

PATIENT

Noun. A person receiving or registered to receive medical treatment.

Adjective. Able to accept or tolerate delays, problems, or suffering without becoming annoyed or anxious.



Improving our understanding of the experience of waiting for care.

I would like to thank the people who have shared their stories of waiting for care for their honesty and generosity of spirit. Your experiences leave us in no doubt that the healthcare system needs to do more to understand the importance of, and invest in, improving the experience of waiting.

It is therefore very welcome that NHS England and Improvement asked National Voices to explore these experiences and to think through what is needed to make things better, as part of the Clinical Review of Standards. This decision preceded the arrival of Covid-19 in the UK, but the impact of the virus on wider healthcare has made it even more important. We are heartened that NHS England and Improvement is learning from the first wave of the pandemic and to prevent the large scale cancellation and disruption of health care that occurred during the spring.

People across the whole of the NHS are working hard to keep non-Covid healthcare going and there is also now a welcome commitment to do better for those people where a delay or cancellation might become unavoidable because of a virus surge. We at National Voices are working with NHS England to develop better information, communication and support for people who have their care disrupted.

Early on in this listening exercise one of the contributors said, “It’s the not knowing that kills you” and these words have stayed with me throughout. Communication is the key to a more positive experience of waiting: receipt of referral, a number to call, an estimate of how long you might wait, regular updates on delays, and access to support and self-management whilst waiting.

Contributors expressed gratitude for our health and social care system and the voluntary and community sector that complements it. We will work with colleagues across the whole health and care landscape to ensure that people who are waiting know they are cared for.

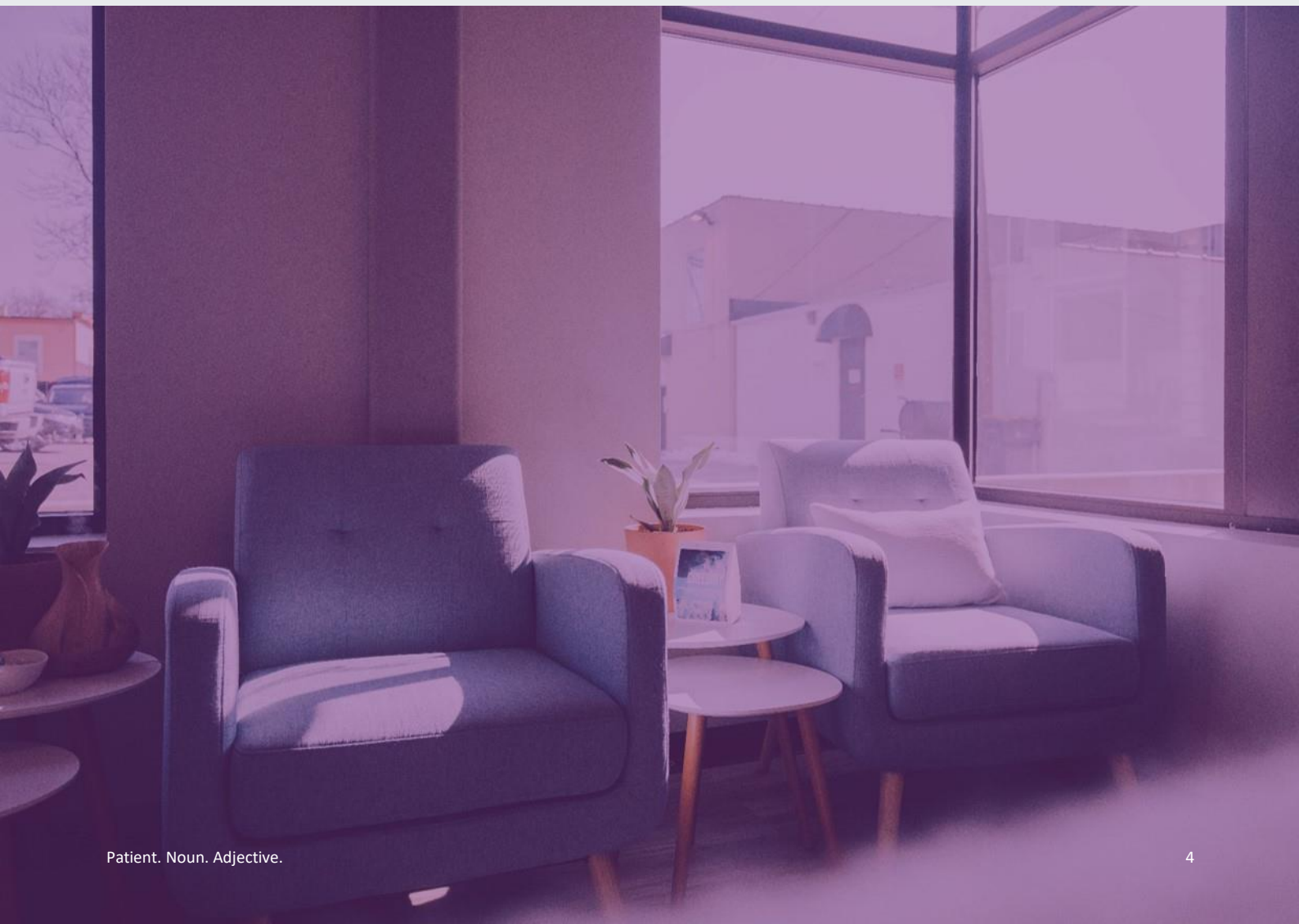
Dr Charlotte Augst, Chief Executive, National Voices

push button and wait
for signal opposite

WAIT

Contents

6	Methodology and Scope
7	Key Themes and Recommendations
8	Good Practice Principles
10	The Existing Research
12	Recommendation One
15	Recommendation Two
17	Recommendation Three
20	Waiting During Covid-19
24	Becoming Patient Focused
26	Bibliography



We wanted to understand how waiting for care impacts on people

National Voices was asked by NHS England and Improvement to explore the experience of waiting for care. We wanted to understand how waits, delays and cancellations impact on people and their families, particularly those living with long term and multiple conditions.

This insight work was commissioned as part of a review of care standards (waiting time targets) for elective care, in the winter before the Covid-19 outbreak. Currently people using the NHS have rights to treatment via the NHS Constitution and for many services there are waiting standards, including the 18 week waiting time for consultant-led treatment.

In March NHS England and NHS Improvement asked providers to postpone all routine surgery for at least three months from 15th April. This will have had a significant impact on those waiting for treatment. For example, even before the onset of the COVID-19 outbreak in the UK, there was a growing number of people waiting for hip and knee replacement surgery, with significant numbers waiting beyond the maximum waiting time of 18 weeks from referral to treatment¹. In 2018, a report by Rethink Mental Illness found that on average people severely affected by mental illness waited 14 weeks for an assessment alone and a further 19 weeks to begin treatment². A report by the All-Party Parliamentary Group on Mental Health highlighted that many people were ending up in crisis because they had been unable to access support in core community mental health services³.

It is clear that people are aware that waiting times will be longer due to Covid-19 restrictions. We have heard through our insight work that people are often reassured by a fixed end-point to waiting (a waiting times target) where this is possible. National Voices members have also gathered evidence that waiting times targets are key incentives for NHS services and as such would support keeping targets alongside the careful co-design and introduction of new standards and a better overall experience of unavoidable waits.

A long and poorly managed wait can have dire consequences for mental health, physical health, work, quality of life and relationships. Standards that “focus the mind” of services on improving waiting, its duration, but also what goes on during this period, are therefore of benefit.

In January 2020 we commissioned a **review of the existing literature**⁴ in the Patient Experience Library, together with an analysis of insights collected by Care Opinion⁵. With the arrival of Covid-19, we adapted our methodology and focus to explore experiences before and during the pandemic, to expand the scope beyond elective care and to include consideration of alternative, ‘virtual’ healthcare service solutions.

We carried out over **twenty interviews with people with a range of physical and mental health conditions who were waiting for a mix of appointments and procedures** and at all ‘points in the journey’, from first symptoms, diagnosis, through treatment (apart from Accident & Emergency).

In addition, we wanted to try and understand **what it is like for people who have been offered alternative, ‘virtual’, service solutions**. We joined with Traverse and Healthwatch to do this and together we have produced a guide: *The Doctor Will Zoom You Now: Getting the Most out of Virtual Health Care Experiences*⁶.

“People are waiting for care and often potentially life-saving treatment. The implications of delays for people who are in severe pain and for whom surgery is the only option is a very serious consideration.”

“Mental health deteriorates considerably while people wait for services.”

“Waiting has patient safety and clinical implications.”

National Voices Members

1. <https://www.versusarthritis.org/media/22366/health-social-care-committee-inquiry-2020.pdf>

2. <https://www.rethink.org/media/2498/right-treatment-right-place-report.pdf>

3. <https://www.rethink.org/media/2579/on-the-road-to-parity-final-report.pdf>

4. National Voices: Improving our understanding of the experience of waiting for elective care. Jackie Goode, February 2020.

5. Care Opinion is an independent online feedback platform for health and social care services across the UK: <https://www.careopinion.org.uk/>

6. *Doctor Will Zoom You Now: Getting the Most Out of Virtual Health Care Experiences*

Methodology and Scope

The literature review was carried out by Care Opinion and the Patient Experience^{7,8} Library. The Patient Experience Library contains over 60,000 publications on patient experience and involvement. These include surveys, studies and policy documents from sources including government bodies, patient voice organisations, health charities and academic institutions. It contains both formal literature and grey literature (defined as publications that are ephemeral, poorly catalogued, or hard to find). It does not contain documents that are held behind journal paywalls, or other literature that would normally be for sale from booksellers. Most of the content is from 2012 onwards.

An initial search covering all documents up to the 25th January 2020 and including both UK and international documents was carried out, using the following search terms: 18 week, appointments, elective care wait, waiting list, waiting times. This initial search delivered 5,000 results, which was further refined to eliminate duplicates, retain only those up to three years old and to keep only those featuring the search terms as a prominent part of their content. A further manual sort excluded those that were concerned primarily with mental health issues, urgent and emergency care, and primary care (42 remaining).

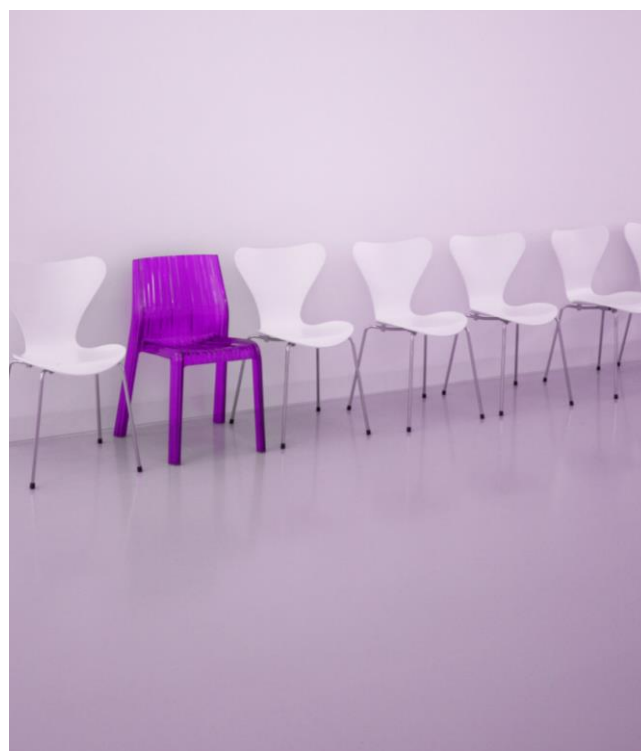
The analysis of the **Care Opinion** data is based on a total of 88 stories. The initial search dated from 2015 to January 2020. 2015 was chosen because of the review of the 18-week Referral To Treatment (RTT) measures conducted by Sir Bruce Keogh, one of the aims of which was to ensure that the policy made sense to patients in practice.

The following search terms were used: 'Wait/ing times' and 'elective surgery' plus the main surgical specialties (cardiothoracic, general, neurosurgery, oral and maxillofacial, trauma and orthopaedic, ENT, paediatric, plastic, urology and vascular). This produced 236 stories. Excluding stories about cancer patients, those concerned exclusively with mental health, paramedic and A&E stories and accounts of time spent in waiting rooms during hospital appointments reduced this set to 47 stories. An additional search was undertaken extending the period covered. This produced a further 251 stories of which 41 met the criteria.

National Voices members helped identify people for a listening exercise which was carried out by Überology.

The key themes identified in the literature review were used to design the **interview questions and prompts**. National Voices members provided additional insights into the clinical standards review and experience of waiting and also helped identify and support people for interviews between May and July 2020. The conversations and questions were open-ended, allowing contributors to talk freely and tell their personal story of waiting: before and during Covid-19.

Participants reported a range of physical and mental health conditions. Many were waiting for a mix of appointments and procedures. For those with long-term conditions most had experienced changes to their regular appointments and treatments due to the Covid-19 restrictions. Many had appointments postponed indefinitely, whilst others had appointments switched to a 'virtual' offer such as phone or video. In some cases, people had in-person appointments, mostly for blood tests, scans, and other tests.



7. National Voices: Improving our understanding of the experience of waiting for elective care. Jackie Goode, February 2020

8. www.patientlibrary.net

Key Themes & Recommendations

We recommend that alongside the effective management of waiting times and pathways, policy leads, commissioners, and providers:



1

Understand the importance of improving the experience of waiting.



2

Invest in developing patient-centred information and communication.



3

Support people while they wait:



Provide and support **self-management and shared decision making**.



Monitor routinely and provide clear pathways to specialist advice.



Explore potential for a carefully delivered **virtual healthcare offer**.



Partner with, and signpost to, **voluntary, community and peer support**.

Good Practice Principles for Designing a More Positive Experience of Waiting



Understand

What is it like to wait for your service?

How do people experience referrals to and from your service?

What **information** do they need and what is the best channel to deliver it?

What additional **support** do they and others need whilst they wait?



Co-Design

Use insights gained and co-design a better wait.

Send people proof of referral and acknowledge receipt of referral.

Help people understand how you will make decisions about waiting, what the wait for your service is like and what might change.

Tell people how to contact you and when (for example if their condition deteriorates).

Check in during the wait.

Make sure that the language you use is easily understood.

Using Shared Decision Making use of tools to enhance good conversations.

Provide/signpost to support and self-management.

Provide/signpost to support for carers and family.

Offer/signpost to peer support and social prescribing opportunities.

Provide on-line and printed information about the appointment /procedure and what to expect/how to prepare.



Improve

Continue to monitor the experience of waiting and make improvements over time.

Empower staff, allow the time, develop skills to re-design and improve services.

Form partnerships with charities and voluntary sector.

Make time to keep up to date with feedback from charities, research and services such as Care Opinion.



The existing research and Care Opinion feedback provides an overwhelmingly negative picture

This project started with an examination of the most up to date literature⁷ on waiting documented by the Patient Experience⁸ Library and opinions shared on Care Opinion. Headlines from this report are shared here:

Most existing literature on waiting has been from a service perspective and focused on the efficient management and improvement of waiting times. The more limited literature from a patient perspective on the lived experience of waiting for care provides an overwhelmingly negative picture of life described at its worst as being ‘on hold’ and often characterised by **physical pain and psychological distress**.

“I am now losing hope that I will ever get my life back.”

Care Opinion stories supported the picture painted in the literature. The largest category of stories by far described patients’ journeys through the system, characterised by waiting/delays before the clock officially starts; stop-starts along the way; cancellations; changing goal posts and reversals, which patients simply did not understand. In some cases, this led to speculation about intentional ‘tactical management’ of waiting list/targets at the expense of patient care.

For patients on waiting lists, **a lack of control arising from the uncertainties** involved in waiting and from fear of further deterioration and of loss of income/employment severely curtails the ability to ‘get on with one’s life’ in a meaningful way and to plan effectively for the future. Waiting impacts on family, work, and social lives. Waiting often leads to an increasing lack of trust in care providers

“...I feel very tired, I want to sleep a lot...I feel very depressed...you get frustrated because you can’t do things and actually I have got to say I just don’t want to do anything...I can’t be bothered and now that I know I am having the operation, I keep saying “I will leave that until I am better”. I don’t bother to do things any more...”

“My daughter has been crippled by 9 months of waiting for a diagnosis...(involving A&E visit, emergency admissions and various consultations with specialists across different departments). She has lost over 2 stones ... and feels her life has come to an end. What we don’t understand is the lengthy times between seeing anyone. It appears that you have to wait up to 2 months between moving on to another consultants department. She has to wait 8-10 weeks to get CT scan results and 2 months to see a pain management team.”

Information and how and when it is communicated was shown to play an important role in patients’ sense of control and their ability to manage uncertainty. In many instances, the availability of such information was considered limited or completely absent.

7. National Voices: Improving our understanding of the experience of waiting for elective care. Jackie Goode, February 2020

8. www.patientlibrary.net

“From my doctor’s referral pre-op, consultation and surgery to my recovery at home the process was painless. And brought in considerably under the 18-week waiting period I had been told to expect”

“I received no pre-operative information and was told that there was none available but five minutes on the internet put me in touch with a charity supporting my condition and the brain and spine foundation and a wealth of information and a helpline. Just a signpost to this information would have been helpful.”

The literature shows a clear **association between low levels of social support and high levels of fear and anxiety**, but on the whole, people perceived that the level and type of support they received was down to ‘luck, opportunity, or persistence.’ Some patients expressed a readiness to **make active efforts towards self-management**, but felt they lacked the necessary professional support to enable them to do so, and as a consequence they reported feeling ‘in limbo’ or in some cases, almost ‘abandoned by the system’.

“He has had 4 courses of antibiotics & on constant pain relief. After 5 months we finally had a Consultation who kindly approved the operation ... however they are now saying he may have to wait up to a year for this to Happen!!! He had already missed lots of time off school & I have lost work too & as a single Parent find it unbearable to keep dealing with... it breaks my heart to see him regularly in pain & find this totally unacceptable. He is a child & looks to me to be his protector but I can’t help him”

The literature also revealed **inequalities in experiences of waiting** for elective care according to nature of condition, regional variations, socioeconomic factors and ‘protected characteristics’⁹. This consideration is especially relevant during Covid-19 as appointment systems and delivery have had to be delivered virtually and with increasing use of technology.

A **variety of barriers** represented by telephone and video-enabled appointments were identified by Healthwatch Calderdale (2019)¹⁰ in relation to those who have: no or limited proficiency in the English language; sensory impairment; long-term conditions; physical or mobility impairment; learning disability; mental health conditions; autism; or who are older/frail. These forms of service delivery required technological skills which were currently lacking, as was the use of assistive technologies and support for carers, interpreters, or others, which might have mitigated the barriers. Perceived additional cost implications of virtual healthcare was also identified as a potential barrier.

9. <https://www.equalityhumanrights.com/en/equality-act/protected-characteristics>

10. Adults’ experiences of Autism Services in Calderdale and Kirklees. Healthwatch Calderdale. October 2017.

Understand the importance of improving the experience of waiting

Those people interviewed as part of the listening exercise know and understand that waiting will be a necessary part of the experience, but it is clear that poorly managed **waits are having an impact on their physical health, mental health, employment, housing, and relationships**. Trust in the system is eroded. People described the deterioration of their conditions while they waited and expressed a belief that delays end up costing the health and social care services more money.

We asked people about their experience of waiting both before and during Covid-19, and from this we can conclude that the themes are unchanged, but that the current situation has further intensified the experience of waiting.

The psychological distress and feeling of hopelessness over time makes things much worse. For many the wait meant **further deterioration of their condition(s)**, with far-reaching implications. This applies to all conditions but is especially tough for people with **mental health issues and those in physical pain**.

“Frustration doesn’t cover it. It affects me in a physical way, I am overwhelmed, really upset, tied up in knots.”

“I really had to fight to get seen. I was very, very anxious, it was the most stressful two weeks of my life. I feel really helpless.”

“My life has come to a full stop.”

Health and wellbeing deteriorates whilst being on a waiting list. For instance, recent polls found that half of those with experience of joint replacement surgery said their physical health deteriorated and one third said their mental health deteriorated while they were waiting¹¹.

In the case of **waiting for mental health services** it is clear that **mental health deteriorates significantly** while people are waiting for help and there is a need for much more intensive support. It is important to mention also, the specific risks for some people waiting for mental health services such as increased risk of detention, being picked up by the police at home, or in the streets, suicide attempts and suicides.

For those in pain, the impact of waiting is far-reaching as many are likely to have been **managing and living with pain for a number of years** before reaching the point of referral for treatment.

Many people waiting for treatment, especially those in pain, or mental distress have had to place functional limits on their life, this often **impacts on work**. Given the current economic climate this has far reaching consequences. This also applies to changing arrangements and delays and the impact of these on people and the organisations where they work.

Carers and close family interviewed also shared this feeling of helplessness and many people waiting for care also expressed concern for, and highlighted the lack of support for, those around them: friends and family.

“People just have to watch you suffer, don’t know if it’s getting worse, don’t know what to do.”

“My dad is really worried. No support has been offered to me or my family. I cried for days when it was postponed. My parents open the letters now.”

“We have had to muddle through.”

11. <https://www.versusarthritis.org/media/22366/health-social-care-committee-inquiry-2020.pdf>

Often, the discourse used by patients was one of **'fighting' the system** and having to manage their own anger and that of others. People talked of 'giving up' and 'not thinking about the wait' in order to protect themselves and keep these concerns in check. Some said that frequently they didn't feel mentally or physically strong enough to make enquiries about the status of their wait and this meant remaining in an information vacuum for long periods of time.

"I am not being listened to. Nobody believes you".

"I am in limbo; my opinion is disregarded."

"I feel as though they palm me off as someone who will cause too much work."

"No one will talk to me."

"I don't mind waiting, but for goodness sake, give us a date as soon as you can so that there is something to aim for and we can organise our lives."

The NHS sets maximum waiting time standards for access to healthcare. This includes a maximum of 18 weeks from referral for consultant-led treatment. In addition, NHS providers are held to account against waiting time performance measures.

There is a difference between how the system and patients **perceive the moment that a wait starts and finishes**. For many, the waiting experience starts with the first symptoms, or a deterioration/new symptoms for an existing long-term condition and the decision to seek professional attention. This confirms the findings in literature and Care Opinion stories which states that to define or limit the patient experience of waiting to that which happens during the period between referral and treatment represents a failure to understand how waiting for elective care is actually conceptualised and experienced by patients themselves¹².

The Healthwatch review of access standards also highlighted the relationship between the 18 week¹³ Referral to Treatment (RTT) target and the experience of waiting. There is a fear that a focus on targets and monitoring systems could lead to the experience of waiting being neglected. The review found that awareness of the RTT target is low, and there is a lack of awareness as to when the clock starts on waiting times and low confidence in meeting targets.

Waiting time targets are important, and the management of the experience of waiting is as important as the management of pathways. A recent poll¹⁴ by Versus Arthritis found that the majority of people with arthritis (96%) said that if they needed surgery it would be important to know that there is a maximum amount of time that they should wait. When people are aware of the target it provides some certainty about timing which can help people to plan the waiting period more effectively.

"Waiting time targets can lead to local investment in services."

"I feel to keep numbers down, people are sent back and forth to other services, sometimes unnecessarily to turn the clock on and off to make it look like people aren't waiting as long as they actually are."

"I think they knew exactly what they were doing. It seems to me that putting patients on a waiting list does not depend on the clinical need nowadays, as the NHS founding principle suggests. It is managing the waiting list, or making it look good on the statistics".

Often, by the time of an appointment with specialists in secondary care, people have had symptoms for a while and been through **a series of waits, delays, tests, and other activities**. From the interviews it is clear that further waiting can increase the expectation and hope pinned on a particular appointment or procedure. This can make a delay or cancellation hit even harder.

Whether true or not, there is a perception that the system "games" the process.

Those interviewed, in particular those waiting for mental health services, often described a period of being 'bounced between services' while the system works out who is best placed to provide them with care. This is also a type of waiting, often referred to as the "missing middle" or "falling between the gaps". For example, people being seen as having needs that are too complex for Improving Access to Psychological Therapy (IAPT) services, but not being considered unwell enough to access community mental health services. Often these people end up with no support at all and become frequent visitors to their GP service. It is important to share examples of services that are addressing this issue¹⁵.

12. National Voices: Improving our understanding of the experience of waiting for elective care. Jackie Goode, February 2020.

13. <https://www.healthwatch.co.uk/news/2019-10-31/people-share-what-good-ae-experience-looks>

14. <https://www.versusarthritis.org/media/21674/clinical-standards-review-nov19.pdf>

15. <https://mind.turtil.co/story/nhs-long-term-plan/page/7/1>

People described multiple, connected symptoms and conditions, however, their experience of the service did not reflect this connection. They described feeling 'like body parts, not a whole person'. One interviewee experiencing a frozen shoulder, had finally seen a health care professional who gave her the option of discussing either her neck pain, shoulder, or arm, but not all three.

People with long term/chronic conditions were often waiting for a range of things in separate services and organisations. They painted a picture of themselves as 'the person in the middle', with experience of that condition, often for a period of years. They felt that they were the only thing connecting and monitoring everything and that the system isn't listening to or considering their knowledge and experience.

"I always have to ring and check. They change things without telling me."

"If one department says no, it impacts on the other."

"I am with different services and providers. There's no one central apart from me."

"I do feel like I've been just left to deal with things and I'm not entirely functional so it would be nice if there was a team dedicated to checking up on waiting list patients, how they are, their symptoms, making sure nothing has changed since referral."

People said that they would like services to understand what it is like to wait and to offer support. This goes beyond important system levers such as waiting standards.

People were more comfortable waiting when a support offer was made, such as personal contact with the service, regular updates on progress, information on anything they could do to support themselves and support offers for their family/carers (where relevant). These activities tended to send a message that they were cared about by the service and their interests were being considered.

This is confirmed by the literature review¹⁶. Support while waiting for elective care was shown to be not simply an organisational matter or one to do with 'systems', but more a matter of taking a holistic, patient-centred, bio-psycho-social approach to thinking about what constitutes support and therefore what kind of provision would be most helpful. Where a patient knew someone, who had undergone similar procedures to ones they were awaiting, they shared experiences and 'tips' on coping.

It is important to note that **support during waiting from the service can be lacking** and often people have to navigate the system themselves. Those interviewed had found a range of ways to get support from other sources, such as social media, friends, family and perhaps most importantly charities. They were keen to reference the work that charities do, in particular during Covid-19: running helplines, providing information and practical support. Many had responded to the pandemic by providing additional services. Of particular note were clinicians who posted short films to help people deal with pain and discomfort whilst waiting for a now further extended period.

One of our contributors described her experience of accessing mental health services.

The initial diagnosis took a while and involved a few waits. After being diagnosed in 2019 she was able to access regular face to face sessions with a clinical psychologist, contact with a specialist nurse, support from a care co-ordinator and some employment support.

In January 2020 after a number of assessments, she was diagnosed with an eating disorder and told that she would be suitable for therapy, starting in March. A care plan was completed, and she was under the impression that she would remain with the same care-coordinator.

At the beginning of lockdown her care-coordinator called to ask her how she was. She indicated that she had been extremely distressed, with suicidal thoughts. The care coordinator also let her know that she would not be staying as her care-coordinator due to the referral to the new service. She was then unable to get hold of the eating disorder service.

"There is nothing I can do, feel really helpless. The first wait was more manageable because I knew my care-coordinator and how to access support."

"I feel worthless, like I have been thrown in the dustbin."

16 National Voices: Improving our understanding of the experience of waiting for elective care. Jackie Goode, February 2020

Invest in developing patient-centred information and communication

The literature and the interviews indicate that the role of information, and how and when it is communicated, has an impact **on patients' sense of control and their ability to manage uncertainty**. Where there were opportunities for people to contact and interact with services, they were much more comfortable and reassured.

"I know who to contact during the wait for my appointments. I was copied into the referral letters so will be able to find the clinic receptionists."

"I don't know how to get hold of them. No numbers."

People were often not informed of what to expect in relation to the length of waiting time. Patients report that providing status updates on waiting or, at the very least, making people aware of the factors that will influence the wait time could help ease anxiety and reassure them that they had not been forgotten. From their perspective it was **not clear which service was responsible** for keeping patients informed of progress (referred from/to). Accurate information would help patients to plan and make decisions, such as work commitments, holidays, whether to pay privately (where this is possible) and caring responsibilities.

After being referred, people tended to hear nothing until the next appointment was confirmed. In fact, of the twenty-two interviews conducted, **only one person was given confirmation that a referral had been sent and then received**. The gap between being referred and the appointment notification can be months and people start to get concerned. Many described chasing referrals only to find that they had been lost. Many shared that after some time had passed and they had heard nothing they would start to investigate, this often resulted in **multiple phone calls leading to further frustration**, with many observing that they felt 'lost in the system', with no clear 'ownership' of their wait.

In the absence of any information, often they find it difficult to find the services they have been referred to. People described having to 'find the confidence to push', 'be persistent'. Some shared that 'insider knowledge can make a difference and gets things moving', this might be support from professionals/support staff, who are perceived to be 'breaking the rules in order to help'. The current system supports a level of patient-initiated follow up and this has an additional negative consequence when health inequalities are considered as others may be disadvantaged.

"I would like to thank the waiting list office ladies who were really kind and tried to help me. They were the ones who advised me when to ring for the best opportunity of getting listed and it worked"

"Our concern is that there is a bias towards activated patients."

The literature and Care Opinion data shows that, in many instances, the availability of information about **what to expect** at a scheduled appointment/surgical procedure, advice on health maintenance and symptom control and how to stay in touch was considered limited or completely absent.

Those interviewed often expressed **high hopes** for the appointment or procedure, and for many the importance placed on this next step made delays or interruptions even harder to handle. Apart from a few exceptions, people were given very little advice and information on health maintenance issues, during the period of waiting.

In the absence of a copy of the referral and no acknowledgement, they had no details to help maintain connections with healthcare providers if/when questions emerged along the way or they needed to discuss ongoing health problems. Notable examples were given in cancer services where people were assigned an accessible specialist nurse. Similar examples were given in mental health, with the support worker role, but the reliability of this contact and support varied.

"There was no information on what to do if things got worse. I wanted to know if I should still take the steroid, I didn't know who to contact."

"Being ignored and not being valued has a huge impact on your mental health."

Channels of communication have changed rapidly during Covid-19, but even prior to the pandemic the research showed that the use of letters was felt to be outdated and more up-to-date processes to support two-way communication are needed. In the phone interviews many reported a preference for email and phone contact.

"It's the only service you can email, it's so much better."

"There is a nurse-led answering machine. it's nice to know it's there if I need it."

Communication and Information

Even before the onset of the COVID-19 outbreak in the UK, there was a growing number of people waiting for hip and knee replacement surgery, with significant numbers waiting beyond the maximum waiting time of 18 weeks from referral to treatment¹⁷.

One of our contributors was referred for a hip replacement, due to osteoarthritis, in December 2019. Up to that moment there had been a number of waits between symptoms, investigations, appointments with specialists, scans, tests etc.

At the point of referral, she was told that they were within the 18-week target, so surgery would be mid-May. The referral letter was shared so she had reassurance that it has been sent. The centre where the operation would be performed acknowledged the referral and she was sent a link to an on-line form where she could record any pertinent information about other health conditions etc.

“I was relieved it hadn’t been lost in the post.”

An information pack arrived containing a letter confirming a mid-May operation “if all goes according to plan”. The pack contained a booklet - Your Patient Journey - with information on how to prepare for the operation, what to do before, during, afterwards, with phone numbers to call for questions and queries. She was sent a date for a mid-April pre-operation assessment.

When the Covid-19 lockdown started she didn’t hear anything for a few weeks. In early April, an administrator phoned and left a message with a number to phone back. She phoned back and was told that everything would be postponed.

“The person, whilst friendly, didn’t really show much empathy. It was an indefinite postponement and it was a big deal for me. Nothing was offered instead. By comparison, I do have appointments at the Institute of Osteopathy, and they have been in touch to offer phone advice free of charge during Covid.”

She phoned in May and spoke to someone, but there was no change.

The sister in charge called at the beginning of June, to let her know that they would be starting surgery again in July—she was given the option to go ahead or wait.

“It was nice to be given that option, given the circumstances, some people might not want to go ahead during Covid-19. I was allowed to stay on the list if I decided to wait. I said that I would like to go-ahead and was told probably August. She didn’t ask me how I was though, or how I had been coping during the delay.”

Following the phone call, she received a **Re-starting Surgery** brochure that contained information on new Covid procedures (cleaning, pre-assessment, COVID-19 testing).

“In some ways, it’s the ideal time, I can’t really go out because of Covid and won’t be able to get about because of the surgery, so I’m getting both things over at the same time. I can see an end to it. I am usually so active I have had to learn to enjoy being at home.”

17 <https://www.versusarthritis.org/media/22366/health-social-care-committee-inquiry-2020.pdf>

Opportunities to improve the experience of waiting

Self-management, shared decision making and personalised care planning:

People interviewed expressed a desire to be more involved in decisions and planning their own care and treatment (personalised care planning and shared decision making) and would value **self-management support**.

Self-management support needs to be co-designed with patients and delivered in a way that suits them. This could be written, visual, on-line information on how to manage symptoms and prepare for the appointment or procedure. A number of charities also provide self-management support and services need to work in partnership with them to design and deliver the right information at the right time.

People suggested the following **activities and services** to help them wait:

- Pain relief and psychological support to deal with pain
- Information and access to mental health support.
- Physiotherapy and other support services such as physical activity interventions.
- Routine monitoring during the waiting time and interim interventions and treatments as required.
- Clear pathways to specialist advice if symptoms escalate.
- Information about employment and benefits.
- Clear communication between primary and secondary care, as patients often speak to their GP for support when waiting for specialist care.

Anything that puts me in control is a positive. It's the not knowing that's unnerving."

"I would like to see the introduction of peer mentor for all conditions, to bridge the gap."

"Everyone who is told to wait should be told about a volunteer/charity support offer, everyone should be told about self-management support, check whether people would value remote care/ can access digital etc."

A virtual healthcare offer:

In order to explore the **virtual healthcare experience** during Covid-19, National Voices partnered with Traverse and Healthwatch. The resulting report¹⁸ features insights from the interviews with people waiting for care and feedback from an interactive on-line platform.

Many of the people we interviewed, with long-term conditions, were offered virtual appointments during Covid-19. We heard from people who had counselling and GP appointments via video. Others had support from a range of clinicians via telephone. The telephone appointments included dental, physiotherapy, mental health support and post-operative follow-up.

People appreciated not having to travel, less time taken out of their day/off work and being able to access healthcare in their home surroundings where they felt safe. Most said that they would be **comfortable with some appointments continuing to be held this way in the future**. There is a perception that this style of appointment can free up time for clinicians to offer longer in-person sessions for those who need them.

One of our contributors had a physiotherapy appointment by telephone.

She was given a specific time and date, but with only two days warning, which was difficult because of work commitments.

The phone rang at the allotted time and the session was 30 minutes.

"I didn't know what to expect. The physio created space to ask about how I was doing. I felt heard and was able to ask questions. It was refreshing.

There was no physical contact and of course she couldn't see me, no visual, but we were able to conduct a shared examination.

A normal physio session would be in a crowded room, five minutes instructions, you practice the movement, they pop back after seeing other people and ask you how you are getting on, it's rushed.

I see about 15-20 health professionals a year and this is the most person-centred session I have had."

18. [Doctor Will Zoom You Now: Getting the Most Out of Virtual Health Care Experiences](#)

The report concludes: ‘there is no one size that fits all solutions. Key to a successful shift to remote consultations will be understanding which approach is the right one based on individual need and circumstance. **A blended offer**, including text, phone, video, email and in-person would provide the best solution.’

A recurring theme was around the efficient organisation of the appointments – technology that works, information, **respecting peoples' time** and providing information on what to expect. It worked best when people were offered an appointment time or time slot; this enabled them to find a suitable place for the appointment to take place and to prepare themselves.

It was appreciated when services warned them of possible delays in advance and those who left messages with numbers to phone back.

For the appointments themselves, many stressed the importance of the quality of the interaction during a virtual appointment. From those interviewed who reported a positive virtual healthcare experience, they felt listened to, reassured, and trusted the outcome.

One of our contributors has struggled with scheduled phone call appointments with no time window, missed calls when no message is left, or a message with no number to call back.

He has had a number of phone call appointments during Covid-19. Often a phone call is arranged, but no specific time-frame is given. Once or twice he was not given the name of the person who will be calling. On a couple of occasions he has, despite sitting anxiously with his phone beside him, missed the call, other times the call hasn't arrived at all.

“It’s surprisingly easy to miss a call, especially on modern phones that only ring a couple of times. Also, I am in a wheelchair and have mobility issues so it’s difficult to take my phone everywhere with me, if you get my drift. The frustration is immense and often followed by frantic calls to hospital switchboards and multiple departments only to find an answering machine, or phone that rings out. The service rarely calls again, so I am left wondering what to do next. Anything that helps to put me in control helps. It’s the not knowing that makes things unnerving.”

One of our contributors had an issue with swollen red painful legs.

She phoned her GP and explained the problem to the receptionist.

A link was sent, via text, to her mobile phone and she was told that the GP would phone.

With her son’s help, she was able to take part in a video call on the mobile phone, using the link sent by text.

The GP was able to examine her, identify Cellulitis which is a skin infection and prescribe antibiotics. The woman was asked to draw a line on her leg to track whether the condition was spreading further.

The GP called back two days later to check progress and new medications were given.

“I felt confident in the diagnosis but needed my son there to help me.”

Patients and providers alike need to be well prepared ahead of the consultation. This includes guidance about how the appointment will work, how long it will take, clear joining instructions, how to use any technology and what to do if something goes wrong, such as technology not working.

People expressed some frustration at having to tell their story multiple times and wished that clinicians would read their notes before the appointment. Receiving information in advance was important for participants to make sure they were prepared and knew what to expect, they felt it was reassuring.

Many of those interviewed would have liked a choice of communication: phone, video, text, app, email and in- person. They also felt that the choice of appointment style needs to vary, depending on the situation, nature of their condition.

One of our contributors was offered therapy by video call during Covid-19.

A link arrived with the date and time for the session (from a no-reply email address). The message indicated that there would be a question form sent separately, when it didn't arrive the woman tried to contact the service to no avail.

She logged on just before the allotted time and was in a waiting room. At the allotted time nothing happened, so she logged off and looked at her emails to check that she had the correct details. She logged in and out of the waiting room a few times and eventually connected with the therapist ten minutes later.

The therapist said that there had been lots of technical difficulties and apologised for her poor broadband. The session took place, but there was a great deal of background noise throughout and it was difficult to hear everything.

"It will definitely take a bit of getting used to, but it's better than nothing. I don't think I said everything that I would have said in person, there's no relationship. I did like being in my own space though. It was better than travelling for an hour on the bus, being in a new building, taking time off work."

However, further work is required to meet the needs of people for whom remote is not possible or appropriate. Many of those interviewed described early nervousness with this style of interaction and a lack of confidence with technology. Some were starting to get used to it, but we know that a significant proportion of the population is **digitally excluded** because they don't have access to the equipment/internet and/or have low levels of digital literacy.

"I'm blind and my mum had dementia so there was no choice but a visit to the GP."

"I can't use the symptom checker my GP sent. My condition can result in a range of symptoms, so a normal day for me, with dizziness, pins and needles, headaches is likely to trigger an alert unnecessarily."

"My mum was called by her GP reception to say that there would be a video consultation the next day. She has dementia and no digital life, so this was impossible. There was no follow up."

"I am blind so the online form the GP sent was impossible. I called and they said that someone would be in touch in 24 hours. No one has called."

The importance of involving the voluntary and community sector:

A recurring theme throughout the interviews was that of the **importance of the role of the voluntary and community sector in supporting people** while they are waiting. People cited a number of examples including helplines, information, peer mentoring, groups and policy information. People were often keen to get involved in charity work by volunteering and this also helped them to deal with their situation.

Charities are an important source of ongoing insight, and services need to invest in dedicating time to build relationships with the relevant local and national groups and keep up to date with their **activities and publications and signpost this information** to people who are waiting.

"The work the charities are doing is second to none."

"I worry about my reliance on charities, for health, but also for socialising. I am in a band with a charity, they might not survive, it was my only social life."

"I had an assessment with a local eating disorders charity, because I have had a relapse during Covid. They dealt with it very quickly. I had a Zoom assessment and a formal referral to the local hospital. The charity have been keeping me up to date and offered counselling to me and to my parents."

"I think that there needs to be more acknowledgment that there are gaps in service, if they can't provide support whilst on waiting lists, then they should be more aware of charities and sign post what's available. I have had to predominantly research off my own back or with the help of my family."

We explored the impact of Covid-19 on the experience of waiting

We asked people about their experience of waiting both before and during Covid-19, and from this we can conclude that the themes are unchanged, but that the **current situation has further intensified the experience of waiting.**

"Everyone is going through the same thing, it's a genuine emergency, but ..."

"Everyone understands, but just let us know."

"My pain levels are going up. I'm stiffer, try to do exercises and weights inside."

"I kept getting the scary shielding texts for days. Nothing since. It would have been nice for someone to call."

"Face to face wasn't an option. Covid. No one knows, I totally get that."

People are fearful of further deterioration of their condition and the impact on their mental health of the uncertainty.

When respondents were asked in Mind's recent survey on mental health and Covid-19 whether their mental health had deteriorated since the start of lockdown, nearly 60% of people said their mental health had either got a bit or much worse¹⁹.

A recent survey²⁰ of Crohn's and Colitis members found that 89% of those who had had surgery cancelled as a result of Covid-19 did not have a new date. The impact of this can include potentially life-threatening complications leading to more extensive or emergency surgery being required, under sub-optimal conditions and with significantly poorer outcomes. A high proportion were unable to access or had delays in being able to contact the specialist team and/or tests and procedures. As a result of this, a significant number had serious deterioration.

"I have five different services in four different providers, none have reached out."

Whilst it is clear that there was a great deal of understanding and appreciation for the current situation and the impact this has had on health and social care, people working in the system now need to move fast to not erode this trust.

People would like to know as soon as possible what is going to happen next for them. From those interviewed in May-July, who had been contacted in March to say that their appointment/procedure would be delayed, only ten percent of people had had an update since.

"Every time, it's me going to them. My mental health is spiralling, I distract myself with work. They don't know what it's like to be me."

"I just wish someone would tell me what's happening."

"They stopped taking referrals. Services on hold because of Covid. No idea what to do if things get worse, call 111, or crisis number. I would have to be in complete distress to do that, there's nothing in-between."

"I had letters; all non-urgent procedures suspended. I have heard nothing since."

During the initial Covid-19 lockdown period, many of those with multiple health and social needs were able to continue to receive some services: pharmacy deliveries, social services and home help (with some restrictions), emergency care and support from their GP (by phone appointments).

Some were philosophical about the lockdown period and reflected that, for them, life hadn't changed too much.

"I have felt at peace during lockdown, a break from the endless cycle, the stress of going around, to hospital all the time, it has all stopped. I feel normal being inside, there is no guilt or sadness that I am wasting my life because nobody else is doing anything. I can feel my stress levels rising as it all starts again."

"My routine hasn't changed. Lockdown is no different to my normal life."

"The whole Covid 19, shielding, that was already my lifestyle, I'm used to it."

19 <https://www.mind.org.uk/media-a/5929/the-mental-health-emergency-a4-final.pdf>

20 <https://www.crohnsandcolitis.org.uk/healthcare-professionals/healthcare-professionals-blog/life-in-lockdown-what-patients-told-us-about-their-healthcare>

“From those interviewed, some had received notification to shield during the Covid-19 lockdown period. In addition, most with long term/multiple conditions had taken the decision to shield despite official notification.

Many spoke of feeling apprehensive of the ‘return to new normal’ and lessening lockdown restrictions. They were particularly worried about taking public transport to health appointments, in particular those who would ordinarily have had patient transport.

I had a letter to say shielding. I was terrified for the first few weeks. I tried to keep busy. I stayed in, but without exercise my situation was getting worse. Six weeks in I spoke to the nurse to say that I would like to exercise, and she said, “Why aren’t you going for a walk?”

“I am registered blind but didn’t get a vulnerable letter. I can’t judge the two-meter distance, my dog just walks into shops, she can’t see the queue. When the pain is really bad, I can’t function. I live on my own. I have my guide dog to look after – she needs feeding and walking. Every step is a struggle.”

For many, contact with the GP has increased during Covid-19 and the vast majority described this as a positive development. GPs were cited as supporting people with new diagnosis, referrals, navigating the system and chasing specialist services and elective care. A number of people interviewed were appreciative of being contacted pro-actively by their GP during the Covid-19 lockdown period.

“Fantastic GP, aware of all my issues, often can’t help, but understands, meds are delivered, request on-line, immediate response to appointment requests, specify if urgent or not. If they call and you miss it, they call you back.”

“My GP is brilliant. She has, for years, single-handedly, kept me functioning, but she’s tearing her hair out to know what to do next.”

“I had to go in. I waited in my car and they came to get me. They had full PPE and wiped the door handle before they opened it. I felt very safe.”

Patients would like more information on what measures are being taken to manage waiting lists and reduce their waiting times. People need to know what to expect, who to contact and what criteria each service will use to manage things. Many expressed a wish to help services to make these difficult decisions. They were curious about how services planned to tackle the backlog.

People who are waiting would like to be consulted on what should happen next. Often people are waiting for more than one appointment and procedure, they talked about the balance between these priorities for themselves and were also conscious that there might be others who should take precedence.

Some were nervous about a possible surge of new diagnosis and the impact of this on already pressured services. It is clear that the way that people are informed of next steps matters and from the service user perspective, the more opportunities for knowledgeable and personal contact (with a clinician) the better.

“There are lots of people much worse off than me.”

“One condition kicks off another. No information on how they will deal with the backlog.”

“I have been calling, chasing, physically begging.”

“There is going to be a massive backlog. New people who are suffering anxiety, grief, job losses and fear. I have no idea how they will prioritise.”

“Unfortunately for a lot of people, there will always be someone worse off than me and so I can’t complain for being in a better situation than many.”

“I use Instagram. I have given and had support from all over the world. I don’t know what would have happened without that.”

One of our contributors was a young woman suffering with endometriosis who had taken the difficult decision to have a hysterectomy which was then cancelled at the end of March.

When we spoke to her in June, she had had no contact from the service since the postponement. She described a journey of decades, with multiple waits and procedures.

"I feel unheard and isolated, forgotten. Your pain matters. There has been no offer at any stage, no physiotherapy for pelvic pain.

Being ignored and not being valued has a huge impact on your mental health.

The term 'non-urgent' hides lots of other things: pain, a condition that leads to other things, chronic health issues.

I feel like an extra pressure on the NHS."

One of our contributors had been suffering from Crohn's since June 2018. Following an MRI in August 2019 she then met her surgeon in October.

She was told that an operation would be her only option and that no other treatment would help at this stage. She was also told that the longer she would have to wait the worse it would get. At the time of the interview in June she had no date set.

"I have waited years for a diagnosis. When I met the surgeon, he said it's urgent. I can't get hold of them. I have phoned everyone, there's a helpline run by nurses, but they say there's nothing they can do. I have been trying to keep busy, distract myself, but I am in terrible pain, I can't eat, I haven't slept, my muscles ache. They don't know what it's like to be me."



THANK
YOU



Becoming patient focused

In conclusion, we hope that this report has provided some insights into the experience of waiting from the perspective of people who use services and will encourage commissioners and services to invest in patient focused improvements.

from this...

Organisation focused – the business of waiting is organised around the needs of the service.

Little or no information provided.

Tick box targets considered the most important.

Little feedback sought on experience of waiting.

Focus on functional and clinical aspects of care.

Most staff feel that they are not empowered to change things for patients.

Silo working culture.

People don't feel listened to.

to this...

Patient focused – waiting experience is co-designed with people who use the services and those who work in them.

Comprehensive, patient focused information. Opportunities for two-way communication.

Design waiting experience, test, learn, improve.

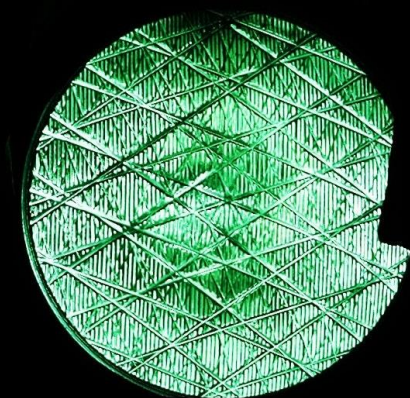
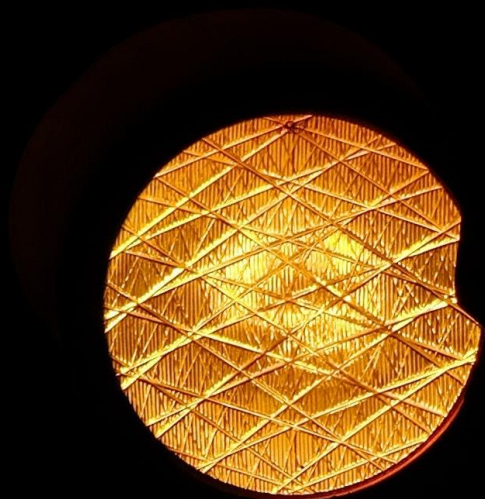
Patient experience of waiting is routinely collected and acted upon.

Relational/emotional impact of waiting and living with a condition is recognised.

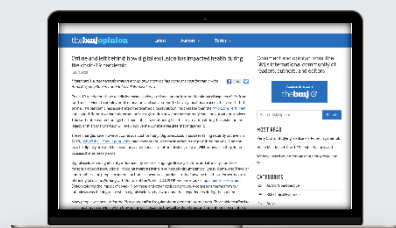
Services and teams are rewarded for providing a positive waiting experience.

Understand the experience of waiting and explore ways to provide more consistent and integrated care across service boundaries.

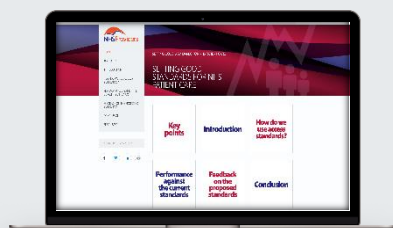
People are supported to be partners in their care and to share decisions.



Bibliography and links



Offline and left behind:
how digital exclusion has
impacted health during
the covid-19 pandemic



Setting good standards
for NHS patient care



Versus Arthritis
@VersusArthritis

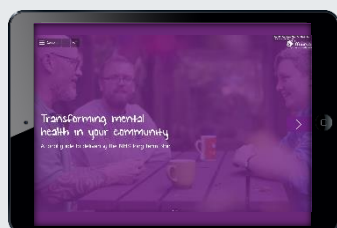


Rethink Mental Illness
COVID-19 briefings

Access to NHS mental
health services for
people living with
severe mental illness

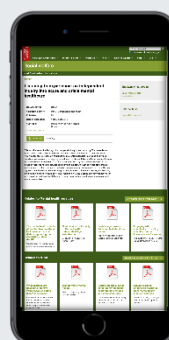


At least half a million more people in
UK may experience mental ill health as
a result of Covid-19, says first forecast
from Centre for Mental Health



Transforming mental health
in your community

A local guide to delivering
the NHS long-term plan



Listening to experience:
an independent inquiry
into acute and crisis
mental healthcare



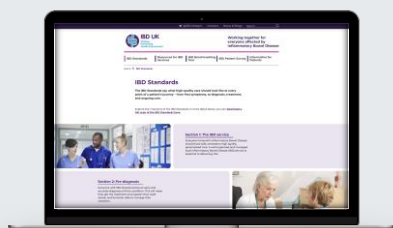
NHS performance and
waiting times

Priorities for the new
government

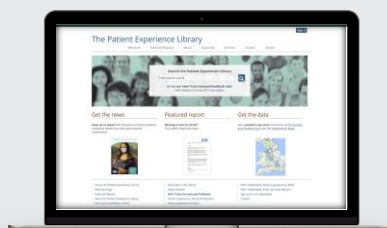


New report: Being A Patient

Bibliography and links



IBD Standards: Explore the 7 sections of the IBD Standards in more detail



The Patient Experience Library

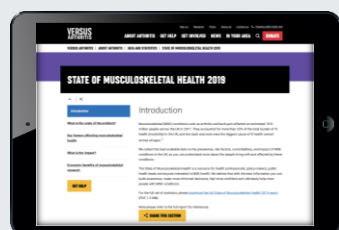


Care Opinion.

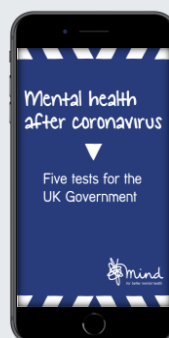
Share your experiences of UK health and care services, good or bad. We pass your stories to the right people to make a difference.



RTT 18 Weeks – What does this mean to you as a patient?



Versus Arthritis
State of Musculoskeletal Health 2019



Mental health after coronavirus: Five tests for the UK Government



The mental health emergency: How has the coronavirus pandemic impacted our mental health?



We still need to talk
A report on access to talking therapies



Published October 2020.

National Voices would like to thank NHS England and Improvement for funding this project.

Sam Hudson from Überology led the research and steered the project to its conclusion, despite the pandemic forcing us to change focus and methodology. Her calm and thoughtful leadership meant that participants, National Voices member charities and our team were never in doubt about the value of this work.

Our members found us people to speak to and helped us make sense of what they already knew about waiting (which is a lot). We are truly stronger together.

Our partners Care Opinion, Patient Experience Library, Traverse and Healthwatch, it has been a pleasure to work with you.

Finally, our biggest thank you is owed to the people who told us about their experiences, during a troubling and isolating time. It was often difficult to know that we couldn't do anything to directly sort your problem. We hope you feel that our work with and for you will make a difference for other people in similar situations. Thank you for driving our work with your generosity and hope.