

Is my life worth living?

Lived experiences of patients
waiting in pain for elective
orthopaedic surgery

September 2021



Accessible Formats

This report is also available in Welsh.

If you would like this publication in an alternative format and/or language, please contact us.

You can download an electronic copy from our website:

<https://swanseabaychc.nhs.wales/>

Or ask for a copy by contacting our office. Contact details can be found on page 44.

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About Swansea Bay Community Health Council (CHC)

Swansea Bay CHC is the independent watchdog of the National Health Service (NHS) within Neath Port Talbot and Swansea. We encourage and support people to have a voice in the design and delivery of healthcare for their families and local communities.

Swansea Bay CHC works with the NHS, inspection and regulatory bodies. We provide an important link between those who plan and deliver NHS services, those who inspect and regulate it and those who use it.

We hear from the public in many different ways. Before the coronavirus pandemic, we regularly visited NHS services to hear from patients while they were receiving care and treatment. We spoke directly to their families and carers too. We also heard from people at local community events and by talking to community representatives and groups.

Since the coronavirus pandemic, we needed to change the ways we engaged with the public and patients. We used surveys, social media and videoconferencing apps such as Zoom, Teams and Skype, to hear from people directly about their views and experiences of NHS services. Apps have made it possible to attend virtual engagement events too. We continue to hear from people through enquiries and our complaints advocacy service. Swansea Bay CHC represents the “patient and public” voice in Neath Port Talbot and Swansea.

Background and Introduction

In line with our Annual Operational Plan 2020/21, we set out to collect feedback from people about their lived experiences of waiting for elective surgery for joint replacement, orthopaedic and spinal surgery.

In November 2020, the Board of Community Health Councils (the Board) published their national 'Feeling Forgotten' report¹ on behalf of the seven Community Health Councils (CHCs) in Wales. The report described the heart-breaking impact on people whose care and treatment was delayed because of the pandemic. Our report identifies similar themes in both feedback received and makes some similar recommendations as things have not changed.

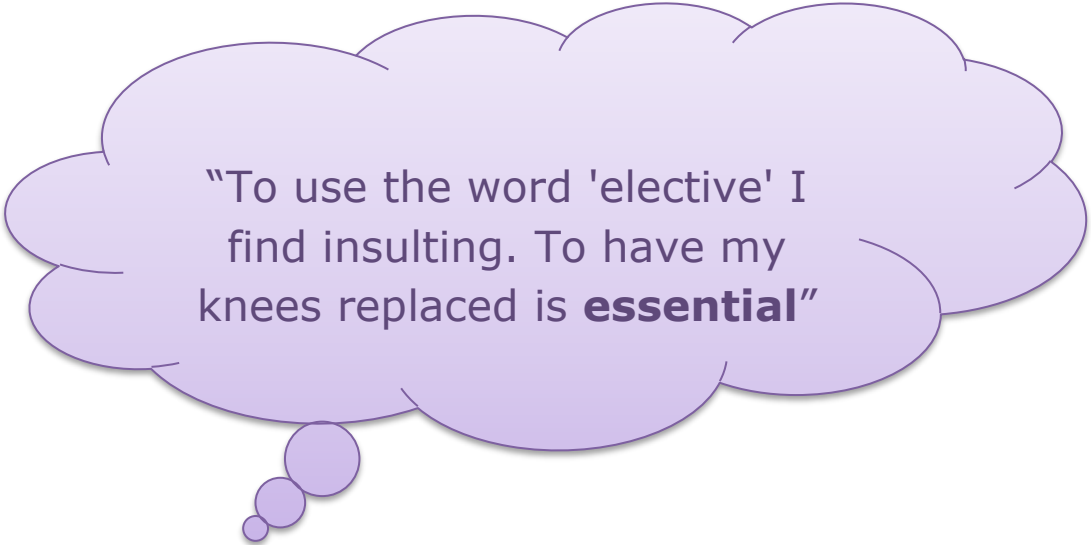
Our report is specifically about waiting for **elective orthopaedic surgery**.

It is based on feedback we received from 948 people, highlighting the impact the wait for surgery is having – **in people's own words**.

What is elective surgery?

Elective surgery is surgery that is **planned in advance but is not** an emergency. While such surgery is described as elective it is often both important and potentially life-changing.

¹Read the full report here: <https://boardchc.nhs.wales/files/what-weve-heard-from-you/feeling-forgotten-waiting-for-care-and-treatment-during-the-coronavirus-pandemic/>



"To use the word 'elective' I find insulting. To have my knees replaced is **essential**"

It can sometimes be provided on the "same-day" without the need to stay in hospital. Trauma and orthopaedic surgeons diagnose and treat a wide range of conditions of the musculoskeletal system. This is the framework of bones, joints ligaments, tendons and nerves that work together to enable movement.

Coronavirus and the impact on 'non-urgent' care

In March 2020, as the coronavirus pandemic took hold in the UK, the NHS in Wales took action to respond to the emergency. Treatment for people with COVID-19 was prioritised with other non-urgent NHS care and treatment being postponed.

Hospital facilities across the Swansea Bay Health Board area were reorganised, leading to the cancellation of all but emergency orthopaedic surgery.

This approach was initially accepted during the early stages of the pandemic, however, many people we heard from noted that **waiting times were very long and continuing to rise before the pandemic.**

The right to start treatment within 36 weeks

Health boards and trusts regularly judge their performance in terms of “Referral to Treatment Times” (RTT). These are Welsh Government targets described in weeks:

- 95% of patients to start treatment within 26 weeks of receipt of referral²
- 100% of patients to start treatment within 36 weeks of receipt of referral

Reviewing performance this way can provide useful data for the Health Board, however, it does not show the real picture of what it is like – **from the patient’s point of view** - to wait for surgery, often in pain or with reduced mobility. That is to say, performance is not currently measured in terms of the impact on individuals and their families. However, the guiding principle is that patients should wait the shortest possible time, based on their clinical assessment.

Record waiting times

Waiting time’s targets are frequently reported in the media as being ‘missed’, with waiting times across Wales often described as being the worst in the country. The waiting lists for surgery have built up even further under the COVID-19 pandemic.

Versus Arthritis, the UK's largest charity dedicated to supporting people with arthritis, launched their ‘Impossible to Ignore campaign’ in July 2020, highlighting, amongst other things, that the cancellation

² A referral is when a GP or other primary care staff refers a patient to a hospital for specialist treatment

and delay of elective surgery has left many people with arthritis in pain and uncertainty regarding their future care³

On 17 June 2021, The Royal College of Surgeons urged the Welsh Government to make waiting times their top priority, as new figures showed a record number of patients waiting to start treatment in Wales. As of April 2021, in Wales:

- 595,272 people were waiting for hospital treatment, with
- 87,918 people waiting for trauma and orthopaedic treatment

Local Waiting times update

At the time of writing our report, Swansea Bay Health Board shared with us the waiting list numbers reported to Welsh Government at the end of May 2021.

For trauma and orthopaedic surgery:

- There were 10,420 patients on waiting list
- 3,215 patients were waiting longer than 26 weeks for first outpatient appointments (Stage 1)
- 6,793 patients were waiting longer than 36 weeks for outpatient appointments and surgery
- 5,858 patients were waiting longer than 52 weeks for outpatient appointments and surgery

³ Read the full article here: <https://www.versusarthritis.org/news/2020/july/uk-governments-warned-that-millions-with-arthritis-left-behind/>

For spinal surgery:

- 1,755 patients were currently on waiting list
- 49 patients were waiting longer than 26 weeks for first outpatient appointments (Stage 1)
- 908 patients were waiting longer than 36 weeks for outpatient appointments and surgery
- 762 patients were waiting longer than 52 weeks for outpatient appointments and surgery

The stories shared in our report and research undertaken by others, including the Board of CHC's in their national 'Feeling Forgotten' report, indicate that a significant number of people are waiting way in excess of the 36-week government target and that these delays to treatment are causing many people great **physical and emotional harm**.

The feedback shared with us identifies a number of common themes, including people experiencing physical and mental pain, worsening conditions, employment and income worries, feelings of isolation and loss of trust in service providers.

Sadly, since publication of the CHC's Feeling Forgotten report, not much has changed. People continue to describe lives as being 'on hold' or 'in limbo'. We heard of feelings of uncertainty, insecurity and tension in relation to family, work, social lives and leisure activities.

We further heard people's feelings of not being in control, not feeling able to 'get on with one's life' in a meaningful way or to make plans for the future. Many told us they felt 'forgotten' or 'abandoned by the system'.

Our report also highlights some distressing feedback. Some patients reported being in so much pain – physically and mentally - they were ready to give up on life. The pain and decreased quality of life made them feel **life was no longer worth living.**

People were keen to share with us their support and praise for everyone working in the NHS throughout the pandemic and gratitude to all healthcare workers was repeatedly expressed.

Ideas were also shared by people about how waiting times could be shortened and patient experience improved in the future. We considered this feedback in developing our recommendations on page 40.

Our report aims to capture the impact that long waits for elective surgery are having on people across Neath Port Talbot and Swansea. The patient stories represent a small percentage of patients across the Swansea Bay area and Wales who are waiting for elective surgery. We recognise that everyone's individual experience will be different.

We believe people's stories demand immediate action from the Health Board and perhaps, Welsh Government, to end long waits and avoidable suffering.

What we did

Between December 2020 and May 2021, we asked people across the Swansea Bay area to share their lived experiences of waiting times for elective orthopaedic, joint replacement and spinal surgery.

During the coronavirus pandemic, people shared their feedback with us by completing our local surveys online, or by contacting us by post, phone, email and website.

In December 2020, Swansea Bay Health Board agreed to send our questionnaire directly to a random sample of 2000 patients across all waiting lists for elective orthopaedic, joint replacement and spinal surgery. We were pleased to receive a postal response rate of around a third (32.35%).

We also reached out to people using social media, including Facebook Instagram and Twitter, providing direct links to our online surveys.

We shared our engagement messages promoting the survey on social media and by email, with many local groups and stakeholders in an effort to reach as many people as possible, including:

- ☺ Council for Voluntary Service (Neath Port Talbot & Swansea)
- ☺ GP cluster networks
- ☺ Local Area Coordinators
- ☺ Swansea Bay University Health Board
- ☺ Local community groups, including Covid-19 support groups
- ☺ Seldom heard groups
- ☺ Local and national charities

We picked up feedback in other ways too, e.g., through our enquiries and complaints advocacy service, local community networks, community representatives and groups, monitoring of health board activities, including feedback and complaints. We also collected feedback through responses to the Board of CHC's national Coronavirus survey⁴.

⁴ This survey invites people to share their feedback on NHS care during the Coronavirus pandemic. Please contact us for further information about this survey.

Who we are hearing from

Here is a snapshot of the people who shared their views and experiences with us through our local survey.

We heard from 948 people through our local survey. Of those who completed our monitoring questions:

99% shared their views and experiences in English

More than half were female (57%), (43%) were male

Around 89% were White (Welsh, English, Scottish, Northern Irish, British)

Age range categories:

The majority of people were aged 45 and over:

Almost 33% were aged 45 – 60 years old

Around 30% were aged 60 – 75 years old

Almost 27% were aged 26 – 44 years old

Around 96% identified as heterosexual

One third (33%) had a long-standing physical condition

Around 10% had a mental health condition

Around 17% had a long-standing illness

Almost 7% were deaf or had a severe hearing impairment

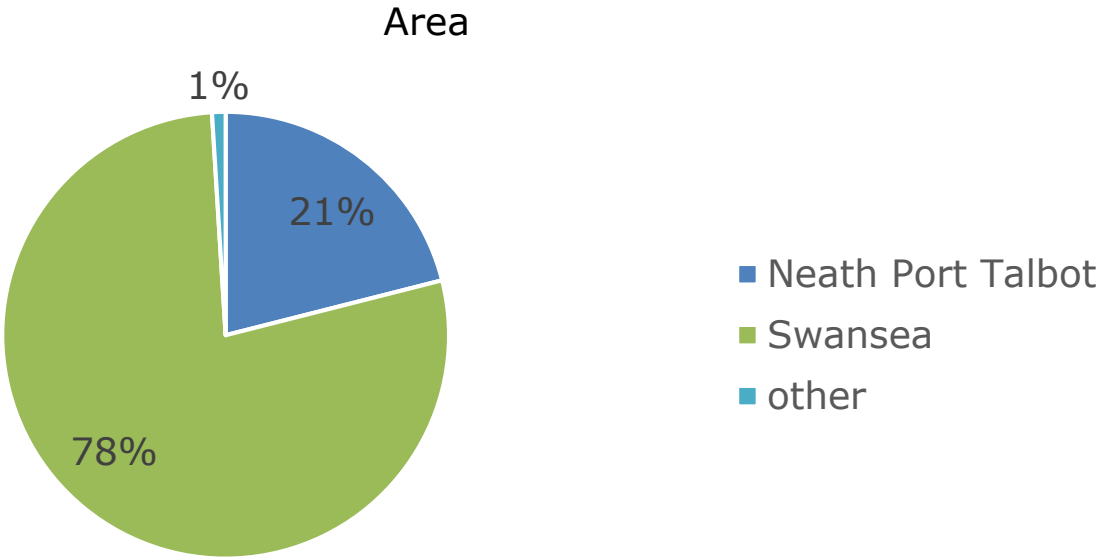
Around 3% were blind or partially sighted

2% had a learning disability

You can find out from our Equality Plan what we are doing to hear from different groups of people so that we can better represent the diversity of the communities we serve. You can find our Equality Plan on our website: www.swanseabaychc.nhs.wales/

What we heard

948 people shared their experience with us. 918 people responded to this question, with 715 people saying they were from the Swansea area and 193 from Neath Port Talbot. 10 people lived in another Health Board area. The pie chart below shows the breakdown.



The majority of people shared their own personal experience with some people responding on behalf of someone else.

Our survey asked people a number of questions about their experiences while waiting for surgery. A copy of our survey is available on request.

What surgery are you waiting for?

The majority of patients (662, around 70%) told us they were waiting for a knee or hip replacement. Others were waiting for shoulder, spinal, hand, wrist or foot surgery.

We heard how people had been waiting anywhere between 1 and 10 years for surgery.



Pre Operative assessment

Before patients have their operation, they are invited to attend the hospital for a pre operative assessment. This is carried out to make sure patients are fit for their operation and for the anaesthetic.

Over half of the people we heard from (478 people, 53%) told us they had received a pre operative assessment with more than a third (223 people, 36%) telling us they had received more than one. Some people reported receiving up to 5 pre operative assessments. Further comments about pre operative assessments can be found on pages 28 & 32.

Pain management

637 people (around 71%) told us they had not been offered any form of treatment to help with pain management during their wait for surgery.

Of those that did receive pain management, the most common treatments offered were cortisone injections⁵ or physiotherapy. A significant number of people told us they took pain killers on a regular basis to help manage the pain. Comments about medication can be found on page 29 & 30.

⁵ A Corticosteroid (or 'cortisone') is an anti-inflammatory medicine, which can be injected directly into the tissues that are causing the symptoms.

Key Findings:



92%

827 people
agreed the length
of time they have
been waiting for
surgery has seen
their condition
worsen

74%

Nearly 3 quarters (654 people)
agreed the length of time they
have been waiting for surgery has
affected their mental health and
well-being



Impact of waiting times

We invited people to tell us in their own words how waiting for treatment was affecting their life. Feedback has been grouped into themes as follows.

Waiting in Pain

The word, "Pain" was used 686 times in the feedback, with many people telling us the pain was beyond words, "constant" and affecting their lives in many ways.

"Pain rules every second of my day to the point I've given up keeping up and about - I save my steps for bathing and toileting. I cry most nights, and endure pain I never felt possible"

"At its worst, I just want to get a chainsaw and cut my leg off to get rid of the pain"

"I am in constant pain to the point of nausea"

"I'm in constant pain now as clearly the bones are rubbing together more than they used to be"

We heard how the pain was having a devastating effect on people's quality of life and affecting everyday activities that people their age could usually do.

Sleeping

Many told us they have a difficult time sleeping at night or getting comfortable because of the pain.

"I am having increased pain during nights with constant sleep deprivation from this"

"Sleep interrupted by constant ache in hips"

"Cannot lie down flat or on my bed and so I sleep in my recliner chair"

Walking and Mobility

Walking was painful for a significant number of people. It was mentioned 347 times in the feedback as being difficult if not impossible for some.

When pain stopped people walking or keeping mobile, we learned how they started to develop other health problems such as depression and worried about gaining weight.

"I have been unable to walk far or take part in any exercise"

"Have gained weight as I am unable to exercise as I am in pain"

"I have gained weight as I no longer walk anywhere, it is too painful"

"It's a vicious circle trying to lose weight from being immobile but unable to exercise or walk due to pain fatigue. This makes me feel depressed as was always very active so have no motivation"

Others told us their condition or pain stopped them taking part in hobbies and sports they loved.

"I was captain of our local bowls team and haven't played for years. I am in so much pain continuously, whatever I do, when walking my knees are scraping bone to bone"

"I'm a musician; my condition is preventing me playing"

"My lifetime hobby and interest is playing the trombone in brass groups and this has now become an impossibility as it is far too painful to continue"

Young people with a passion for sport and promising futures were forced to stop doing what they loved and were worried they may never play again.

"My mental health has been affected to the point where I feel I would be unable to play rugby again due to the length of time it has taken for me to have my operation. If I think about it, I usually cry and become very depressed over the thought of me never playing again. I was chosen for the emerging Welsh rugby side and started playing for the []; however, this has come to a complete standstill since my injury"

"I am a sport student in my third year at university and am unable to participate in many sports such as rugby & football. I have a continual ache in my left shoulder. I am unable to lift weights or go to the gym with my friends and colleagues due to my injury, which has affected my studies, health & wellbeing"

Falls and the fear of falling stopped others doing things too.

"I'm less confident to go out as I have had a few nasty falls"

"I am so afraid of falling which I have experienced more than five times"

"Even the thought of travelling frightens me. I feel apprehensive of falling"

"I can hardly walk, and can't get out much, and I have fallen a couple of times in the house"

"I had a nasty fall (outside) recently and it has affected my confidence immensely"

Work and money worries

Not all those waiting for procedures were retired. Many people told us about significant effects waiting for surgery was having, on their work and careers. People also worried how they would make ends meet and continue to provide for loved ones.

"I am struggling to remain in work despite reluctantly reducing my working hours. I live alone and rely on my wage to pay the mortgage. The threat of losing my house is constantly on my mind if I can't remain in work because I am not having my operation in a timely manner"

"I worry about my job, as I find it more difficult to do my job. I can't afford to give up work full time. I have reduced my hours as I cannot afford to lose my job altogether as working full time was putting a strain on my joints"

"Finding it increasingly hard to work as a postman. Since lockdown I have worked in a depot as I don't drive, so unable to go out on deliveries. It has affected my mental health as I know I am expected to go back on deliveries and I would have to go on long term sick or possibly be medically finished, so I have a constant worry about my job"

"I cannot walk without a leg brace. I run a restaurant and it's severely affecting my capacity to do my job. Even to the point where I now believe my employers will ask me to leave. I have 2 young children and a mortgage. It's really worrying me"

"My daily work life as a builder is affected. Throughout the day I'm in constant pain which leaves me mentally exhausted when I get home. Also as the company I work for is my own, the constant worry of my finances are affecting my wellbeing as I feel that I will be unable to work with the pain much longer"

Feeling isolated

We learned how pain when moving stopped many people from socialising and enjoying family time. This led to people feeling lonely and isolated. We heard how people disabled by pain lost the power to travel beyond their homes' four walls.

"It stops me going out so I'm stuck in my house without seeing anyone so it's not what my life was like"

"Miss walking and enjoying nature. Miss days out, I miss living, the list goes on. I feel like a prisoner in my own home"

"Because I cannot leave home like I used to I feel lonely and isolated"

"It's too painful to walk or even want to go out leaving me feeling very isolated"

"My mobility is severely limited. I do not drive and bus stop is too far to walk. I live alone. I am becoming isolated and depressed due to inability to socialise"

"Feeling of isolation because I'm unable to do the everyday things with my 3 children"

Patient "Harm"

Some patients feel they are suffering harm due to treatment delays and believe the longer they wait for surgery the less effective it will be, if at all.

"Because of pain in left foot I am overcompensating by putting pressure on my right leg resulting in pain at knee joint on right leg"

"The other major concern, is that the level of mobility that I am able to regain through orthopaedic surgery, will dwindle further, the longer that I wait, effectively leaving me in a permanent state of disablement"

"I am concerned that I will become inoperable and I feel I am suffering as a result"

"I am really fed up and living with the constant fear that I won't be offered surgery at all in the end"

"Also affecting my other knee and my lower back due to walking out of alignment"

"Fear about degenerating condition"

Lives on hold

Many patients told us their lives are on hold while they wait for surgery.

"Have been putting my life on hold. All my sentences start with, "when my hips been done we'll ..."

"My life has been on hold as I am in constant pain and only able to walk short distances"

"I suppose really that my whole way of life has been placed on hold until I have the replacement procedure done"

While the physical and mental pain is too much to cope with for some

"My back and legs are getting much worse. I desperately need my operation. I can't go on much longer"

"My mental health is suffering.....sometimes leads to a feeling of hopelessness and what's the point in carrying on"

Relationships

Many people reported a severe effect on family life. These effects ranged from being unable to spend quality time with grandchildren to feelings of guilt that they found it difficult to carry out caring responsibilities or contribute to family life as they used to.

"I am in constant pain to the point of nausea, I struggle to sleep, I struggle to walk most of the time, my mood is severely depressed and I am struggling to fulfil my responsibilities as a Carer to our disabled son and to a lesser extent, my wife who suffers from chronic illness"

"Taking grandchildren out for walks playing with them in garden"

"The pain is getting worse. I am unable to enjoy my life and grandchildren as I should. The pain is restricting my mobility"

Several people highlighted that pain, lack of mobility, lack of sleep and feeling a "burden" made them short tempered and "grumpy" with family members.

"The amitriptyline no longer help me sleep, I was sleeping 3/4 hours a night. I became unbearable to be around. My mental health has deteriorated and it has started to affect my relationship with my partner"

"Pain in my knee makes me 'grumpy' I am told by my family which in term affects our relationship"

"Short tempered with family members due to pain and lack of mobility"

"I feel a burden on my family and friends"

Independence

Loss of independence and reliance on partners and family for support led to feelings of guilt and sadness for some.

"It has stopped my independence due to the constant pain and immobility. I need help with every aspect of my life. It is making me very depressed..... My husband and family are my life savers"

"My independence is impaired"

"Taken away my independence as I can't go anywhere on my own. I have to rely on my husband"

"Once I was an independent man now I have to rely on my wife, this has impacted me mentally as I cannot do what I did before"

Is my life worth living?

We were very concerned to learn that the wait in pain for procedures was having a very serious impact on some people's mental health and well-being.

The constant pain and suffering made some people feel life was not worth living.

"Is my life worth living? I have constant pain"

"I am in constant severe pain, fall far more, require a wheelchair. Housebound bar health appointments. My mental health has deteriorated & I frequently feel suicidal"

"I have been put on different antidepressants due to me being close to taking my own life due to the pain"

"I have contemplated ending my life due to the pain"

"Pain has increased to the point I have thought of taking my own life"

"The pain is constant and almost unbearable. I cannot walk any distance, now have blue badge, so exercise is difficult really affecting aspects of my life and getting to the stage I don't care if I wake up in the morning as it will be another pain filled day!"

Feeling forgotten

The lack of communication from those delivering services and long waits for surgery has led to some patients feeling forgotten

"Feelings of being abandoned by the system, an NHS that I have cherished all my life"

"I feel I have been forgotten"

"Feel as if I have been forgotten"

False hope

Some patients view the pre-operative assessment as a sign their operation would soon follow and were disappointed when this was not the case.

"After each pre-operative assessment my hopes are raised and then dashed"

"Repeatedly being invited for pre-op assessments, to no avail"

"Have recently had hospital pre op assessment but letter says, 'operation not imminent' "

Forced to go private

Intolerable levels of pain and mobility problems had led to some people paying for private treatment even though they could not afford it.

"Hip became agonising and ulcerated. I took out a bank loan and had a private hip replacement March 2020"

"I have been very depressed, housebound, I have got into debt to go private to have my hip replacement, which I recently have had done, but my health is still suffering"

Painkillers

Many people relieved their pain with medication. Long-term use of painkillers were a cause of concern with some people telling us were worried about side effects, reduced effectiveness, over reliance and addiction.

".....The pain levels continue to rise as does the level of Morphine I am having to take to control it. I have been using Morphine to control my pain now for at least 5 years and fear I may have become dependent on it for life"

"I do not want to rely on medication to be able to cope with daily activities"

"I continue to take the prescribed chronic pain medication but the dose prescribed of tramadol no longer eases the pain as it used to. These drugs were prescribed by the chronic pain team prior to diagnosis in 2019....I do not want to increase my drugs as they are addictive"

"I am having to take controlled drugs to manage my pain which I feel is not suitable for long term use and ineffective, this is causing additional anxiety"

"The stronger painkillers I was on were causing side effects which I couldn't cope with so I am now on milder painkillers which have little effect on the pain levels"

How would you rate your experience of NHS services?

548 patients (63%) rated their experience as 'good, very good or excellent'. 168 patients (19%) rated their experience as 'fair', and 157 patients (18%) rated their experience as 'poor' or 'very poor'.

We invited people to share with us the reasons for their ratings. Feedback was mixed with people sharing feedback about care before and during the pandemic. We have summarised under positive and negative headings below.

Positive Feedback

Positive themes included the following:

- Sympathy for the NHS dealing with the coronavirus pandemic:
 - People generally understood the pressures on services
 - Appreciation was given to healthcare workers for their commitment, dedication and kindness at this time
- Previous NHS care and treatment
- Staff attitude

Negative Feedback

Negative themes included the following:

- Waiting times for surgery, including waiting times pre-pandemic
- Lack of communication and updates
- Feeling "forgotten"

"I understand the reasons for the delay but it is difficult sometimes not to feel that I have been forgotten about and just written off because of other priorities"

- Being left in pain / no pain management
- No emotional / well-being support
- Pre-operative assessments

"To have a pre-op assessment and no idea of surgery will take place is a total waste of time and money"

"Do NOT call patients for pre op assessments if the operation isn't likely to be imminent i.e. within a short period of time e.g. within 2 months"

"Please don't call people in for pre assessments giving false hope that surgery is imminent"

- When patients do not understand the reasons for delays or when they are not successful in their efforts to find out, some suspected there might be tactical factors at play.

"When people are told they need an operation and will be put on the waiting list, actually put them on the list. Don't have policies to make the list look better that cause 6 month delays, as happened to me"

- Cancellations in particular were experienced as adding to the negative impacts of waiting

"Stop cancelling the operations. My left knee replacement was cancelled 8 times"

"Had two cancellations for surgery on the morning which has a huge mental impact. Families have to be prepared for, meals, sorting out young children etc. so to have it cancelled twice on the day was devastating"

Peoples suggestions for the Health Board and Welsh Government, to improve services and 'patient experience' for patients waiting for elective surgery

388 people shared their views on what they felt could help improve waiting times and patient experience. While being supportive of healthcare staff during the pandemic and appreciative of the care they received prior, many people made a number of information and communication-related suggestions for improving services and patient experience. Others shared more system wide ideas. We have summarised the feedback received as follows:

- ⌚ Waiting times
 - Provide information to patients on what measures are being taken to manage waiting lists and reduce their waiting times
- ⌚ Better communication to help manage patients' expectations
 - Provide status updates to ease anxiety and reassure patients that they have not been forgotten, and

"Telephone calls to reassure patients they are on the waiting lists and haven't been forgotten about. Just someone that rings and asks how you are doing so patients don't feel like they have been forgotten about. Talking to several friends also waiting for replacement, the lack of communication is the biggest gripe"

"Send out a letter or phone call just so we know we are still on the radar"

- Do not make patients feel that it's their responsibility to seek updates

"Not knowing what is happening with the surgery has been stressful and even more so when trying to chase up information as no one knew how to respond"

"Keep patients informed - the patient shouldn't have to chase the relevant departments for news"

- ⌚ Provide more accurate information to enable patients to make decisions on whether to pay privately

"Tell the truth about waiting times. Will have to go private to get the quality of life back"

- ⌚ Signpost patients to additional support services while they wait such as how to improve mental wellbeing and quality of life

"Offer them a few helplines or services that they could access while waiting for surgery."

"I think it would be of help if there was some sort of follow up during the waiting period to provide physical support or support with mental health to overcome the feeling of abandonment"

Dealing with the backlog

Peoples concerns are growing about the size of the backlog created because of the pandemic. Others were frustrated that elective services seemed to be slow to restart across Swansea Bay compared to other areas and put forward ideas to help tackle the backlog.

"Utilise the field hospitals for the purpose they were built. There used to be isolation hospitals for Tuberculosis (TB) etc. Why not utilise them in this fashion? The NHS needs to get back to their day job treating regular patients"

"Please try and start up surgery services as soon as possible after dealing with the virus"

"Swansea Health board needs to find a way to START elective orthopaedic surgery... Elective surgery is still going ahead in many parts of the rest of the UK"

"Put money in to Health Boards to provide a team to carry out routine work and clear some of the backlog. I don't think any money has been spent propping up staff when there are shortages caused by the pandemic"

"Don't know if it's practical but possibly after covid dies down allocate an area or certain hospital for catch up of what must be the massive backlog of ops"

"Why couldn't some wards/theatres been isolated away from the rest of the hospital in Morriston. Patients will have to be suffering for years until all the backlog is cleared"

- ⌚ Make use of private hospital facilities
- ⌚ Funding

"The issue is one of resources and availability, especially in these times when NHS staff are under great pressure as a result of under resourcing. Difficult to know how this situation be resolved without substantial amounts of funding"

- ⌚ Increase staff

"It appears there is a shortfall of staff qualified to carry out orthopaedic surgery"

- ⌚ Increase beds / 'ring-fence'⁶ surgical beds for planned operations

"Increase beds on surgical wards"

Many people are frustrated that hospital beds for planned operations are used for other purposes.

"Appears that consultants themselves are frustrated by breakdown and blocking of surgery in Morriston - a year before the covid pandemic. Now pandemic blamed for ineptitude of Morriston hospital"

"Stop using the designated orthopaedic beds for other purposes"

⁶ To 'ring-fence' surgical beds means to put restrictions on them, so that they can only be used for that purpose.

Learning from what we heard

The stories shared with us illustrate what life is like for some people across Neath Port Talbot and Swansea who are waiting for life-changing surgery.

People are frustrated by long waiting times and the uncertainty is causing them emotional distress, particularly if they feel they have been 'forgotten' or 'abandoned'.

Constant pain, anxiety, depression, fear, isolation and disability are other effects reported to us by waiting patients. These stories are a powerful reminder to those responsible for planning and delivering NHS services of the harm that can be caused to people – physically and emotionally - as a result of long waits for surgery. This includes the additional stress that can be caused when communication is poor and people feel it is up to them to chase for updates and arrange the various elements of their care.

Whilst Swansea Bay Health Board has managed the immediate challenge of dealing with COVID-19, many patients waiting for elective care have experienced longer waiting times and changes to their treatment plans, often at short notice.

Our report draws conclusions from the views and experiences shared with us and makes recommendations based on these. We recognise that services had to adapt quickly during the pandemic. The recommendations suggest ways to improve waiting times for patients and improve patient experience based on what they have told us.

The number of stories in this report equate to only a fraction of the missed targets reported each month by the NHS in Wales.

Since waiting times targets were set by Welsh Government in 2010, Swansea Bay and other Welsh Health Boards have frequently struggled to meet these targets. While it is important to look at other aspects of the quality of care beyond waiting times, the frequent struggles to meet targets is a clear indication of the much deeper pressures the health care system is facing. It is a signal that the NHS is unable to meet patient needs with the resources it has available.

This measure is unlikely to hold much meaning for those who shared their experiences with us. Instead, most people measured their wait in terms of the impact on their day-to-day life, quality of life, their relationships, their jobs and careers, their independence and their futures.

It is vital that waiting time targets provide assurance to the public and drive sustained improvement and outcomes. In their current form, they do not appear to be meaningful to anyone.

On 1 June 2020, The Health and Social Care (Quality and Engagement) (Wales) Act became law. It is set to come in to force in spring 2023. This Act brings meaningful opportunity to set out a more effective basis on which performance is measured. A new **Duty of Quality** will require more than just meeting service standards. Health Services will be required to demonstrate a "system-wide way of working to provide safe, effective, person-

centred, timely, efficient and equitable health care in the context of a learning culture”⁷

While it is understandable that elective operations needed to be postponed during the pandemic, it should not be forgotten that thousands of people are enduring longer waits for surgery. They are often in severe, debilitating pain; their lives ‘put on hold’.

As the feedback in our report identifies, delays to treatment can risk serious physical and mental health implications. It is vital that people waiting for elective surgery receive clear communication about their care, as well as support and advice on pain management and mental health and wellbeing, so they are as well as they can be when surgery does safely resume.

With record numbers of patients in the Swansea Bay area and across Wales waiting for elective surgery and many waiting way in excess of the 36 week waiting time target, waiting times across Wales for elective surgery should become a key priority. Our Health Board urgently needs to share its plans to bring down surgery waiting times safely.

We hope that Swansea Bay University Health Board will utilise local people’s feedback in this report creatively to improve waiting times for surgery and patient outcomes. People desperately need that to happen.

⁷ The Health and Social Care (Quality and Engagement) (Wales) Act: summary, June 2021.

Recommendations

The Board of CHC's national 'Feeling Forgotten' report found similar issues across service areas as those identified in our report. Although our report is specifically about elective orthopaedics care; we reiterate the Feeling Forgotten recommendations where these are relevant. People's more recent experiences do not show improvement. We therefore ask the health board to respond to the worries people have shared with us by making sure:

- ⌚ Healthcare teams keep in regular contact with people waiting for care and treatment. This will help them know what is happening, how long they might need to wait, the reasons for the delay and what the delay might mean for them in the longer term
- ⌚ Where the 'waiting time clock' is stopped for any reason (e.g. where a patient is unfit for surgery) take steps to ensure that:
 - the patient is actively involved in this process
 - the patient is referred again and joins the waiting list at the most clinically-appropriate stage
 - Ensure account is taken of time previously waited across various pathways when prioritising patients for treatment
- ⌚ Communicate with patients about how plans have changed during the pandemic and timescales for reintroducing services
 - ⌚ People waiting for care and treatment know how to get advice and support while they are waiting, particularly in respect of:
 - Wider emotional and mental well-being services
 - Pain management

- ◡ Ensure surgical waiting lists are:
 - Clinically validated to allow waiting lists to run effectively. This might include:
 - checking on a patient's condition and establishing any additional risk factors
 - establishing the patient's wishes regarding treatment. Communicating effectively with patients, carers and GPs
 - Where waiting times have changed for priority groups, be open with patients about how long they might have to wait
 - Technically validated - Some people who responded to our survey told us they were no longer waiting for surgery. Others told us they were not waiting for any treatment at all:
 - ensure the waiting list is accurate and up to date
- ◡ Elective surgery is critical to an individual's quality of life and function:
 - Involve people and clinicians in developing prudent orthopaedic plans that both meet people's needs now and are sustainable for the future. Whilst recognising long-term strategic plans are in development for orthopaedic services, we would invite the health board to develop plans to expedite treatment in the short term. The poor prospects of receiving treatment soon is evidently having a devastating impact on people's lives and emotional wellbeing

We recognise that in order for the health board to develop short term plans to address waiting times for orthopaedic treatment, the Welsh Government might have a role to play. The CHC movements 'Feeling Forgotten' national report made several recommendations to Welsh Government that are relevant to this report. Swansea Bay CHC will work with the Board of CHC's to consider what further actions might be appropriate in light of the similarity of our findings and those of the Feeling Forgotten report.

The pandemic has shone a spotlight on how bad waiting times were prior to the pandemic and these devastating stories demonstrate that things urgently need to change.

Thank you

We thank everyone who took the time to share their views and experiences with us about the impact waiting times for surgery are having on their lives and for sharing their ideas to improve waiting times and patient experience.

We would like to thank our partner organisations for sharing information and our questionnaire and for supporting us to access seldom heard groups.

We hope the feedback people have taken time to share influences decision makers to take action where they need to as quickly as they can to make things better.

Feedback

Swansea Bay CHC would love to hear what you think about this publication, and any suggestions about how we could have improved it, so we can use this to make our future work better.



Contact details

	Swansea Bay Community Health Council First Floor Cimla Health & Social Care Centre Neath SA11 3SU
	Landline: 01639 683490 Mobile: 07970 682000
	swanseabay@waleschc.org.uk
	https://swanseabaychc.nhs.wales
	@SwanseaBayCHC
	@SwanseaBayCHC
	@SwanseaBayCHC

If you write to us in Welsh, we will answer in Welsh. This will not lead to a delay in responding to your correspondence.

We welcome telephone calls in Welsh.

**Swansea Bay
Community Health Council**