



Seeking patients' views on delays to planned care

caused by the pandemic



June 2022

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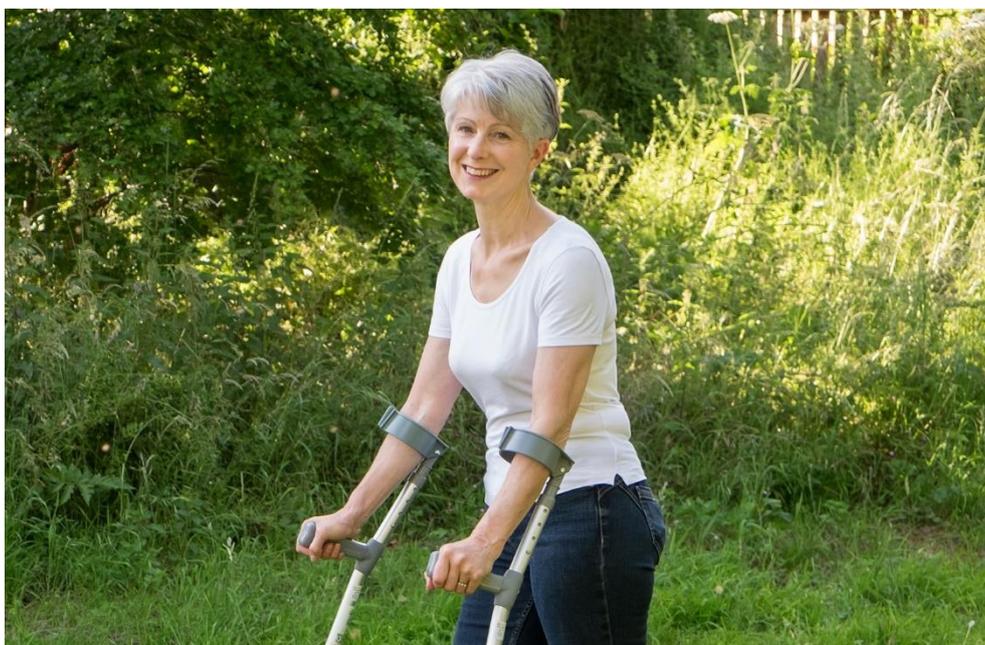
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Introduction

What is planned care?

Planned care is also known as 'routine' or 'elective' care. It is treatment that people decide to have to help manage a health problem, rather than emergency treatment for an urgent (life-threatening) medical condition or following a serious accident. People are usually referred to hospital for planned care by their GP or other healthcare professional.

Planned care covers many different medical procedures including joint replacements and cataract surgery. It also includes outpatient appointments and tests to diagnose and detect diseases such as cancer and other serious medical conditions.

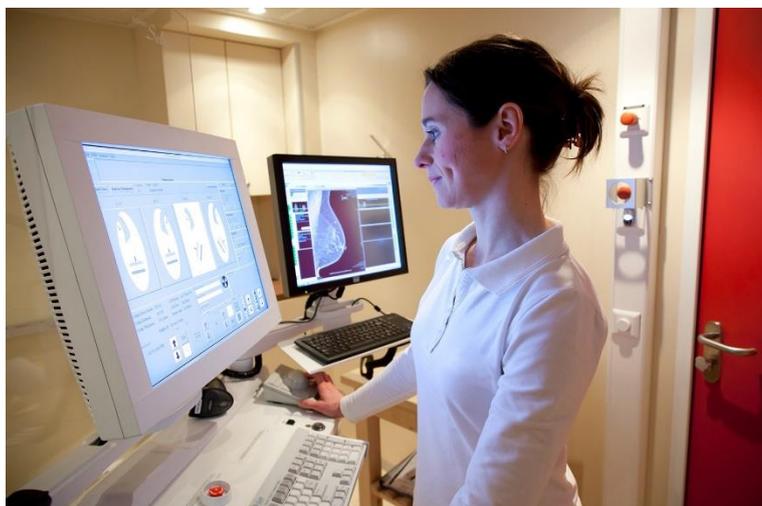


Improving our planned care services is one of the West Yorkshire Health and Care Partnership's main priorities and we have an Improving Planned Care Programme that focuses just on this work. The programme works with local hospitals through the West Yorkshire Association of Acute Trusts' Elective Recovery Programme and this collaboration is called the West Yorkshire Planned Care Alliance.

How Covid-19 has affected planned care services

The pandemic has had a stark impact on planned care services across the country. The initial outbreak of the virus in March 2020 forced the NHS to postpone a huge amount of planned care activity to free up staff and beds for people seriously ill with Covid-19. This difficult decision to temporarily stop non-essential healthcare services has affected millions of people waiting for planned care.

Throughout the pandemic, and as an ongoing priority, hospitals have continued to carry out urgent surgery and diagnostic tests for cancer and other potentially life-threatening conditions. However, the need to treat Covid patients, along with staffing and capacity issues, and the essential safety restrictions created a growing backlog of people waiting for planned care procedures, which are not immediately life-threatening or linked to treating urgent cancer cases.



Planned care services that were temporarily stopped at the start of the pandemic have since been brought back in the safest possible way for patients and staff.

Unfortunately, high numbers of Covid cases resulting from new variants, and ongoing staff shortages and safety restrictions mean that we are still in a situation where some planned care procedures are being delayed and many patients continue to face long waits for treatment.

However, all our hospitals are doing all they can to address the backlog of patients waiting for a planned procedure and are using feedback from the Partnership's Planned Care Citizens' Panel to help them do this.

Our Planned Care Citizens' Panel

In June 2021, a new citizens' panel was introduced in partnership with [Healthwatch](#) to support communications around delays to planned care services in West Yorkshire. The panel of nine volunteers from across the area, all patients on the waiting list for planned care, was in place for 12 weeks from June to September 2021.

The feedback of nine people may not be considered by everyone as 'worthwhile' but we disagree. Panel members had a great deal of experience of accessing planned care services over the years. In addition, most panel members had friends and relatives who were also waiting for a planned care procedure, a referral, or a diagnostic test, so they were able to share their experiences of having a close connection with someone affected by the delays too.

Having just nine panel members gave everyone the opportunity to share their experiences in detail and contribute their ideas without having to be cut off due to the restrictions of a larger group. By taking the time to listen to panel members, we also gained a great deal of insight into other healthcare services, not just planned care. This insight has been shared with the relevant programmes including Mental Health, Personalised Care and Social Prescribing Services.

Panel members met online for two hours every fortnight throughout the 12 weeks. At these meetings clinicians and other colleagues shared details with them about how we are working together as a system to reduce the backlog of planned care cases resulting from the Covid-19 pandemic.

All panel members were extremely keen to support this work and help improve the situation for others in the same position. They shared their own experiences of waiting for treatment in detail, asked relevant and important questions, and provided valuable insight into the main issues affecting patients who have been referred to hospital for a planned care procedure.

The key themes taken from over 12 hours of discussions at panel meetings are detailed on the following pages. You'll also find information about how the panel's feedback is supporting progress as the number of planned care procedures being carried out across West Yorkshire is increasing week after week.

1. The experience of waiting for planned care

We know that delays to planned care have had a significant impact on people's lives but hearing the personal experiences of patients first-hand really brought it home.

When panel members shared their own experiences at the first panel meeting on 24 June 2021, it was very difficult for us to hear because we know this will be the case for the thousands of patients across the region who are waiting for planned care. And because we also know this hasn't come about through any lack of effort by the NHS and healthcare staff – quite the opposite in fact.

What panel members told us

"I've been waiting over 16 months for a routine operation. The delay is having a big impact on my physical and mental health."

"I am waiting for a hip replacement. I am on various pain medication but struggle on a day-to-day basis, particularly with regards to my mobility, sleeping and general household chores. I am no longer able to leave my house and rely on my family and friends. I am a completely different person now."

"I'm waiting for shoulder surgery. I haven't been able to see a physiotherapist due to Covid so am doing home physio and taking painkillers."

"I am simply 'grinning and bearing it' as I don't have any further options at this point in time."

"I've been living with a hip condition for four years and am now in chronic pain all the time. I'm still waiting for surgery which has been promised in January 2022."

"Every patient's idea of what a 'reasonable waiting time' is under the current circumstances will be different, depending on what their condition is and what the surgery is for."

"The last time I asked, 'Am I on the list for my hip replacement yet?' I was told I was the 47th and would get it done around January 2022. I feel like I have been pushed to the back of a lot of people's queues and I'm quite upset about that."

“I ended up ringing my surgeon and asking them what was happening because I’d not heard anything. There needs to be more communication and more continuity between services. I’m upset because it’s been a long, frustrating, and difficult journey.”

“The situation now is that my condition has deteriorated so much whilst I’ve been waiting, the surgery options I was originally given are no longer viable and my surgeon needs to think about something else. I’m willing to try anything and everything to get this moved on and I know I’m not the only person who is like this.”

“I have been struck down by many illnesses since March 2020, so Covid has impacted on referrals for treatment. I have suffered with depression as a result, and I feel that I’m not being taken seriously.”

“The thing that has stuck with me is how big a job healthcare services have but also how common our experiences are unfortunately.”

The panel’s recommendations

- Healthcare services must understand how these delays are affecting people mentally as well as physically and the ‘not knowing’ or ‘feeling forgotten’ only makes the situation worse. This can be alleviated with regular contact and updates.
- Many patients would be happy to travel further afield if it meant that they could be treated sooner. Consider all options for accessing services across West Yorkshire and beyond.

Progress

1. The [West Yorkshire Association of Acute Trusts](#) (WYAAT) has introduced a collective way to look at the total waiting list across the West Yorkshire hospitals. This makes the best use of capacity across all local hospitals and focuses on those who have been waiting the longest.
2. Weekly data on capacity in the independent sector (private hospitals) is identifying opportunities for best use across the area. Negotiations are ongoing with independent sector providers to increase capacity for planned care waiting lists. Tens of thousands of

patients have already been transferred to the independent sector since October 2020 for treatment funded by the NHS.

3. Elective recovery funding has been approved for the development of three 'green' (non-Covid) elective sites at Wharfedale, Pontefract and Chapel Allerton. These sites will increase capacity to carry out planned care procedures across the area. See 'Proposals for increasing capacity for planned care' on page 12.
4. We are actively planning to try and treat everyone who has been waiting for more than two years by July 2022, and those who have been waiting over 18 months by April 2023. This can be achieved by delivering around 30% more planned care activity by 2024/25 than before the pandemic. Reducing diagnostic waiting times, including cancer diagnosis, is helping to speed up assessment and increase the number of patients who can be treated.
5. The introduction of the national patient platform [My Planned Care](#) is helping to improve communications with patients. The online platform will enable patients to be informed that they may receive treatment from a different trust, to ensure they are seen as quickly as possible. This will also include information on how patients may be able to access support with travelling to their hospital appointment.



2. Prioritisation of patients on the waiting list

At the second panel meeting on 20 July 2021, members of the hospitals' Elective Co-ordination Group talked to the panel about how the process of prioritisation for patients waiting for planned (elective) care follows the [clinical validation of surgical waiting lists](#) framework.

This framework is a national document first published in October 2020 and last updated in December 2021. The document was developed by the Royal College of Surgeons as a way of giving guidance to hospital consultants about how they should clinically prioritise their planned care patients in the following categories:

- P1 - Emergency (treatment within 24 hours)
- P2 - Elective treatment within one month
- P3 - Elective treatment within three months
- P4 - Elective treatment can wait until after three months
- P5 - Patient wishes to postpone elective treatment due to Covid-19 concern
- P6 - Patient wishes to postpone elective treatment due to non-Covid-19 concerns

The [clinical validation of surgical waiting lists](#) framework introduced the P5 and P6 categories to ensure that patients who do not want to proceed with treatment at this time for whatever reason remain on active, visible waiting lists. The P5 category, which is national guidance, and the P6 category which is a local (West Yorkshire) agreement, may be limited so that patients are only able to decline the offer of treatment for a specific number of times.

The framework document also outlines the importance of:

- checking on a patient's condition and establishing any additional risk factors
- establishing the patient's wishes regarding treatment
- providing good communication with the patient (and carer if appropriate) and their GP.

What panel members told us

“How can your condition be assessed for urgency of treatment if you can’t get an appointment with a GP? If they aren’t seeing people, how can GPs determine if a patient’s condition has deteriorated and refer them to the hospital to be seen and potentially moved higher up the list?”

“How as patients, do we correspond with the hospital doctors - to tell them our conditions are getting worse? How can we do that?”

“There are those people who can live with it and will just wait, and there are those people where it’s having a significant impact on their livelihood.”

“How would clinicians know, when reviewing your treatment, that your symptoms have got worse if you have not had an assessment or appointment since being referred? My symptoms are getting worse and worse. It’s whether or not you can convince your GP to escalate it, not just me as a patient wanting it to be escalated.”

“How do you assess if issues are worsening? What safety-net is in place to stop patients who are ‘not urgent’ from continually been pushed down the list until they’re at the point that the condition has deteriorated so severely it is impacting on other areas of their lives? And do you ask patients if it is impacting on other areas of their lives?”

The panel’s recommendations

- A leaflet or letter (sent in the post) explaining what concerning signs of deterioration to look out for would be helpful. This should also give details of what patients should do and who to contact if they feel their condition is getting worse.
- Another possibility could be to call patients, to give them the opportunity to speak to someone if they just need a little bit of guidance.
- More GP appointments should be made available so that patients waiting for planned care can be assessed.
- People need to be given the ‘supported waiting’ information they need to be able to manage their condition effectively (see page [15](#)).

Progress

1. Every patient on the waiting list has been clinically validated in line with national guidance and prioritised accordingly. In addition, those patients who have been waiting the longest have had a further review (not always in person) to minimise any additional harm from waiting. We continue to prioritise patients who are clinically urgent and those who have been waiting the longest.
2. The panel identified a real concern that patients might not know what to do if their condition deteriorated whilst they were waiting for a planned care procedure. Our trusts are addressing this concern and developing their pages on the patient platform, [My Planned Care](#), so that this information will be available in the future.

We know that this online resource may not be accessible for everyone. Patients with concerns can also contact their GP, consultant or the hospital's Patient Advice and Liaison Service (PALS). Patients can find their trust's PALS office on the [NHS website](#), or phone their GP practice, hospital or NHS 111 for contact details.
3. A consistent approach to prioritisation of patients for treatment (following the [clinical validation of surgical waiting lists](#) framework) is making sure that all patients have equal access to planned care services across all our hospital trusts in West Yorkshire.



3. Proposals for increasing capacity for planned care

At the second panel meeting on 20 July 2021, we also looked at proposals for increasing capacity to try and get people treated as quickly as possible and reduce some of the backlog. One of the proposals discussed was the development of 'green' (non-Covid) sites that will increase capacity to carry out planned care procedures across the area. These specialist sites will focus in the first instance on low complexity day case activity because that's the safest, least complex surgery to be able to transfer to another site easily.

We asked the panel for their views about travelling further afield in West Yorkshire to be able to access surgery at one of these new sites, and what would encourage patients to take up an offer of having treatment elsewhere.

What panel members told us

"If lots of people go to one place for similar treatments that would be a good idea."

"I think that anything, including sites further away, that adds capacity would be welcomed as long as people are not penalised for lack of transport or care responsibilities which meant they had to decline the option."

"Don't do late cancellations as people would need to make arrangements for pets, family, caring etc."

"How many times could a patient refuse one of these appointments if they were always a long way away? I have seen that happen - where someone refuses a couple of times and then they're basically taken off the list. I think as long as you let patients know this, they will understand. The worry is that if you are on more than one list, you will be taken off another."

"I think it's a good idea by the way!"

"I'd welcome being asked to go to another centre somewhere else. For me it could be anywhere in Yorkshire or beyond. If they could do my surgery, I would happily go tomorrow. I'm so desperate to get this sorted out after years of waiting."

“I think the use of private hospitals for NHS patients has been really beneficial. It has certainly moved my treatment along. That's one of the positives to come out of Covid, the fact that it's opened up these services to a lot of other people is really very good.”

“I would go to any location. I do foresee that a lot of people will say yes because they'd just be so relieved to be having treatment.”

“I personally would be quite happy to travel anywhere in West Yorkshire to be able to access surgery, knowing that I could rely on friends or family to drive me.”

“I think transport is going to be a biggie because we must try and protect patient transport for life saving treatment.”

“Most people going for day case surgery are driven there and picked up afterwards by a friend or relative so I suppose even a taxi might be an option. Could this be paid for by the NHS?”

“We just want treatment now. You can send me to the other end of the country, I will travel there no problem.”

The panel's recommendations

- These sites would appear to be of no benefit to patients who are not suitable for day case surgery. But be clear that, because they allow more people to be treated and therefore leave the waiting list, others with more complex cases can also be treated sooner.
- Patients who were not previously suitable for day case surgery may now be suitable so this should be considered as patients are being assessed.
- If a patient declines the option to be treated at an elective site, they should not be disadvantaged and removed from the list, after a specified number of refusals for example.
- If people are given the option to travel further away from their home to be able to access treatment sooner, that service should include transport to and from the site because not everyone has a car or can use public transport. We must not penalise people who are unable to make their own way there.

Progress

1. National funding has been approved for the development of three 'green' (non-Covid) elective sites at Wharfedale, Pontefract and Chapel Allerton. These sites will increase capacity to carry out planned care procedures for patients across West Yorkshire.
2. We learnt from the panel that many patients who are experiencing long waits just want to have their procedures done wherever they can to be able to get on with their lives. Trusts want to give patients the choice of having their treatment at a site that can offer it sooner but are finding that many patients are declining such offers, choosing to stay on their own hospital trust's waiting list instead. We are looking at what will encourage more patients to take up these offers, particularly in the key specialties including orthopaedics (muscles and bones), ophthalmology (eyes), gynaecology (women's sexual and reproductive health) and paediatrics (birth to age 18), and for patients who have been waiting the longest.
3. Details of how patients can access support with travelling to their hospital appointment will be included on [My Planned Care](#), the new patient information platform. Patients who fall within an eligible category will be provided with transport. Other patients can apply for refunds for their travel expenses, if eligible.



4. Supported waiting

We discussed supported waiting at the fourth panel meeting on 3 August 2021. Panel members talked about their experiences of accessing social prescribing services. These are activities and alternatives to medication such as exercise classes or peer support groups for example. Social prescribing services are not provided by the NHS but by voluntary community and social enterprise (VSCE) organisations.

There's a realisation nowadays that social prescribing has a much bigger part to play in preventing ill health. These services can help people manage their long-term health conditions and any mental health issues. Social prescribing really should be built in as an option across health and care. Anyone can self-refer into a local voluntary sector or community organisation that offers a social prescribing service.

What panel members told us

“I don't believe my GP practice has the facility for social prescribing.”

“In my experience, there are some people who don't know that much about how to care for themselves. I do wonder what people know about self-care and how easy is it to access information from reliable sources?”

“Our GP practice has ‘wellbeing prescriptions’ that detail voluntary and community services based around the practice. These look like real prescriptions and are something that the doctor gives to the patient. It's a way for patients to get involved in the local community.”

“I've researched certain things that I thought would work for my condition but when I've contacted the service about it, I've been told, ‘you're out of area so you can't use that service’. There are some fantastic facilities in certain areas but not in others. It just seems silly to have patients, especially people that really want to help themselves, missing out on opportunities because of their postcode.”

“For people with restrictive mobility or people who suffer with social anxiety, having groups and activities delivered online such as chat groups and exercise classes has been beneficial. They don't have to travel to get there, and they don't have to have their camera on if they are

feeling self-conscious. This is creating opportunities for people who would not normally feel confident about accessing community services, but they might need support to do this and to take the first step.”

“As patients, are we expected to go and find all of this out ourselves? Should our GPs or social prescribers be pointing us in the direction of these things because in my experience, that has never happened.”

“I've never in my life been offered any social prescribing. Is that because I've just not said the right key words? I've got a really complex condition that affects lots of areas of my life, so I think it's brilliant that these things exist, but I just wonder if patients know about them.”

“I know that every primary care network has a social prescribing link worker, but I don't think social prescribing services are being used enough.”

The panel's recommendations

- Make sure that people know about social prescribing services in their area.
- For some people, the wait for treatment is causing massive money worries. People are worried that they're going to lose their jobs. If you can signpost effectively to people who might be able to help with things like benefits and claims, it could improve their wait.
- There are, for example, loads of mental health resources that are free. We should make sure that people who are waiting for treatment know about such services.
- There are many excellent social prescribing services, but they are not available in all areas. If the need for a service is identified and an individual or group wants to introduce that service in their area, then an apprenticeship or work shadowing scheme with the already established service could be a great way to get that new provision up and running.
- We need primary care networks to know about all the different community health and care services available in their local areas so they can recommend these services to patients if appropriate.

Progress

1. Every patient on the waiting list should have a supported waiting plan that includes any local social prescribing services the patient could find beneficial.
2. Prehabilitation, often shortened to 'prehab' is an area of focus for all our hospital trusts. Prehab is all about getting a patient's body and mind ready for surgery. Whilst waiting, patients can take simple steps to improve their physical and mental health. This can also reduce the risk of complications from surgery and increase the chance of a better outcome.

The patient platform [My Planned Care](https://www.myplannedcare.nhs.uk) will provide information and guidance around prehab to help patients be in the best health possible prior to their surgery.

3. There are many community services that can help people with prehab too. These include services that support lifestyle changes such as stopping smoking, increasing physical activity, and improving diet. Patients are advised to ask their GP practice to put them in touch with its social prescribing link worker who can signpost them to suitable services in their area (see 5. on the next page).

4. A new service to improve the health and wellbeing of people suffering from musculoskeletal (MSK) conditions was piloted in Keighley and Bradford in 2021. To address health inequalities, the service was aimed at people potentially experiencing barriers to accessing services, including those facing long waits for planned care. We are bringing together all the best practice and learning from this pilot service to enable any primary care network or VCSE organisation to take a similar approach in supporting patients waiting for MSK and other planned care treatments.



www.myplannedcare.nhs.uk **NHS**

Are you waiting for a hospital operation or appointment?

See My Planned Care for the latest waiting times and help and support while you wait.

Your hospital team will be in touch as soon as they can and you can check **My Planned Care** before contacting them or your GP. Your relatives, carers and medical teams have access too.

www.myplannedcare.nhs.uk

5. Every primary care network now has at least one social prescribing link worker who can connect people to an appropriate local group or activity. There has been a lot of promotion of these roles recently, including posters in GP practices and leaflets as shown below.



Many GP practices have 'Health Champions' who actively promote social prescribing services in unique ways. This example of a well-being prescription was shared with us by one of the panel members who is a Health Champion at Chapelthorpe Medical Centre in Wakefield.

Well-Being Prescription		Chapelthorpe Medical Centre Health Champions
"Great, just what the doctor ordered!"		
<input checked="" type="checkbox"/>	Select as many as you like:	
<input type="checkbox"/>	Arthritis - Organised events, activities and speakers	
<input type="checkbox"/>	Boccia bowling - For those with less mobility	
<input type="checkbox"/>	Caring & Friendship - Compassionate chat & talks	
<input type="checkbox"/>	Crafty Creatives - Enhance your skills with Art, needlecraft, knitting, model making, decoupage, games & more or just come for a chat and a brew	
<input type="checkbox"/>	Day Trips x 2 - A coastal visit and a place of interest	
<input type="checkbox"/>	Eat Well - Healthy eating options and taster days	
<input type="checkbox"/>	Epilepsy Support - Informal group with speakers	
<input type="checkbox"/>	Jiggle with a Giggle - Be active with light dancing	
<input type="checkbox"/>	Patient Coach - Tailored help for life's issues - work, housing, debt, benefits etc	
<input type="checkbox"/>	Patient Participation Group - Have your say!	
<input type="checkbox"/>	Sing-a-Long - Dementia friendly group	
<input type="checkbox"/>	Walk & Talk - Healthy, fresh air then tea or coffee	
<input type="checkbox"/>	Live Well Wakefield - Personalised Support 01924 255363, www.livewellwakefield.nhs.uk Email: swy-tr.livewellwakefield@nhs.net	
<input type="checkbox"/>	If you are interested in any of the above then please leave your name & contact details below then <u>drop off at reception</u>	
No. of activities selected	<input type="checkbox"/>	If you would like more information, please tick this box, and someone will try to contact you <input type="checkbox"/>

5. Patient information

Patient information was another topic covered at the first panel meeting on 24 June 2021. At the start of the pandemic in March 2020, the NHS was forced to postpone a huge amount of planned care activity to free up staff and beds for people seriously ill with Covid. As planned care activity reduced, so unfortunately did communication to patients on the waiting list for a planned care procedure.

Only the most urgent and life-threatening operations were carried out, including those patients with cancer. Whilst more could have been done to communicate better with patients on a planned care waiting list, many resources were redirected towards patients with Covid-19.

What panel members told us

“I’ve been waiting over 16 months for a total shoulder replacement. No communications from the hospital for nearly a year now. I appreciate that it has been an extremely difficult time for the NHS and sympathise with the workload but feel that we haven’t been kept in the loop.”

“I’ve had no communications from the hospital for over a year, so I don’t know if I’m still on the waiting list or not. I just feel forgotten.”

“I’ve got two letters saying that I was down for elective surgery but that was 16 months ago, and I’ve had nothing since. What is going wrong?”

“To know that you haven’t been forgotten about, when you have been waiting all this time, would be better than nothing at all.”

“I feel that patients should have communication specifically from their consultant, regarding when they are going to be contacted and what the plan of action is going to be.”

“I haven’t even received a notification from the department dealing with my referral to say that they’ve received my referral, so I don’t know if I’m on the waiting list or not.”

“I’ve not had any communications from anybody so to hear all this in a press release would make me angry. Those affected by delays to care should be given the information first.”

“People are not going into GP practices and clinics, so they aren’t seeing messages on screens and posters, or picking up leaflets. How do we get these messages across? I’m conscious of the fact that we’ve lost a massive way of communicating with people.”

The panel’s recommendations

- Explain to patients clearly why there has been a lack of communication. Patients will understand.
- Patients should be told what to expect and when to expect it. They shouldn’t have to ring up all the time and be made to feel like a nuisance.
- Be honest about the waiting times and tell people what you are working to. This way, patients will know what to expect and when they might need to start chasing things up. Being open and transparent is always the best approach.
- Basic communications with patients should include where they are on the clinical pathway, what will happen next, who will see them, what the approximate waiting times are, what they need to do to look after themselves whilst waiting and who to contact if they deteriorate or need help.
- For patients who are going to be waiting a long time then maybe a letter or some form of communication every few months so they know they haven’t been forgotten, and with a contact number on so if they need to get in touch they can.

Progress

1. We had to delay thousands of planned care procedures during the first wave of the pandemic. Patients with complications of Covid, and those needing urgent and emergency care were the priority and this unfortunately meant that many planned care patients did not receive updates about their treatment.

We cannot change this, but we can learn from it and apologise for the lack of communication. For example, Leeds Teaching Hospitals NHS Trust is writing to all patients who have been on the waiting list for more than 18 weeks to apologise for the delay, and to update them on their care. These patient letters acknowledge the impact

that delaying medical care can have on patients and offer reassurance that the patient has not been forgotten. The letter also includes guidance on what the patient should do if their condition has got worse whilst they have been waiting, or if they are worried about new symptoms.

2. The [West Yorkshire Association of Acute Trusts](#) (WYAAT) will be producing some information around the current situation with planned care services and the progress made, including website updates and a series of case studies.
3. Calderdale and Huddersfield NHS Foundation Trust produced [this information](#) using messaging developed with the Planned Care Citizens' Panel.
4. [My Planned Care](#) has been developed in response to feedback from NHS staff and service users, including the Partnership's Planned Care Citizens' Panel. The panel's feedback has been instrumental to the development of the platform. In addition to waiting time information, the platform includes helpful details about pain management, mental health, keeping healthy and accessing financial help, along with other local support options for patients whilst they wait.
5. Trusts are looking to develop an orthopaedic app, specifically for patients waiting for a hip or knee replacement. In addition to having online exercises and prehab guidance, patients would be able to use the app to contact occupational therapists, physiotherapists or consultants with any questions or concerns, and even share images. Some trusts have already developed their own videos for use with the app, including [Shape Up for Surgery](#) created by Leeds Teaching Hospitals NHS Trust.



6. Hospitals and secondary care

During most panel meetings, panel members who were all patients on the waiting list for planned care at the time (June to September 2021), shared their experiences of secondary care. All panel members commented that in their experience, hospital staff could not be faulted and deserve a huge amount of praise, but there are issues related to some hospital processes and communications that could be improved for everyone's benefit.

What panel members told us

"I've had two incorrect referrals to consultants that have added another 12 months onto my wait and wasted two appointments that could have been had by other patients."

"I had a review when my consultant couldn't even see my notes. A clinician not having access to your record is pretty much not acceptable these days in my opinion."

"Some of my referrals have gone to the wrong departments. It is extremely frustrating waiting for scans or tests only to find out that the referral has gone to the wrong department. I'm then back to the end of the waiting list. The GPs and consultants often do not know what the other is or isn't doing."

"It is frustrating trying to get information from appointment centres. I think it goes back to that single point of contact – who do I contact and when? Not all trusts have a single point of contact. Sometimes you ring the secretary directly, other times you go into a call centre arrangement because they evolve their own structures and that makes it a challenge as well."

"Patients having things like steroid injections don't need to have them in a hospital. If that reduces staffing time, and we often talk about reducing the waste of hours, would that not free up some staffing time for more hospital procedures?"

"It's important that patients get support after surgery to make sure they're doing the right things. I've had knee surgery but it's going back to how it was, and I can't get hold of anybody. I wish I could have seen somebody earlier to ask about what's happening. Maybe I'm doing something I shouldn't be doing. Maybe I'm being too active, or not active enough. Until I can get hold of somebody, I'm not going to be able to ask."

The panel's recommendations

- Make sure that when people leave hospital, they have information about possible side effects of any medication they've been given, or symptoms to look out for. This will help patients leaving hospital to know what's 'normal' as opposed to what is of concern and needs to be checked out.
- Better conversations between hospital consultants and GPs to avoid incorrect or unnecessary referrals.
- Make sure that patient records are available at appointments with hospital consultants.
- Look at having a single point of contact or be clear about how patients can get in touch.
- Some things that have always been done in a hospital could now be done in a community setting instead, to free up capacity in hospitals. This might involve extra training but in addition to freeing up hospital capacity, it could be a smoother pathway for the patient with fewer car parking issues and reduced travel costs.
- It would be better if patients could self-refer to the consultant instead of waiting for their follow-up appointment. Follow up appointments are scheduled, and the patient has no choice in it. People should be able to come back when they want to come back, not because the NHS tells them to come back - unless there's a very specific reason of course.
- The Covid testing procedure prior to admission to hospital can be confusing. Hospitals need to be clear what the procedure is and make sure patients know what they need to do.

Progress

1. Since the start of the pandemic, hospital trusts have been working even more closely with local GPs and there's a lot more referral triage going on in the background. This is helping to ensure that referrals are necessary and accurate.
2. GPs and hospital consultants are working more closely together to make sure that the patient's referral pathway is shared across primary care (GPs) and secondary care (hospitals).

This joined up approach may mean that patients don't need to be referred to secondary care at all if solutions are available in primary or even community care.

3. Patient initiated follow-ups (PIFUs) give patients and their carers the flexibility to arrange their follow-up appointments as and when they need them. Reducing the number of unnecessary follow-up appointments also gives hospital consultants time to carry out more surgery to help cut the NHS backlog and long waits for care.

For some patients, PIFUs may not be necessary or safe so their clinicians will decide whether to offer them or not. Patients who are offered PIFUs are advised on the most appropriate time to request a follow-up appointment, and who to contact to book it.

4. All hospital trusts are working towards improving electronic patient records to ensure that a patient's information is available at their appointment.
5. Covid testing advice prior to admission may be different depending on the surgery or procedure the patient is having, and where they are having it. For planned healthcare such as surgery and certain diagnostic procedures, patients will receive specific advice relating to Covid in a letter, text, or telephone call. If a patient needs to have a swab test, someone will be in touch with them to help arrange this. Patients will also be told if they need to self-isolate before going into hospital.



7. Health inequalities

At the final panel meeting on 1 September 2021, the panel talked about health inequalities related to prioritisation of patients for treatment. We discussed non-clinical factors, for example a patient's need to have surgery done to be able to earn a living, and if such factors should also be taken into consideration when patients are prioritised.

The panel also expressed concerns that people who may not have the confidence, knowledge, or ability to request or access healthcare services could be missed.

What panel members told us

"If I ask for some specific treatment for a condition, and you prioritise me because I need to work because I've got young family over somebody who's just living on their own, then isn't health inequality being built in there?"

"Is there also prioritisation based on disabilities? The death rate from Covid is very high for people with disabilities, as is the inequality pre and during Covid. This is a disparate group so can be hard to reach, especially for people with specific learning differences such as dyslexia and ADHD."

"I'm really well managed but that's because I'm able to self-advocate and I'm very outspoken. There are a lot of people who are not confident so how do we reach those people?"

"All the changes in the way we are doing things, more services going digital for example, must be increasing health inequalities."

"Some people can access services easily and push themselves, but other people struggle to do that. If we're not careful, we're going to make things worse with regard to health inequalities, rather than better."

The panel's recommendations

- Are social factors, such as the need for treatment to be able to work, considered during the prioritisation process?
- Can the NHS, or maybe the voluntary community social enterprise sector, offer support for people who do not have the knowledge or confidence to be able to fight their way through the system?
- We need to make sure that people with specific lived experience are involved in the work of healthcare services so that they really meet the needs of the people that access them.

Progress

1. Ultimately, prioritisation must come down to clinical need. Prioritisation criteria set out in the [clinical validation of surgical waiting lists](#) framework were all developed by the Royal Colleges at the height of the pandemic to make sure people were treated in levels of clinical urgency. This consistent approach to prioritisation of patients for treatment is making sure that patients across all our hospital trusts have equal access to planned care services.

Patients with the most urgent healthcare needs are seen first, however a piece of work across all trusts in West Yorkshire is looking at other factors that affect health inequalities as part of the overall prioritisation process.

2. Patient letters always include details of who to contact at the hospital if the patient has any questions or concerns. If for some reason this contact is unable to provide the information required, patients, relatives or carers can access PALS, the [Patient Advice and Liaison Service](#). All our hospitals have PALS officers that offer confidential advice, support, and information on healthcare matters.

In addition, West Yorkshire campaigns such as [Together We Can](#) are helping people to understand and navigate the healthcare system by signposting to information about local services.

8. Patient and public involvement going forward

At the last panel meeting on 1 September 2021, we talked to the panel about how local healthcare services could continue to benefit from their experiences. Throughout the panel meetings, it became clear that each panel member had their own area of expertise related to their health condition and in some cases, to their current or previous occupation.

Panel members were keen to stay involved however they could with programmes and initiatives taking place across the area. They were also keen to meet up a couple of times each year to give updates on what they've been involved with, and to check on progress with all the recommendations that came out of the Planned Care Citizens' Panel meetings, as detailed in this report. The next follow-up meeting is due to take place in June 2022.

What panel members told us

"It's been great that we've had the opportunity to voice our issues and our concerns. It's about actually wanting to see things progress and improve, and making it better for everybody, not just for us - far from it."

"Being a member of the Planned Care Citizens' Panel has given me a little bit more momentum and a bit more confidence to actually go and query things that are wrong, especially in my medical notes. And to be able to find these routes to try and better myself and my health."

"I think this panel has been really good. It's been good to listen to other people in a similar position. I think the staff on the panel have been really open and I think it's been a really positive experience with the staff. They've been very willing to listen, and I understand from what you've said that you're going to do your best to raise this in many different areas, so I think that's really positive."

Recommendations

- Patient panel members, lay members and other public representatives do not get paid for their time (usually just expenses) but this can mean that only certain people are able to give up their time for free to get involved and share their thoughts. Could some form of remuneration be looked at?

Progress

1. With regard to paying public representatives, we currently follow the [NHS England policy for working with our patient and public voice partners](#). This policy sets out how NHS England supports public representatives to be involved in the work of health and care services through reimbursing expenses and, in certain circumstances, offering involvement payments.

Many citizens do not want to be paid, other than expenses, for getting involved but that does not work for everyone. We are committed to developing a solution for recognising and rewarding our public representatives, an approach that helps rather than hinders involvement.

2. We have linked some of the panel members who have experience in particular areas including mental health, diagnostics, eye care and community services into programmes where their input will be invaluable.
3. The [Delivery plan for tackling the COVID-19 backlog of elective care](#) details the importance of targeted support information for patients who are on the waiting list. The plan explains how the new national digital platform [My Planned Care](#), which launched on 24 February, will contribute to this.

My Planned Care has been developed in response to feedback from NHS staff and service users, including the Partnership's Planned Care Citizens' Panel. Their feedback has been vital to the development of the platform. In addition to waiting time information, the platform includes helpful details about pain management, mental health, keeping healthy and accessing financial help, along with other local support options for patients whilst they wait.

**Afterword by Catherine Thompson,
Associate Director for the Partnership's Planned Care Alliance**

Establishing the Planned Care Citizens' Panel has been one of the most rewarding things I have done in my work in planned care.

I found it such a useful process and I know that my colleagues who attended the panel meetings to speak and to listen, and the other contributors to the sessions, have found it really helpful, and moving as well.



It has quite a deep effect on you as a professional to hear from people what they're experiencing. It has been very worthwhile, and I would like to thank all the panel members so much for volunteering, and for sticking with it because the meetings took place over 12 weeks at such a busy and stressful time for everyone.

I am so grateful for the panel's honesty and their contributions, suggestions, and thoughts, and for all the time they each put in outside of the meetings to look at draft letters and campaign materials and think about them to comment on them – it was a lot to ask.

I am very, very grateful to the Planned Care Citizens' Panel members - Beverley, Charlotte, Connie, Jayne, Lisa, Mark, Sara, Shirley, and Valerie. And for the support of all my colleagues who attended the meetings to get involved in discussions and answer the panel's questions. I'd also like to thank Karen Huntley, Director Healthwatch Calderdale, for her invaluable support.

It's been a great experience to meet all the panel members and get to know them and learn from them through these meetings.

Catherine Thompson.

West Yorkshire
Health and Care Partnership



A Partnership made up of the NHS, local councils, care providers, Healthwatch, voluntary and community organisations and charities.



If you would like further details about any of the information included in this report, please contact the Improving Planned Care Team

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