPs recognise that there are issues with booking appointments and securing referrals, and fear that these will get worse if demand does not abate and / or there continue to be staff shortages.

“

*I have been a GP for a long time, my colleagues are competent and we step up to the plate when we are needed. The natural assumption is that we will get up and do it again everyday, but **I think quite a lot of GPs have had enough now. Primary care is teetering on the brink of falling over, and when primary care falls over, the NHS will collapse.***

HCP, GP, South East

”

But GPs' attempts to manage this workload conflict with patients' and the public's desire for more access

Public and patients **want greater access to primary care**, expecting increased availability to it can be their first point of call for all medical needs.



GPs want to be able to **manage access and prioritise patient care**, for example by more use of triage, or by channelling patients through other services (e.g. pharmacists). There is also a desire for active management of public expectations of GP surgeries.

“

They need to improve access to GP surgeries. I don't like the way that it is now, it is so impersonal.

Public focus group, Sussex

”

“

*We should free up GPs more. A lot of admin work could be done by other people, but we should also be making better use of people like pharmacists for patients... **Patients want to talk to a doctor, but don't always need to talk to the doctor.***

HCP, GP, South West

”

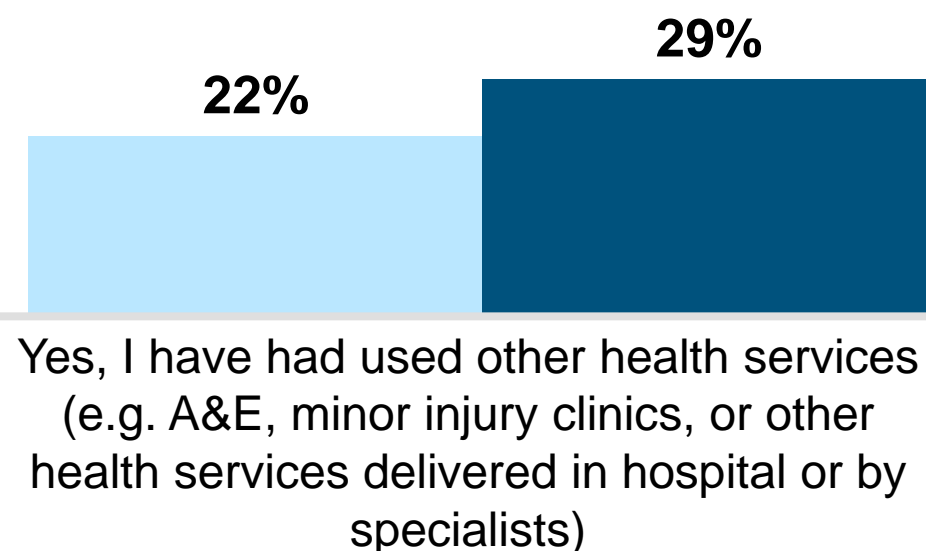
Secondary care deep dive

Similar to primary care, an increase in the proportion of people who have used secondary care has been accompanied by a decline in experiences of access and the quality care

Have you used NHS services since the start of the pandemic in March 2020?

Showing % of respondents who selected each option

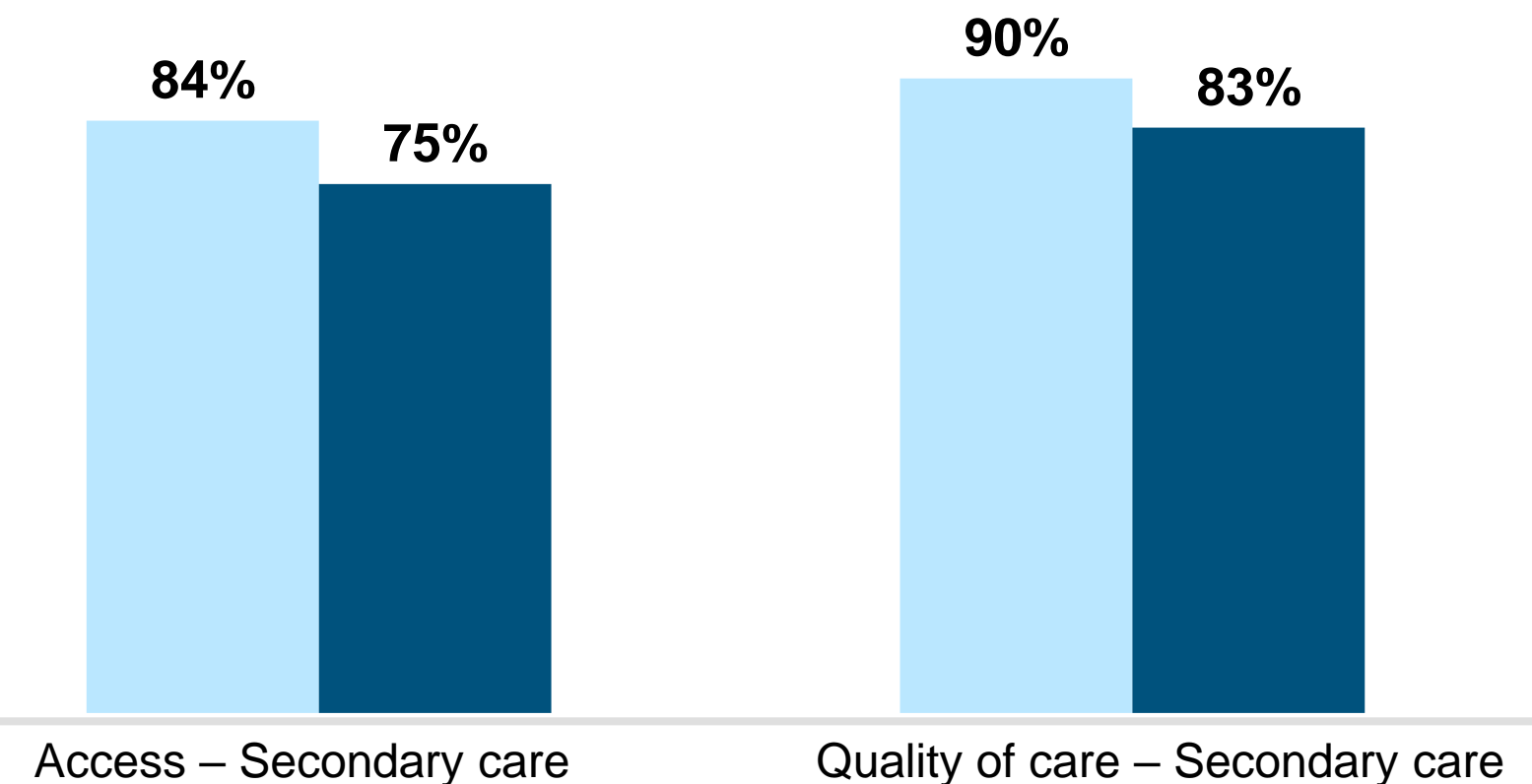
Phase 2 (Feb 2021)
Phase 3 (June 2021)



Have would you rate the experience of accessing care / the quality of care you received?

Showing % of respondents who selected 'NET: good'

Phase 2 (Feb 2021)
Phase 3 (June 2021)



Q. We'd like to understand your experiences of accessing NHS services since the first lockdown in March 2020. Have you used any NHS services since the start of the pandemic in March 24 2020? Base size: all respondents in Phase 2 Feb 2021 (n=2104) and Phase 3 June 2021 (n=1723)

Q. Please tell us how you would rate: the experience of accessing care; the quality of care you received. Base size: all respondents who have used other health services in Phase 2 Feb 2021 (n=471) and Phase 3 June 2021 (n=515).

Concerns about secondary care coalesce around waiting lists: the NHS's ability to tackle this will be a key metric by which it is judged moving forward

- **27% of respondents identify waiting lists for secondary care as one of their biggest concerns for the NHS** over the next few years – making it second only to funding.
- In the qualitative research, **spontaneous mentions of waiting lists have increased over all phases of research.**
- There is, however, **scepticism about the NHS's ability to make meaningful progress** in this area in the short to medium term.

“

Long waiting lists have been an issue for a long time, there is room for improvement. Your appointment doesn't seem to arrive, and when it does, it gets cancelled.

Public focus group, Midlands

”

“

*I've been on a waiting list for **nearly a year, still no word**. I did call a couple of times and they said I'll probably hear about May or June. **So I'm hoping to hear soon, but you just don't know.***

Patient, Mental health and long-term condition, Sussex

”


For those who are in the secondary care system, experiences of access and quality of care are inconsistent

Referral process

- Whilst some patients report being satisfied with the speed of referrals, **some patients within the sample have already been waiting over a year for an appointment.**
- Delays add to mental strain and force patients to self manage issues, often leading to worsening health conditions.

Ongoing care

- Across various specialist teams, patients report receiving **mixed levels of ongoing care and support once their referral has been processed.**
- Access is key: those with a clear contact point report an improvement in their conditions whilst others report being unable to get ad hoc support in the case of a flare up.



Patients agree that the **quality of communication plays a vital role in shaping their experiences of care**, with failure to keep patients up to date, or not knowing who to contact with questions significantly exacerbating issues.

Community care deep dive

Community care is less top of mind and less well understood than primary and secondary care, but there is an assumption that it is experiencing the same pressures as other parts of the service

Most do not have specific understanding of how community care services operate and / or what they cover – with NHS community services often being conflated with social care.

This leads to an assumption that services are **under-funded and under-resourced due to budget cuts and staffing issues**, problems which are blamed on the Government.

*I think the problem is probably that **their workload is a little heavy**... They only have a certain amount of time in a day that you can get workload done*

Public focus group, Greater London

The small number with direct experience of the service highlight the importance of consistent and predictable care

Positive experiences involve:

- Frequent and consistent contact/visits
- Access to staff with strong interpersonal skills as well as medical knowledge
- Clear communication and expectation management.

“
My mum caught Covid-19, she was in hospital and then got aftercare afterwards. All I've seen is good service being put in place.
”

Case study: Ali*

Ali's* elderly mum caught Covid-19 in 2020 and had to be admitted to hospital for over a week with serious breathing issues. Due to her old age, the family feared she would not make it, but she managed to pull through.

Following her recovery and discharge from hospital, she received additional community support in the form of daily visits from nurses to monitor her condition and help her with basic tasks whilst she regained strength. These services exceeded Ali's expectations of community care based on what he'd heard about services in the media. This support not only aided Ali's mum's physical health, but improved her mental wellbeing, whilst also reducing pressure and strain on Ali to provide the support himself.

03

Attitudes towards the NHS and experiences of healthcare

- Impact of Covid-19 on perceptions and experiences of the NHS
- Patient deep dives

We conducted deep dives into our four patient types:

Mental health



Long term health conditions



Cancer patients



Surgery patients



Overall summary of experiences

Cancer patients

Patient experiences have improved over the three phases of research. 2020 saw significant issues in cancer care including delays and poor communication. This has now **improved through a return to more in-person care and clearer communication.**

Surgery patients

Patients in the sample **have now had surgeries** which were delayed at the start of the pandemic. However, **access to aftercare has been mixed.** While some have had access to services such as physio, others feel there are **expectations to self-manage recovery.**

Mental health

Patients are still reporting issues with access and quality of care, with a perception that **care is only available once they are in crisis. Remote appointments are felt to be insufficient for patients' needs.**

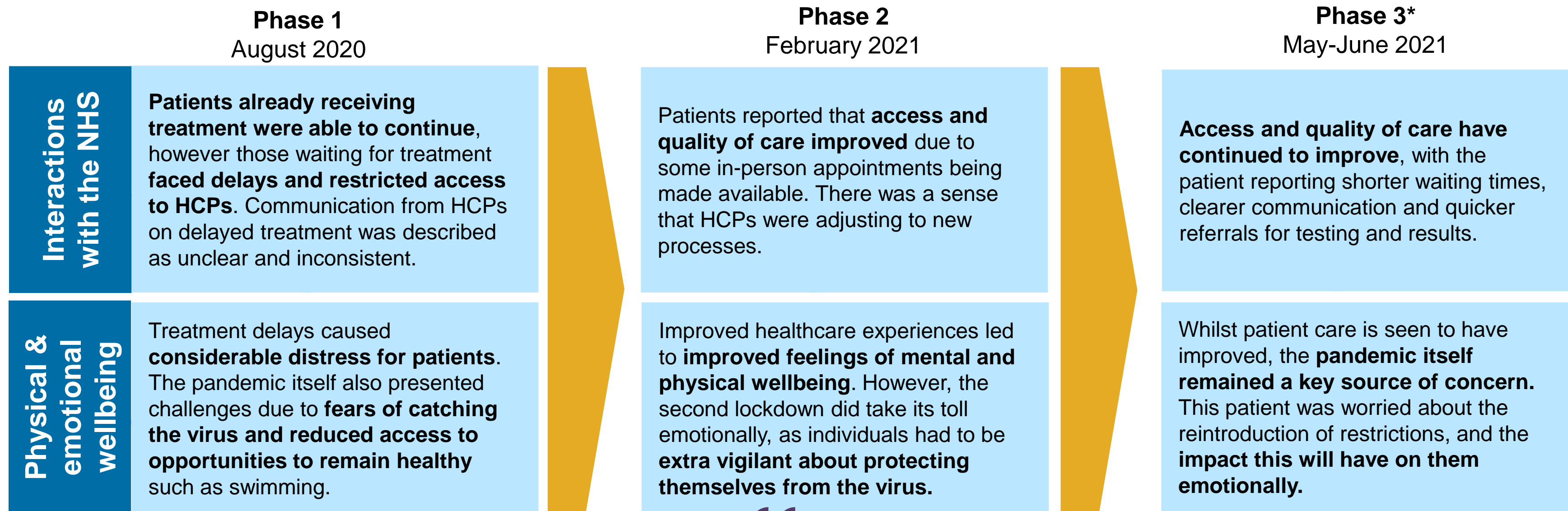
Long term health conditions

Patients have faced a continual decline in access to and quality of care due to **the temporary closure of specialist clinics.** Patients **have been forced to rely on GPs (who often have limited knowledge of their conditions), and on their own ability to self manage.**

Improvements in experiences across the three phases of research

Deterioration or sustained issues in experiences across three phases of research

Patients with cancer have reported improved access to and experiences with care



*I feel like there is no help there. I feel a bit bad saying it because I know they have been there for everybody, but **I don't feel like they have been there for me...** Everybody else has been left aside. I just feel let down.*

Patient, Cancer, Greater Manchester, Phase 1

*They've been a lot better recently. I have been seen a lot quicker. My annual mammogram was on time, I was referred from an emergency to secondary care and had surgery quite quickly. **Whenever I have needed to see a doctor or nurse, that has been fine.***

Patient, Cancer, Greater Manchester, Phase 3

*Note: only one cancer participant in Phase 3

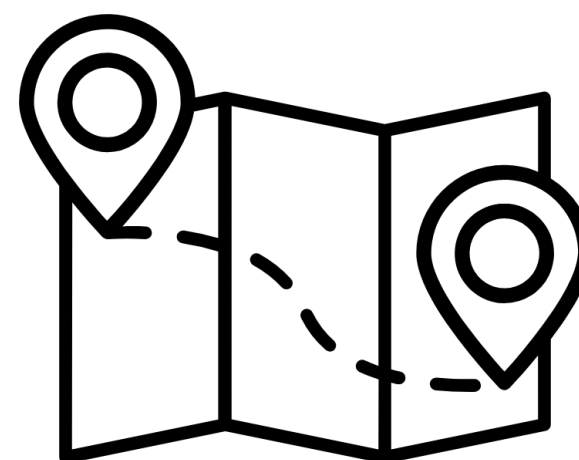
Case study: Rebecca*

Condition(s): Breast cancer, diabetes, autoimmune inflammatory disorder

Phase 1 & 2

Rebecca was able to complete some treatment before the pandemic hit, but the need for in-person care limited her ongoing treatment. She received an injection every month (to reduce the risk of relapse) but was told by a GP receptionist that these might not be able to continue due to Covid-19 restrictions. Many of Rebecca's appointments were changed to phone calls, where she struggled to communicate concerns and often felt rushed off the phone. During her one in-person appointment, Rebecca was afraid of the infection risk, as someone near her was turned away due to their high temperature.

By the second phase of research, Rebecca had discovered a new lump on her breast which was cause for concern. She was able to schedule an in-person appointment for this, and while she was still nervous about Covid-19, she was positive about the oncologist, who understood her health conditions and needs. Rebecca also began to have more positive phone consultations, describing her GP as going 'above and beyond'.



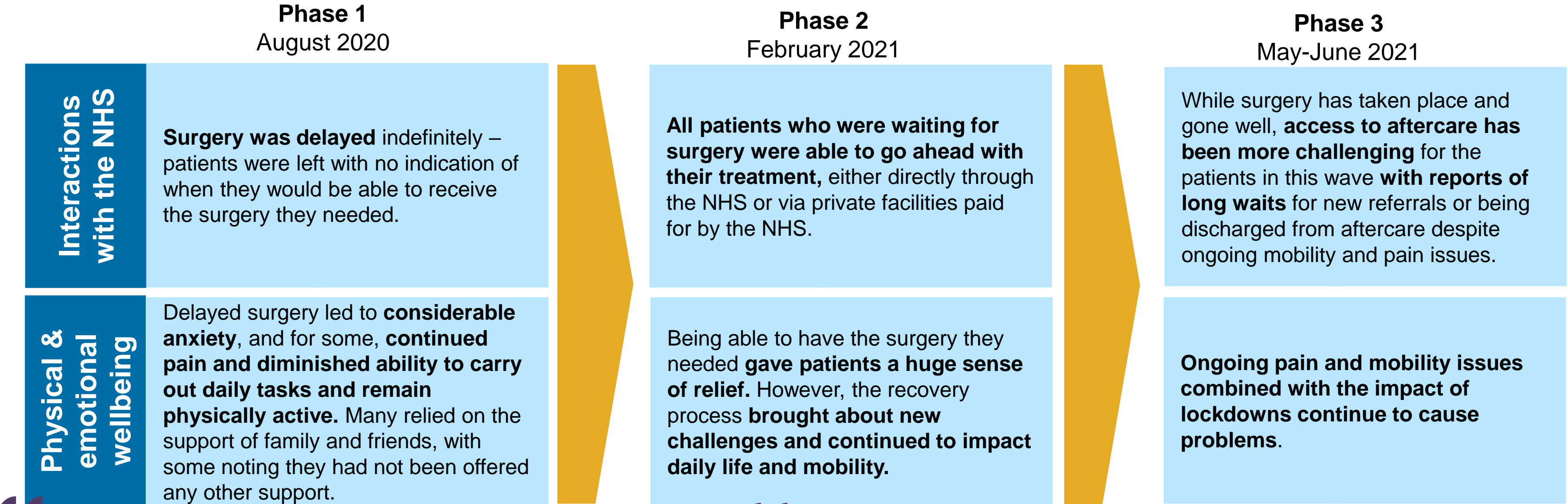
“When I was diagnosed with my cancer, they found a mass on my ovary but said it was benign. Then I started bleeding and shouldn't be... they sorted out an emergency CT scan right away”

Phase 3

Rebecca's experiences with the NHS have continued to improve since the last phase of research. Upon presenting with a new lump on her breast, she was pleased with how quickly this was addressed by HCPs. She received an emergency CT scan to investigate this and her GP kept her updated on results. She then received confirmation that the lump was not a new tumor, which was a huge relief.

Despite these improvements, however, Rebecca has been struggling more generally with the pandemic. She has felt emotionally drained; while she is positive at the seeming 'end in sight', she worries that more delays or new lockdowns might be announced. Due to her cancer diagnosis, Rebecca feels she has been in effective lockdown since 2019, and wants to be able to return to normal life, in particular to see family and friends she has not met in person since her cancer diagnosis.

Many patients who finally underwent their delayed surgery in Phase 2 are now reporting prolonged waiting times for after-care



*I've been to see the surgeon who is going to do the hip surgery and he told me there's a long wait. I've asked for the cortisone injection you can have, but **I was told I would have to wait** for that as well.*

Patient, Surgery, Midlands, Phase 1

*Nothing has really changed in quickness and things. A few weeks ago [in April] I had an MRI and then had a letter about my follow up appointment which is scheduled for 24th June. **It seems a long time to wait.***

Patient, Surgery, Manchester, Phase 3

Case study: Jim*

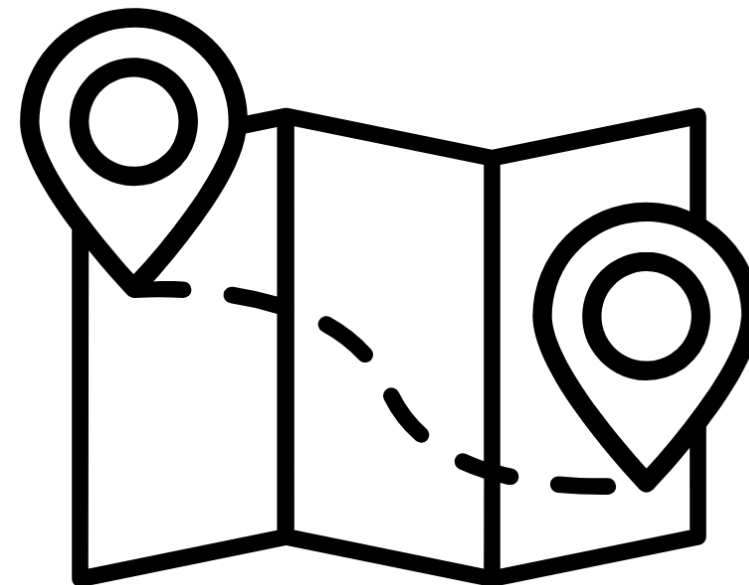
Condition(s): Musculoskeletal, hip replacement

Phase 1 & 2

Jim was told he would need hip replacement surgery at the end of 2019, and was put on a waiting list. When the pandemic hit, his waiting time was increased. While he was understanding and felt he would be seen eventually, his health issues had a big impact on his mental wellbeing.

Jim then had a further negative experience with the NHS after suffering a fall which impacted his back. He received a rushed service and was forced to be treated in a hospital corridor, which left him feeling improperly cared for.

By the second phase of research, Jim had been able to get the surgery he needed. He received a call before Christmas, and his surgery was scheduled for a few weeks later. It took place at a private facility but was paid for by the NHS. Jim was pleased by the speed and ease of this process but found his follow up physiotherapy difficult.



“ There was about a month between my physio appointments and then she said, ‘I think you’re doing well, we don’t need to see you anymore’. I was surprised, as I still had pain in my back at the time, which I told her, but she just gave me exercises to do at home. ”

Phase 3

Jim has continued to struggle with ongoing pain and mobility issues since his surgery, including new pain in his back. He spoke with the surgeon a few times after his operation, including one in-person appointment, and was told the pain was to be expected and would settle down eventually.

Jim also had physiotherapy appointments, the first a month after his surgery. After only a few appointments (with long waits between), the physiotherapist said he was doing well and did not need to be seen anymore, giving him exercises to do at home. This came as a surprise to Jim who felt that his condition had not improved enough yet. He has since continued to struggle with pain management and mobility. As a result, he has contacted his GP again to report the ongoing issues and return to physiotherapy.



Patients with mental health conditions report some improved access to remote appointments, compared with previous research, but limited change in their overall condition

Phase 1
August 2020

Phase 2
February 2021

Phase 3
May-June 2021

Interactions with the NHS

Remote appointments replaced **face to face**, with patients saying that this led to a decline in quality of care. Those on waiting lists saw **increased delays**.

Patients continued to report **significant access and quality of care issues**, including requests for support not being followed up on, and continued perceptions that remote care was not adequately meeting patients' needs.

There has been **improved access for those in crisis**, but beyond that long waits remain. **Remote appointments also remain**, despite ongoing challenges with this format.

Physical & emotional wellbeing

The start of the pandemic added to existing mental health challenges due to concerns about catching Covid-19.

Lack of access to healthcare **resulted in adverse affects on patients' health**. Lockdown was also found to **be emotionally exhausting**, depriving patients of the usual sources of relief and support (such as seeing family).

Improved access and the easing of restrictions has led to **some improvements in patient health**, however this is described as 'up and down' at best, as many still **feel let down by NHS services**.

There are a lot of challenges in actually getting to see someone. It's gotten incredibly hard to see a general health doctor or a mental health practitioner. I was referred to a new psychiatric doctor in July – it's February now and I've not spoken to them at all.

Patient, Mental health, Midlands, Phase 2

*I guess you feel like you're more able to contact the health service about normal things, [but there are] long waits now. **It's gone from, you can't contact at all, to being able to contact but having long waits...** it's better but in some ways you do still feel you're on your own, because the health service is so overstretched.*

Patient, Mental health, Sussex, Phase 3



Case study: Louise*

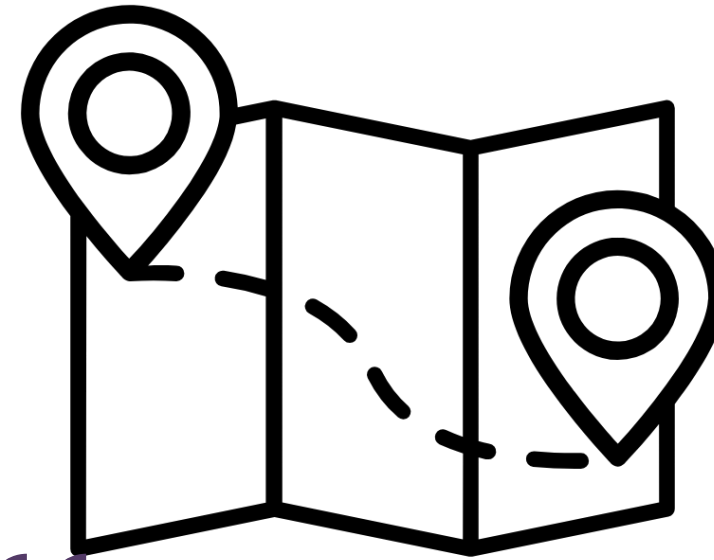
Condition(s): Depression, anxiety and autism

Phase 1 & 2

At the beginning of the pandemic, Louise struggled to manage her health concerns, which were exacerbated by the stresses surrounding Covid-19 and lockdowns. Her dog 'kept her going', helping with her anxiety which in the past has prevented her leaving the house.

Louise was on a waiting list for further mental health support. She was concerned that waiting lists had increased since the start of the pandemic, but felt unable to follow up to ask for a quicker referral. She was put under the care of a social worker but felt they were overstretched, having been tasked with 45 patients rather than the usual 25.

By the second phase of research, Louise felt little had changed. The lockdowns were emotionally draining, and her dog had passed away. While she was able to access an in-person chiropractor appointment for a slipped disc, other appointments remained virtual. She had one call with her GP, and a few with a mental health support team, but was still on waiting lists – with one having a 24-month delay.



It's very hard to get through on the phone... When I finally was able to, the appointments have been about 3 months apart. But the doctor is quite good, she gives me quick calls before her clinic to check in.

Phase 3

Louise is still facing ongoing challenges with her mental health, including experiencing depressive mood swings and anxiety, as well as exhaustion.

She has noted improvements in access to HCPs, however this has not always led to improvements in care and outcomes. Louise has been able to speak to her GP on several occasions but with mixed levels of success, as she feels that they do not have the time or expertise to properly manage her conditions.

Louise has also been able to get more access to a psychiatrist which she finds more impactful for her. However, these phone calls often 'fit in' around the doctor's other clinics, meaning they are somewhat 'unofficial' in nature. As a result, Louise has experienced issues such as not being informed of a cancelled appointment when her doctor was unwell herself. Louise waited an hour for the call before calling reception, an experience which negatively contributed to her feelings of anxiety.



Many patients with long-term conditions are still reporting challenges in accessing care and expectations of self-management

Phase 1
August 2020

Phase 2
February 2021

Phase 3
May-June 2021

Interactions with the NHS

Many saw **access to specialist care become restricted**, with treatments and tests cancelled.

Continued lack of access to specialist care left many patients having to **self-manage their own symptoms, without feeling that they had the support required** to do so effectively.

Patients still report limited access to specialist care, with long waiting times and delayed appointments. Expectations for **self-management continue** and GP support is viewed as **insufficient for those with more complex conditions**.

Physical & emotional wellbeing

For most patients, the pandemic had a significant negative impact. Lack of access to care caused **health to decline**, and in turn **led to anxiety and concerns about mental health**.

Lack of access continued to impact patients mentally and physically. Some were **concerned about the infection risk**, and **others described the second lockdown feeling more difficult emotionally than the first**.

Some participants note that the **easing of restrictions has led to improvements in their mental wellbeing**. However, **limitations to specialist care continue to impact their physical health and mobility**.

*I used to go to a pain management clinic, but unfortunately now things like that have stopped. I'm waiting to have some bloods done and I am due to have a blood transfusion, but **I have been waiting months** for that now.*

Patient, Long-term condition, Midlands, Phase 1

*It has been rejection after rejection - the specialist doctor will only see someone without a diagnosis. **I am stuck in this middle ground where no one will pick me up...** I know I will be a long-term burden on them if I don't get the support... The specialist is probably the only gatekeeper, but I know she won't see me.*

Patient, Long-term condition, Greater London, Phase 3



Case study: Ellie*

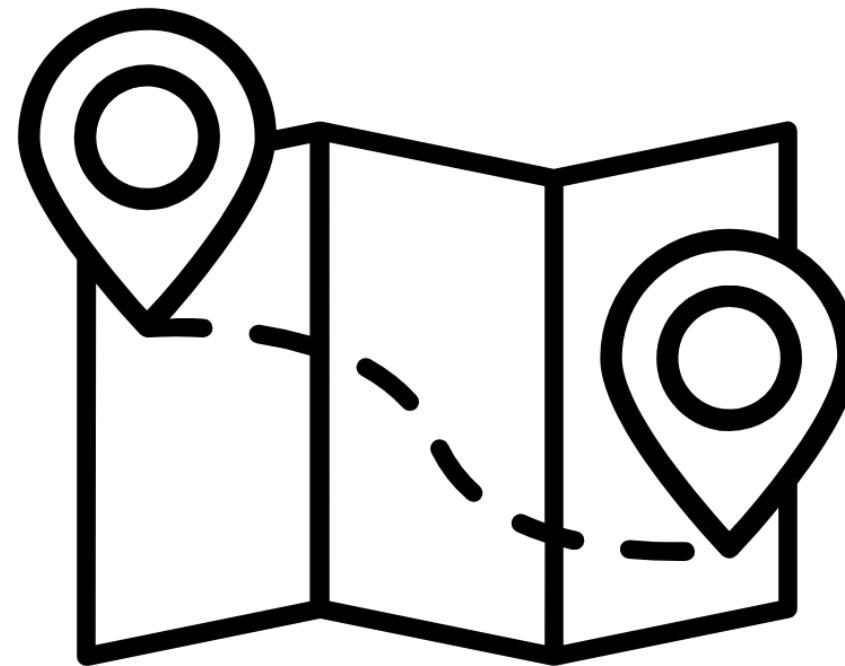
Condition(s): Ehlers Danlos Syndrome

Phase 1 & 2

Before the pandemic, Ellie attended a specialist care unit with a consultant, support team and facilities to manage her condition. All of her appointments were cancelled at the start of the first lockdown, and she no longer had access to facilities vital to managing her condition.

Ellie's symptoms worsened, leading to her dislocating her hip trying to get out of a chair. She was unable to reach her consultant directly, and her GP surgery has minimal knowledge about her condition.

Ellie reported that her health was continuing to decline in the second phase of research. She had virtual physiotherapy appointments but did not find these helpful. Her issues were compounded by additional complications, including winter weather further limiting Ellie's movement and becoming ill with Covid-19 resulting in fatigue. She feels her condition has relapsed to the level it was prior to receiving any treatment.



“It's been absolutely awful. I have run into doctors who has asked me to 'grow up and get on with my day'... to the point where I thought about leaving my GP practice, and I have been there since I was born.”

Phase 3

Ellie has continued to struggle with a deterioration in her condition since the second phase of research. She feels she will have to 'start over' with the process of improving her condition when she can access support and has had to make life changes to cope with her symptoms, such as socialising less and using less public transport.

Ellie's specialist care unit has remained closed, and she has not been able to secure an appointment with her usual consultant, who is currently only seeing those who are undiagnosed.

This has resulted in Ellie being entirely reliant on her GP practice. Here, her experiences have been heavily dependent on who she has seen on any given day – some have been unequipped to properly manage her condition, whilst others have been completely dismissive of her concerns, causing a great deal of distress. She has only felt positive about the care of one GP, who provided her with more information and resources.

04 Health inequalities

Whilst around half of patients and public we spoke to had heard the term 'health inequalities' previously, real understanding of its meaning is low

I just don't see it, I don't think there are any.

Public focus group, Greater London

It's not something I've read about before

Public focus group, Greater Manchester

No, I can't think of what it might mean, everybody is treated the same. If you're talking about race... there are lots of different races when you go into hospital.

Patient, Surgery, Midlands

*I think one thing that comes to mind is elderly people being less prioritised... **Ethnic minorities, poorer people, those not as articulate struggling to access services.***

Patient, Mental health, Sussex

HCPs have greater awareness of the term, however understanding of its meaning is not consistent

Many HCPs recognise how health inequalities can impact their patients, and spontaneously discuss the relationship between factors such as race, ethnicity and socio-economic status and health outcomes. Their specific focus is driven by the areas most relevant to their specialism or area of work.

However, **understanding is not consistent across all HCPs**, with some conflating access issues with health inequalities.

“

Health inequalities are a significant issue for the NHS, there are so many inequitable groups – BAME groups, learning disabled groups, out of work, people who are in work and can't get to a GP.

HCP, GP, South East

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“

Socio-economic status comes into mind with diabetes. You need background info on good choices, good exercises. Some people struggle with this. They don't always understand the severity of it in the future.

HCP, Nurse, Manchester

”

Participants were provided with the following definition of health inequalities:

“The NHS defines health inequalities as the unfair and avoidable differences in health across the population, and between different groups within society. Health inequalities arise because of the conditions in which we are born, grow, live, work and age. These conditions influence our opportunities for good health, and how we think, feel and act, and this shapes our mental health, physical health and wellbeing.”

Where further explanations were needed, participants were also shown a variety of news headlines relating to health inequalities e.g., 'Miscarriage rates over 40% higher in Black women' and 'Poor Britons have worse health than generation born a century ago'

Whilst the definition helped to increase understanding, confusion remained for many

No understanding

Minority view, held by some patients and members of the public of lower SEG/education.

Do not understand health inequalities based on definition and require further data to validate / understand the claims.

“ I have heard about those things; I don't believe it to be honest ... **how can giving birth be different for someone because of the colour of their skin?** ”

Patient, Long-term condition, Midlands

Limited understanding

Majority view, held by individuals across all participant groups.

Are able to make a connection between some limited factors (e.g. geography, age) and health outcomes, but failed to recognise broader patterns and tend to revert back to viewing health inequalities through the lens of individual experiences.

“ Age, north/south divide. **It always seems to be if something happens in London, it gets resources, money.** If you're up North, they die younger. ”

Public focus group, Greater Manchester

Strong understanding

Minority view, held by some HCPs and public/patients of higher SEG/education.

Recognise how wider socio-economic factors such as race and education levels intersect with health outcomes.

“ **It's about the circle of disadvantage** – a lack of education leads to worse career prospects, that leads to reduced finances and being trapped in poverty. ”

Public focus group, Midlands

Those with no or limited understanding had a greater tendency to respond negatively to discussions on health inequalities due to perceptions that there was an implied blame on individual HCPs for unequal experiences.

Understanding corresponds with expectations: those with greater comprehension see more value in addressing health inequalities

No understanding

Health inequalities are seen to be a **low priority** for the NHS, driven by a lack of understanding as to what they are and how they could be addressed.

Limited understanding

There is strong claimed support for ensuring equal NHS services for all. However perceptions that inequalities are down to individual experiences rather than broader patterns mean that this is seen to be a **longer-term change that the NHS could work towards**, rather than an urgent action.

Strong understanding

Addressing health inequalities is viewed as a **necessary and important investment into the health of the nation and the NHS itself**. It is tied with preventative care and improved societal health which could lead to reduced strain on the NHS.

However, even those who indicate more support for tackling health inequalities question whether the NHS could or should lead the way

ABILITY: Due to the perceived financial pressure the NHS is under, there are questions about whether or not it has the resources available to tackle this issue.



RESPONSIBILITY: Many feel that effectively addressing health inequalities goes beyond the NHS's remit and strays into the responsibility of other organisations – leading to questions about whether they would be better placed to address them.

Any initiatives or work done in the field of health inequalities would need to be done in close collaboration with relevant partner organisations.

“

*I would not feel very confident. **They [the NHS] don't have the resources to do it on their own. They need more funding.***

Patient, Mental health, Sussex

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*It's down to the government creating a better environment with a holistic approach, rather than blaming it on NHS. The NHS has been firefighting for years, **they aren't able to address the root causes.***

Public focus group, Midlands

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Ultimately other issues within the NHS are more top of mind for the public

When asked about key concerns in the NHS, **only 3% of the public chose:** *‘That some groups will find it harder to access healthcare because of factors such as their race, age or where they live’.*

The topic of health inequalities in the NHS **does not come up spontaneously.** Even for those with higher levels of understanding, **issues of funding, staffing and quality of care are deemed more urgent.**

“

*It is important, but **there are other problems we need to focus on first.** They need more funding for staff, and more resources*

Public Focus group, Midlands

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Building an understanding of the terminology in a way that avoids perceptions of blame will be a crucial first step to building public support for tackling health inequalities

In the first instance, communications should...



Demystify the terminology

The terminology of 'health inequalities' needs to be **clearly explained in a way that is simple and accessible for all audiences and does not appear to 'blame' HCPs / other individuals for differences in outcomes.**

And then....



Highlight the end benefit to the NHS

Addressing health inequalities should be positioned as an **effective means of preventative care** that could **alleviate pressure** on the NHS in the long term.

This will provide **reassurance in the context of high levels of concern about funding.**



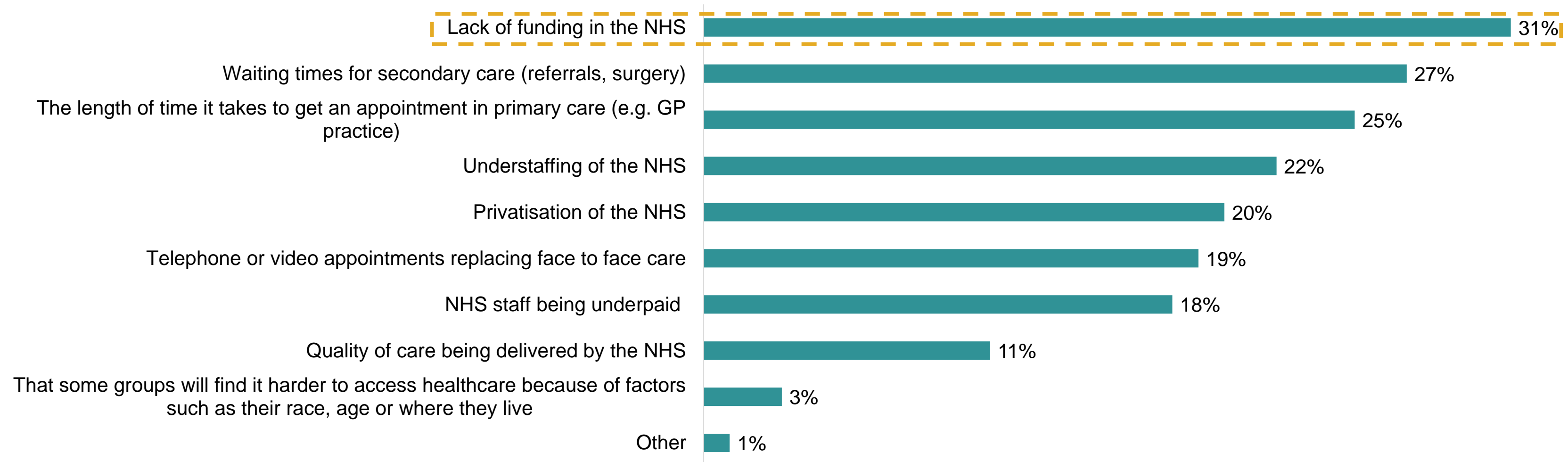
Be clear that change would be a collaborative effort

Positioning addressing health inequalities as collaboration between different sectors, with clearly defined responsibilities will **help address concerns about NHS resources being redirected outside its 'core' remit.**

05 Future of the NHS

Consistent with previous waves, funding remains the biggest concern, followed by access

And thinking about the next two or three years, what are your biggest concerns in the NHS?
Showing % of respondents who selected each option

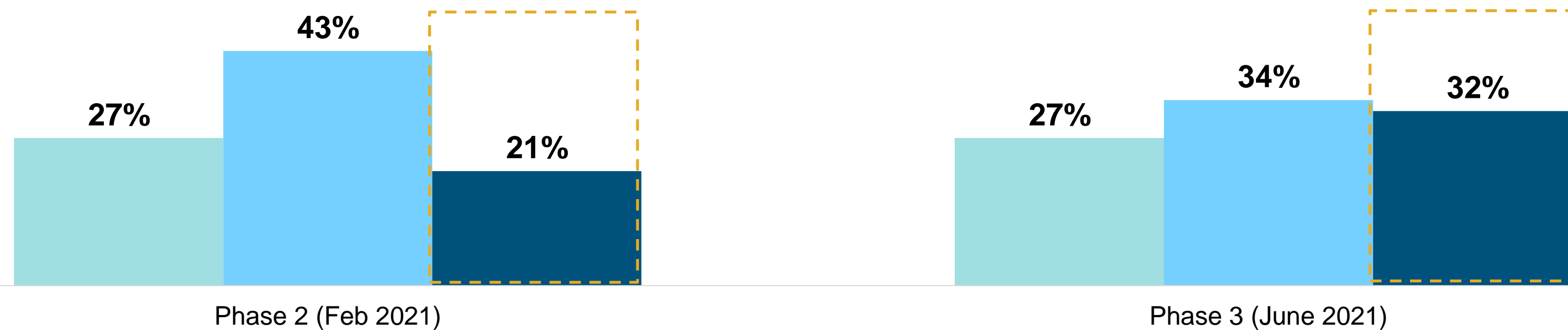


The public are less positive about the standard of care the NHS will be able to provide over the next 12 months than they were in February

Do you think the general standard of care provided by the NHS over the next 12 months will get better / worse / stay the same?

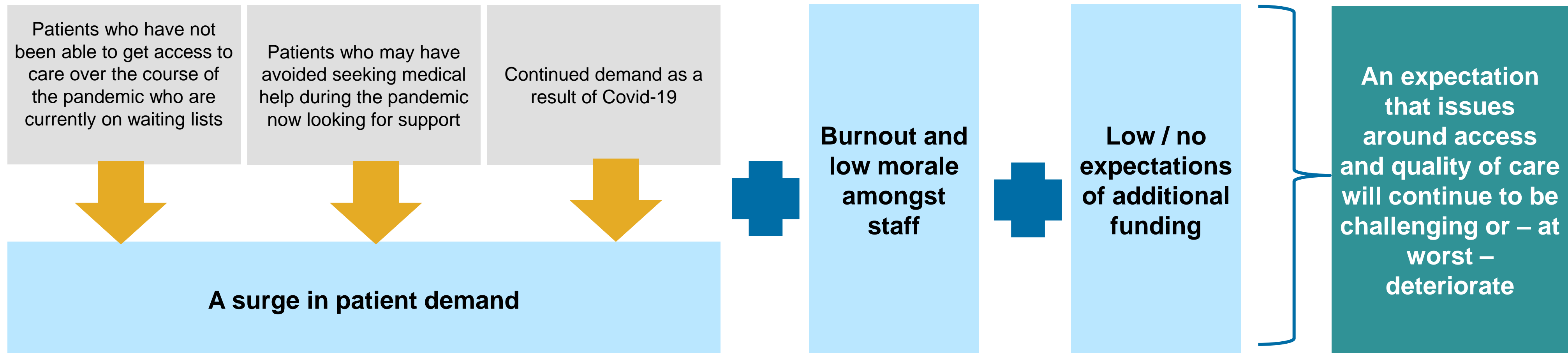
Showing % of respondents who selected each option

■ NET: Better (incl. 'much' and 'slightly better') ■ About the same ■ NET: Worse (incl. 'slightly' and 'much worse')



Across all phases of research, older people are less likely to feel optimistic: in Phase 3, 39% of 18-24 year old's said 'better' compared to just 28% of 65+.

Pessimism is driven by a perception that, even if we are able to move past the pandemic, pressures on the NHS will continue



“

There are things that should have been highlighted six months ago that weren't highlighted and they will come to roost in six months' time.

HCP, Physio, South

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The challenge is to catch up. From what we've heard it's going to be a big job. More patients are now needing medical attention.

Public Focus group, Midlands

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For some amongst the public and patients, questions about HCPs' commitment to returning to 'pre-pandemic' care also drives pessimism

The return to face-to-face appointments are often the flashpoint for pessimism, with patients and the public who are most keen to see a return to face-to-face appointments questioning whether **the perceived time and convenience benefits that accrue to HCPs from remote care will be prioritised over patient preferences.**

However, this does not align with HCP feedback, with most indicating **a strong desire to resume face-to-face care where needed.**

“

I don't think it ever will go back to the way it used to be, I think they are pushing for it all to be online long term.

Public Focus group, Sussex

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“

*You don't have the same relationship virtually. Its fine for getting information and getting changes for medication. People aren't opening up as much. It's a bit more matter of fact over Teams. **You don't get the personal connection, and I feel that maybe that they aren't as honest.***

HCP, Nurse, Manchester

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HCPs are also acutely aware of patient concerns, and are concerned about a decline in public support

There are calls from HCPs for an open and frank conversation with the public about the state of the NHS, the challenges it is facing and trade-offs that may need to be made moving forward.

“There needs to be an honest dialogue about the funding mechanism in the NHS. **Either, funding is significantly increased, or service provision needs to be pared back – you can't have both.** The public needs to understand this is a service to be used sparingly.

HCP, GP, London”

As part of this conversation, HCPs are keen to stress that **some positive changes to the NHS** (e.g. technological innovations) arising from the pandemic, **should be retained and used as appropriate, with clear communication to patients about the reasons for this.**

“There are some positives in terms of **IT systems which were historically bad have been updated.** We can now have virtual clinics, and people can upload their information to us virtually. That's been a long time coming.

HCP, Nurse, Manchester”

06 Key findings

Key findings

1

For the first time in this programme of work, there are indications that the Covid-19 ‘grace period’ is coming to an end.

- Whilst the public and patients continue to praise the NHS, there is a growing expectation of a return to ‘normal’ characterised as a return to face-to-face and improvements to waiting list times. This is accompanied by questions from a minority of those we spoke to about the commitment of those in the NHS to delivering this.

2

Overall, patients who have used primary care remain positive (68% rate the access as good, whilst 78% rate the quality of care they received as good).

- However, both scores are down from the previous wave, and 28% of those polled had to wait longer than 2 weeks for an appointment.
- Moreover, the qualitative research indicates that a growing gap between low expectations and generally positive experiences is leading to participants attributing these positive experiences to ‘luck’ – rather than to the system performing effectively.

3

Similarly, in secondary care whilst perceptions remain positive overall (75% rate the access as good, whilst 84% rate the quality of care they received as good), scores are down from the previous waves.

- Concerns in relation to secondary care coalesce around waiting lists; tackling waiting lists will be a key metric by which the NHS is judged moving forward.

Key findings

4

Spontaneous understanding of health inequalities amongst the public and patients is low, and tackling health inequalities is not widely seen as a priority for the NHS.

- Even amongst those HPCs and members of the public for whom this is seen as a more pressing issue, the complexity of health inequalities and the range of organisations involved leads to questions about whether the NHS has the funds or – on its own – the ability to resolve the challenge.

5

The public are more pessimistic about the standard of care that the NHS will be able to deliver moving forward than they were in February.

- In February, 21% of those polled expected the standard of care to get worse of the next 12 months; this has now risen to 32%.
- Pessimism is driven by an expectation that, even if we are able to move beyond the pandemic, pressures on the NHS (high patient demand, staff burnout, lack of funding) will continue.

6

HCPs are aware of patient concerns, particularly in relation to access, and are worried that they are seeing declining public support as a result.

- This is leading to calls for an open and honest conversation with the public about what they can expect from the NHS moving forward.

Thank you

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