

**‘Patients in waiting’ - experiences of hospital treatment pathways
and how to change to ‘patients in preparation’ for treatment.**



July 2022

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Executive summary

Covid-19 has impacted nationally on the management of hospital non-urgent treatments and operations creating a record number of people waiting for NHS treatment in England, currently around 6.5 million¹. As part of the management of hospital services non-urgent treatments and operations have been postponed, delayed, and rescheduled. The backlog will take several years to clear, which means 'patients in waiting' will be living with and needing to manage their health conditions for longer.

A report by Healthwatch England (HWE) states that people in deprived areas are waiting longer for treatment². Based on the average deprivation score Sandwell is ranked as the 12th most deprived local authority in England³. Healthwatch Sandwell (HWS) wanted to build upon the HWE findings to explore what the backlog in NHS treatments means for Sandwell resident patients and consider what might improve the 'patients in waiting' experience.

HWS engaged with Sandwell residents who were 'patients in waiting' for hospital treatment to hear about their experiences and any impacts of Covid-19 on their hospital treatment pathways.

HWS asked patients about the quality of communication, information and support provided while on the journey to hospital treatment.

HWS also asked patients whether they felt well informed and involved during their hospital treatment pathway and explored what it might take to change 'patients in waiting' to 'patients in preparation' for hospital treatment.

Patients told HWS that there was room for improvement and shared views on what services could help make waiting for treatment a better experience. This report reflects the project findings alongside patients voices and views.

HWS makes **4** recommendations to Sandwell and West Birmingham NHS Trust to:

1. establish a patient reference group to help inform and develop improvements to the "patient in waiting" experience and move towards 'patients in preparation' for hospital treatment.
2. ensure all communications are accessible by using plain English and, where required, that reasonable adjustments are made to meet patients specific communication needs.
3. review information provided to patients waiting for hospital treatment ensuring it is comprehensive, timely and easy to understand.
4. exploration of options with health and care service partners to establish an information and support system that helps improve the patient experience of waiting for hospital treatment and enables patients to be well informed and prepared for treatment.

¹<https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/nhs-backlog-data-analysis>

²<https://www.healthwatch.co.uk/news/2021-09-27/people-living-poorest-areas-waiting-longer-hospital-treatment>

³https://www.sandwelltrends.info/deprivation_west_midlands_context/

Introduction

The Healthwatch Sandwell (HWS) project builds upon the Healthwatch England research to gain specific insight on the local Sandwell picture. HWS did not seek to identify waiting list numbers as services are aware of their own back logs.

The project aims were to:

- Look at pathway experiences of ‘patients in waiting’ for hospital treatment i.e., referred from primary care services and awaiting hospital treatment:
- Obtain an overview of the Sandwell picture of treatments awaited, timelines involved and progress along treatment pathways.

Specifically, to gather insight from ‘patients in waiting’ of experiences and views about:

- communication, information and contact points
- interim health, care and support services
- preparation for hospital treatment
- patient informed and involved in treatment pathway/options
- impacts of delays in hospital treatment on health and well-being.

and to:

- explore with patients what might make the “patient in waiting” experience better.

This report reflects the Sandwell residents experiences, voices and views

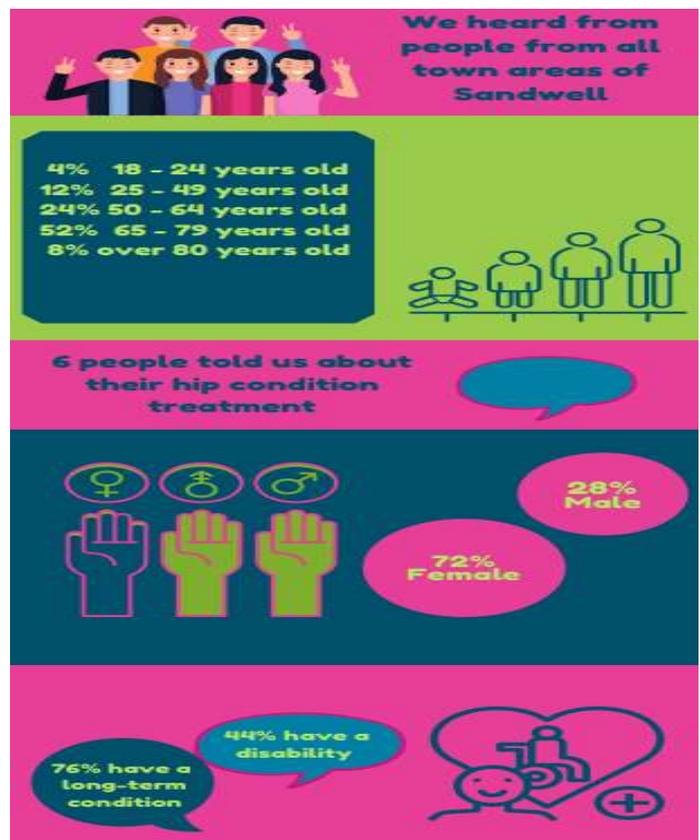
Patient profile

The HWS project aimed to consider some key areas of the patient journey on hospital treatment pathways. Patient experiences and views were gathered through completion of questionnaires and individual and group conversations. The project ran from January to March 2022 which meant Covid restrictions had an impact on operation of the project. The report findings are based upon the following project engagement outcomes:

46 individuals engaged in conversation

3 community support group conversations

25 questionnaires completed.



52% of patients that HWS engaged with were waiting for hospital treatment needed for Orthopaedic procedures, the majority related to hips and knees including those with arthritis. HWS heard from some elderly patients whose treatment for hip problems were no longer progressing.

Other patients HWS engaged with were mainly awaiting treatment for heart, digestive, gynaecological and eye problems. HWS also spoke to **5** patients receiving treatment for cancer.

Key findings

Hospital treatment pathway progress:

HWS explored patient progress along their hospital treatment pathways. Covid-19 had impacted and been the reason for some cancellations and delays for some patients treatment pathways. HWS found that:

- treatment had been completed for most patients
- treatment of cancer patients was prioritised
- some patients with nerve, back and digestive problems had been waiting over 2 years.

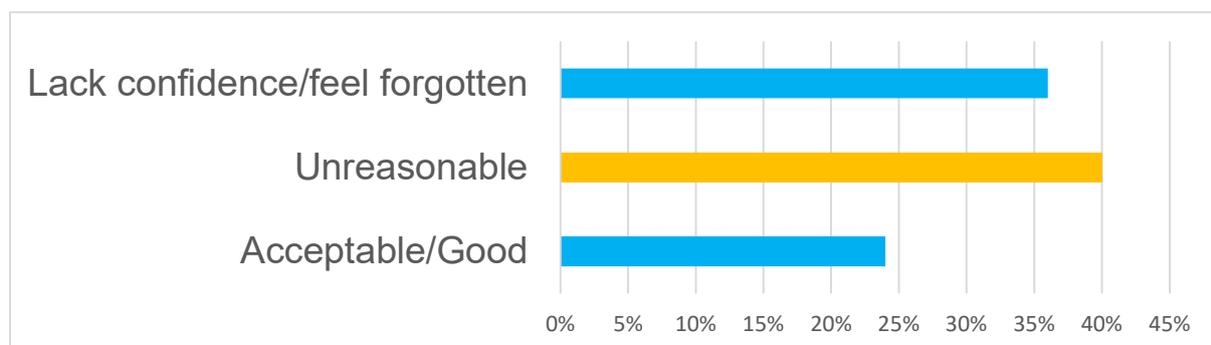
HWS heard that:

- **16%** of patients experienced a cancellation of their first outpatient appointment
- a small number stated a scheduled test, procedure or operation had been cancelled
- a lack of progress with hospital treatment for some patients with debilitating conditions
- some delays in post hospital follow up care
- some elderly people had not received full treatment for hip conditions.

"I was all prepared, a last-minute cancellation was like adding salt to the wound"

"I feel like we have been written off by the NHS due to being over 80 years old"

HWS asked patients how they felt about the hospital treatment waiting times they were experiencing:



However, **48%** of patients felt that overall delays in hospital treatment were understandable with Covid-19 pressures on the NHS system.

"I think that I have been quite fortunate considering the present climate"

Impact of delays in hospital treatment

HWS heard from patients who had experienced significant delays in hospital treatment and in some cases still had treatment outstanding. The case story below illustrates delays in treatment and the impact of Covid-19 on the hospital treatment pathway.

Treatment experience of a patient with a debilitating degenerative condition

The patient developed problems in their hands and feet in 2018 but struggled to get a G.P. referral until 2020 by which time the condition had worsened significantly and become very debilitating. The impacts of Covid-19 saw treatments cancelled and then the case became lost within the system. A complaint was raised, and an operation was completed in 2021.

Patient feedback included that:

- follow up after treatment or physiotherapy was not offered
- condition information was not provided – the patient researched on the internet.

HWS asked patients about the impacts on their life and wellbeing. The percentage of patients expressing negative impacts on life and wellbeing were:

60% level of pain

75% physical health

53% mental wellbeing

70% carrying out day to day activities

43% ability to care for someone else.

"I am unable to travel far with my condition so have missed visiting family or joining on holiday, even though I am retired with time to do so"

"I get anxiety- if I go out where will the toilet be?"

"I sometimes get distressed about it, checking the post expecting a date"

A patient with spinal stenosis developed in 2020 yet to receive treatment

"I have good days and bad days. Luckily I have only missed a few days at work being off sick. It has taken some time to adjust to the impact it has had on my physical and emotional wellbeing. Mitigations have been put in place to relieve some of the pain I have experienced, which has made a considerable difference. I have an ergonomic chair at work, and I have purchased an orthopaedic bed at home."

NHS communication

HWS asked for patients views about the quality of communication received from the NHS. **Patient feedback indicates that there is room for improvement.**

20% of patients said that communications from the NHS had not arrived in good time.

"A text for my appointment was useful but I never received the letter needed with information to prepare me for the test"

"What has Covid-19 got to do with good communication - it should not affect it"

28% of patients said that communications from the NHS were not easy to understand.

"Make letters clearer, as they are hard to understand" "Simplify language"

A patient with Parkinson's disease told HWS about communication struggles

"I have a long-term degenerative condition so see a lot of health services. I find it confusing knowing which appointments are for what and keeping up with them all. Eye clinic appointment letter was very confusing stating wait to receive appointment, if not heard by certain date use access code to book appointment. I do not understand the access code, I don't use technology much, I don't have a smartphone - my Parkinson's condition makes it difficult"

16% of patients stated the communication received was not in a format suitable for them.

"I am deaf - British Sign Language is my first language - I would need someone to interpret letters for me"

HWS heard about experiences of patients with **Learning Disabilities** and **Autism** and found:

- **Hospital Passports** not always recognised, understood or used by hospital staff
- **Learning Disability Nurses** not always connected with patient or in good time
- people supporting Learning Disabled or Autistic patient are not always listened to
- lack of connections with **Community Learning Disability Team**.

"I panicked when I woke up and saw tubes in my body, hospital staff had to settle me down" The patient had not received any support in advance of treatment to help him understand processes or been linked with the Learning Disability Nurse.

"Hospital staff were not paying attention to us as parents or using the hospital passport. My son was distressed and un co-operative." The Learning Disability Nurse became involved and spent good time on relationship and trust building, prepared the patient, familiarising the hospital staff team, enabling the operation to occur.

The NHS Accessible Information Standard (2016)⁴ states that NHS funded health and social care providers must meet the information and communication needs of people who access services. People with disabilities, impairments or sensory loss, their parents or carers have rights to reasonable adjustments. It appears that some General Practice (G.P) and Hospital services communications are not consistently meeting such needs.

HWS commenced a project in June 2022 - **Accessibility for patients – meeting information and communication needs**. HWS will be exploring experiences with patients and supporting their voices and views to be heard. HWS would welcome interest in the project.

HWS recommends that NHS communications are made accessible by using plain English and, where required, reasonable adjustments are made to meet patients specific communication needs.

NHS information:

HWS asked for patients views about information received from the NHS:

44% of patients said they had received a good or adequate amount of information about hospital processes and their health condition.

40% of patients said they had not received any or sufficient information about hospital processes.

"I just want to know what to expect - my husband is waiting for an operation too - I am hoping our treatments do not clash."

47% of patients said they had not received any or sufficient information their health condition.

"I have not had enough information about my potential options bearing in mind this is a degenerative condition"

Over half of the patients said they had received information about their condition. However, **68%** of patients indicated they would like more information while waiting for treatment on:

- pain relief options
- treatment procedures and options
- hospital delays
- a contact person about their hospital treatment pathway journey
- support to help prepare for surgery.

HWS recommends a review of information provided to patients ideally with the involvement of a patient reference group.

⁴<https://www.nhs.uk/conditions/learning-disabilities/going-into-hospital/>

Supplementary information and support

HWS has found that some people lack the confidence or knowledge of how to follow up on progress along their hospital treatment pathway. 'Equally' some people had not taken the initiative to do so, particularly during Covid-19 where the general perception was that delays were inevitable.

"It frightens me that some people are being left behind if they can't find their way through systems. Not everyone can negotiate more complex systems or use technology and they are dependent on help."

Around a third of patients waiting for hospital treatment accessed and received additional services to help manage their health condition and support their wellbeing. The remaining **70%** of patients said they would find it helpful to be able to access support including:

- help with day-to-day tasks
- support to keep physically fit and well
- physiotherapy
- mental wellbeing support
- a local support organisation
- a local support group or forum
- financial guidance/support.

"Regular contact, wellbeing calls and to confirm still in the system"

"A holding letter would be good to know what was going on and not feel forgotten"

"Having multiple appointments to go to can make life confusing."

"We wanted care in place for peace of mind but were told it was too early to plan"

"Very hard for elderly people who are caring for a loved one"

An elderly patient with osteoarthritis of the hip

Six monthly injections stopped in 2020 during Covid-19 – no further treatments planned. The patient shared some of the impact on his life:

"It's been very stressful dealing with hip pain and eye issues alongside caring for my wife who has recently gone into a residential home due to her advanced dementia. No-one else could help I felt very alone, luckily I have BUDS⁵ to support me now."

⁵Better Understanding of Dementia for Sandwell <https://www.buds.co.uk/>

The case story below helps to illustrate the impacts of communication and how additional support can help improve wellbeing and managing ill health.

A patient with prostate cancer shared their hospital treatment experiences

The patient was referred by the G.P. in June 2021, initial procedures were cancelled pre operation due to insufficient communication regarding medication and Covid-19 precaution measures. The patient accepted the final operation date offered in February 2022 but received subsequent conflicting communications changing, postponing and cancelling the operation (it is possible the wave of Covid-19 Omicron variant and impact on NHS services may account for these confusions). The operation was rescheduled.

The patient fed back on support received during the process which included:

- guidance from District Nurse re medical support aids
- mental health support through other services the patient was registered with
- access to a **local support organisation** which provided:
 - links to a local support group
 - access to financial guidance and support - *"an unexpected bonus!"*
 - information about treatment and help preparing for surgery.

HWS recommends that options to establish a Patient Preparation Information Hub are explored.

A comprehensive service could include a single point of access service to:

- answer patient queries on hospital communications
- give access to pain management guidance
- confirm and ensure patient progress on hospital treatment pathway
- provide information on hospital treatment procedures
- provide information to support patient preparation for treatment
- signpost planning for post operative care and support
- be a contact point if necessary for family during patient operations
- signpost to support organisations for specific health conditions
- establish working links with local support services to benefit patient wellbeing.

The service would need to offer the full range of access options for patients including:

- in person visiting
- phone
- e-mail
- on-line
- text
- accessible communication to meet needs for disabilities, impairment and sensory
- interpretation services to support any language barriers.

The service would logically link into the national NHS "my planned care"⁶ resource which currently has limited information to support patients, including for Sandwell and West Birmingham, but is in development. The proposal of a Patient Preparation Information Hub is in line with findings and recommendations within a briefing provided to national health and social care stakeholders by **Healthwatch England**.

⁶<https://www.myplannedcare.nhs.uk/mids/sandwell/>

Improving patient status

Sandwell and West Birmingham Hospitals NHS Trust has developed a set of Care Standards⁷. HWS considered two of these standards and asked patients whether they felt **informed** and **involved** in decision making about their treatment options. Patient views were split equally between those who felt they were well informed and involved, and those who did not.

"Yes, and very grateful. When he got the diagnosis, we were taken to another room to get more information and ask questions"

"No. I don't know why my medication got changed and has now switched back again, or the results of the test or whether it will happen again"

HWS wanted to explore how **'patients in waiting'** might become **'patients in preparation'** for their hospital treatment pathway.

"A mindset is needed for patients to take a level of responsibility for their own condition and be proactive."

HWS suggests the following aspects would help ensure patients feel **well informed** and **involved** in their hospital treatment pathway:

- quality, relevant and timely information provided in:
 - simple plain English
 - other formats suitable for individual patients needs
- a fully accessible service such as a Patient Information Hub for patients to:
 - clarify and stay well informed on progress along hospital treatment pathway
 - be empowered to be involved and well prepared for their hospital treatment
 - maintain their overall wellbeing through information and holistic support offers.

HWS recommends a patient reference group is established to help develop a service offer that enables and supports 'patients in waiting' to become 'patients in preparation' for hospital treatment.

Conclusion

The ongoing impacts of Covid-19 include extended waits for some hospital treatments. HWS found that Sandwell resident patients understand the landscape the NHS services are operating under. However, improved communication and information provision is required, complemented by supporting services to better enable them to cope and manage their health condition during the waiting period.

HWS believe the findings and patients experiences, voices and views reflected in this report provide a useful guide to the NHS and wider health and care services to be able to consider and develop an improved offer to 'patients in waiting' for hospital treatment. By health and care services working together, using the patient views captured in this project, to achieve positive outcomes as well as transforming 'patients in waiting' to empowered, well informed 'patients in preparation' for their hospital treatment pathway.

⁷<https://www.swbh.nhs.uk/about-us/our-values/>

Recommendations

The HWS report makes the following recommendations to Sandwell and West Birmingham NHS Trust to:

1. establish a patient reference group to help inform and develop improvements to the “patient in waiting” experience and move towards ‘patients in preparation’ for hospital treatment.
2. ensure all communications are accessible by using plain English and, where required, that reasonable adjustments are made to meet patients specific communication needs.
3. review information provided to patients waiting for hospital treatment ensuring it is comprehensive, timely and easy to understand.
4. exploration of options with health and care service partners to establish an information and support system that helps improve the patient experience of waiting for hospital treatment and enables patients to be well informed and prepared for treatment.

Acknowledgements

Healthwatch Sandwell appreciates the support for the project and engagement with Sandwell residents from the following voluntary and community sector organisations.

'Thank You' to:

Smethwick Friends and Neighbours



Further information

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