



**Knowing
Works®**



{ Long-term pain management
Briefing: People's experiences in Suffolk

Published March 2026

About Knowing Works CIC

Knowing Works CIC is a large-membership social enterprise delivering insight to shape businesses, services, and decision-making across sectors.

We passionately believe that listening and responding to people's lived experiences is vital to create businesses and services that work for everyone. We bring lived experience and compelling evidence to the fore that changes minds and brings about sustainable change.

Knowing Works CIC delivers the local Healthwatch service in Suffolk. It is a statutory service gathering people's lived experiences to shape, influence and improve better standards of local NHS and social care.

This report

This report has been created with the support of funding from the NHS in Suffolk and north east Essex to assist NHS commissioners in their review of current long-term pain services.

What's included?

This report brings together evidence from projects delivered by Knowing Works CIC and our Healthwatch Suffolk service. This includes:

- Feedback logged to the Healthwatch Suffolk Feedback Centre - an online platform people can use to find, rate, and review their local NHS and social care services.
- Core Healthwatch Suffolk research

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“The physio has been amazing. I've had six sessions in total with two members of staff. The pain is still an issue but I wouldn't be where I am without them.”

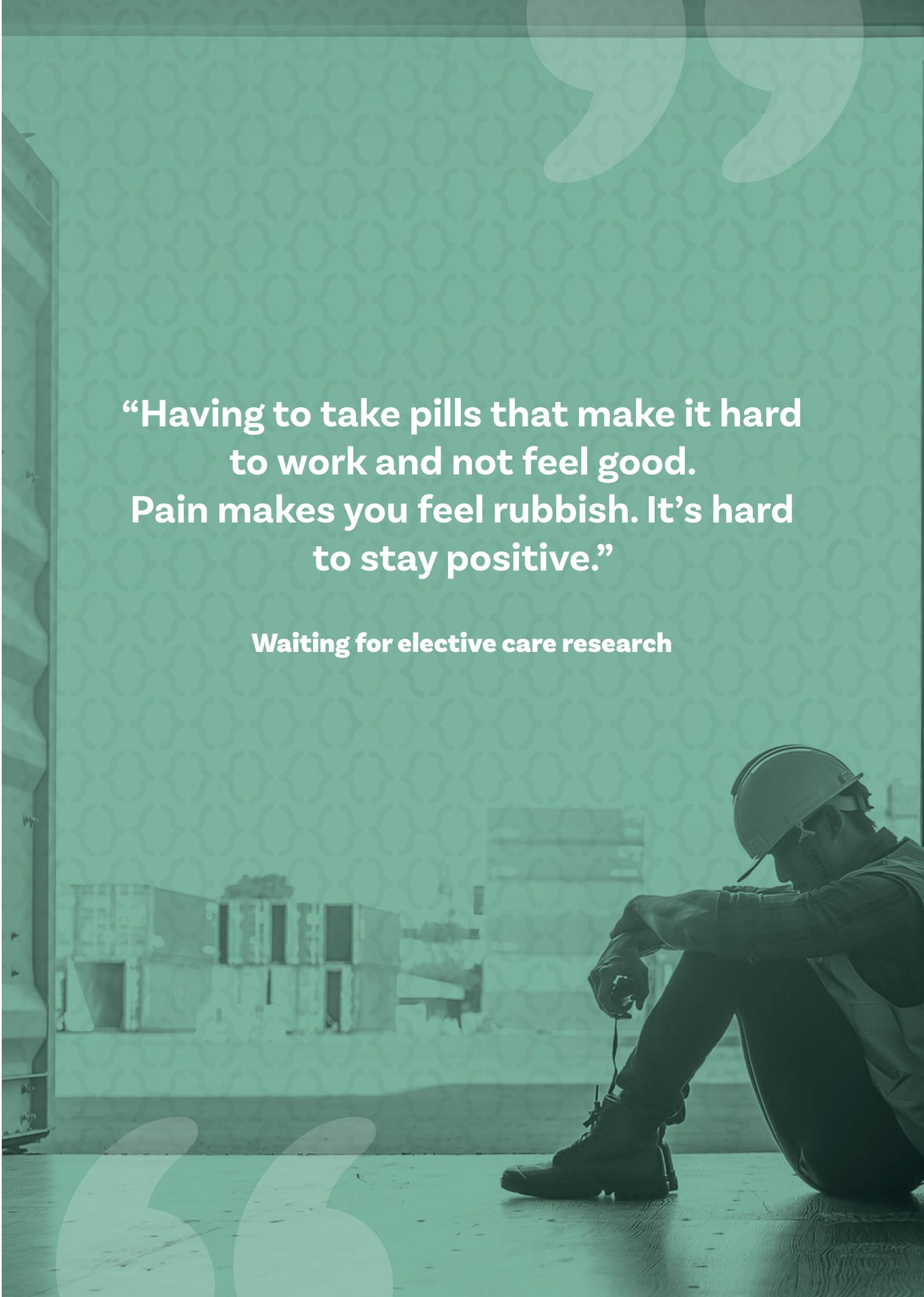
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exploring people's experiences of waiting for hospital treatment and care.

- Knowing Works research exploring people's experiences of back, neck, and spinal care.

In Suffolk and north east Essex, long-term pain management services are provided by West Suffolk Foundation Trust, East Suffolk and North Essex Foundation Trust (ESNEFT) and North Essex Community Services. People also receive support for pain management in other NHS services, such as local GP practices and physiotherapy.

Analysis of Feedback Centre data is described and summarised according to these commonly reviewed service types, providers, and departments.



**“Having to take pills that make it hard
to work and not feel good.
Pain makes you feel rubbish. It’s hard
to stay positive.”**

Waiting for elective care research

Our data

Between 26th February 2024 and 26th February 2026, Healthwatch Suffolk identified a total of **68** comments that appeared to mention experiences of long-term pain management or support (e.g., over weeks, months or years).

Of these, **29** comments were about hospitals, **24** were about GPs, and **15** were about community-based services (particularly Allied Health Professionals Suffolk).

This feedback is described and summarised below according to commonly reviewed service types, providers, and departments.

Important note

Healthwatch Suffolk did not ask people to write reviews on the Feedback Centre about long-term pain management or specific aspects of pain management support. Any mentions of pain management in Feedback Centre data are purely by chance, reflecting issues that were important to people when they submitted their feedback.

The number of comments reported are unlikely to be representative of every person's experience of accessing long-term pain management support in Suffolk. They should be considered together with other sources of evidence, such as the research projects highlighted in this document and other sources of experience data that may be available to the NHS.



What is the Feedback Centre?

The Feedback Centre is provided by the Healthwatch Suffolk service for the public to easily find, rate, and review their local NHS and social care service. It is accessible at;

www.healthwatchsuffolk.co.uk/services.

Hospitals in east and west Suffolk

Within the **29** comments about hospitals, most were about the East Suffolk and North Essex Foundation Trust Ipswich Hospital site (**14**) or West Suffolk Foundation Trust (**12**).

Half of the comments about the Ipswich Hospital were about the orthopaedics department, two were about the pain management service provided by the Trust, and the remainder were about other departments.

All but one comment about the West Suffolk Foundation Trust were about the pain management department. There was one comment about the Newmarket Community Hospital. Finally, one comment did not specify a hospital name.



“They identified the problem I have and started treatment straight away. Until this point, I felt dismissed and made to feel it was in my head. I was finally validated. I now visit for injections and they are controlling the pain.”



West Suffolk Foundation Trust - pain management service

The department received **11** reviews in the period.

This included **five** that were entirely positive, **three** describing effective treatment and improved quality of life, and **two** comments offering praise about the information and advice they receive from the department.

“Amazing results giving me a near normal few months of very low pain, a reduction of headache by 80% meaning I have been able to work a lot harder and happier in my daily life.”

“I have been treated for a number of years... they have made my life so much better.”

“I’ve received information that has really helped.”

“The online session was good and it gave a lot of information.”

Six comments were either completely negative or mixed in sentiment, with descriptions of limited or ineffective support (**6**) and long wait times to be seen (**3**). Some also commented about a lack of support or advice while waiting.

“There are long waits to be seen by the pain clinic. I’ve been told it will be about a year and I’ve been given no advice while waiting.”

“I’ve had a 14 month wait to be seen by the pain clinic, and then I’m facing another 7+ months to wait for injections.”

“I do not find that the pain clinic is very useful and they can’t offer anything helpful, but maybe that’s because of my specific issues.”

“The suggestions at times are a bit limited but the staff are friendly.”

“The pain clinic just gives medication, but doesn’t really offer much else. So I’ve decided to go private. But the physios were great, and they ensured I was referred on to the appropriate department.”

Other West Suffolk Hospital Departments

The remaining review about the West Suffolk Foundation Trust was about an experience of ongoing gynaecological pain not being taken seriously. The individual described a negative experience with a member of staff.

“(The staff member) was not interested in anything I had to say about the symptoms I was experiencing. They then had the audacity to tell me my appointment was a bit of a waste of time. I had to hold back tears when I told them I had enough of living this way. They also told me that fibroids do not cause bleeding or pain. It’s my body.”

Ipswich Hospital’s Orthopaedics Department

Half of the comments (**7**) received about the Ipswich Hospital were about the orthopaedics department.

Negative comments included long waits for

operations and surgery cancellations while managing pain. **One** person described a particular difficulty, where they were offered two necessary surgeries within one week of each other and faced the challenge of deciding which one to cancel.

“I’m waiting for two different operations, and both have been delayed, but of course I’ve been given new dates within a week of each other. Now I’ll probably have to make a decision about which to cancel when both are needed. I’m delaying making a decision because one or the other might be cancelled again. I’ve had times when I’ve been prepped for surgery and then told the surgery isn’t happening. It’s heartbreaking.”

“Waiting for the operation was hard due to pain and that is why I considered going private.”

“I have had to wait 33 weeks so far and I am still waiting. I am in so much pain. I will perhaps have to pay to go private.”

In addition to long wait times, **two** people highlighted difficulties with support while waiting for surgery. Both reviews described difficulties accessing effective and lasting pain relief.

“I’ve struggled to get adequate pain relief to help cope in the meantime.”

“They’ve tried to control the pain while I wait and I was given an injection but that wore off.”

Positive comments about the orthopaedics department related to the impact that surgery and physiotherapy had on managing people’s pain (**2**), while **one** person felt included in decisions about their care based on their own pain levels rather than examination results.

“The physio has been amazing. I’ve had six sessions in total with two members of staff.”

The pain is still an issue, but I wouldn’t be where I am without them.”

“My recovery has been very good and I’ve done the physio as much as possible to aid my recovery.”

“The consultant agreed to operate on the knee that was more painful, rather than the one that looked worse on the X-ray.”

Other Ipswich Hospital Departments

Waiting for care

- **Two** people were waiting to access the pain management clinic.
- **One** person was negative about their wait for spinal surgery, despite an urgent referral.
- **One** person described waiting months in ‘huge pain’ for a colonoscopy to remove a polyp.

Ineffective support

- **One** person described a lack of support for pain management in paediatrics, being told ‘there was nothing they can do to control the pain’.
- **One** person described exercises given to them to have made their symptoms worse, feeling that the exercises were generalised and not tailored to them.

Pain management in GP practices

There were **24** comments about pain management at GP surgeries. Key themes are highlighted below.

Lack of support

Seven people described a lack of support,

“I was told in a very blunt and short message that I probably have endometriosis and may have difficulty having children. They then immediately closed the chat, so I couldn’t even go back with any questions I had. It was so blunt and felt they were dismissing my concerns.”

“I experienced a difficult birth and raised concerns for months. In my 6/8 week check, they focused on the pain I was in, but I was never examined. It wasn’t until five months later I saw another GP - they did a physical exam and referred me to hospital. I now have a long wait to be seen and it’s affecting my daily life so much - all the way I was just dismissed.”

including feeling dismissed, unheard and inadequately supported.

Some described GPs as reluctant to prescribe pain relief, experiencing rejections and difficulty being taken seriously. Alongside this, people described little to no face-to-face consultations or support beyond medication.

“Nurses at the surgery have been superb. Doctors are very reluctant to give any medication when people are in chronic pain. Never get to see a doctor in person, only can get a telephone appointment.”

“I have been left with no pain medication as the new doctor that doesn’t even know my case has rejected my request for pain meds. Now 111 will not give me any as she has rejected it with no explaining.”

Referrals

Six people described experiences seeking referrals from GP practices for ongoing pain issues. While **one** comment was positive, describing the GP as responsive and caring, **four** people were entirely negative. They mentioned not being taken seriously or experiencing late referrals.

“I saw the GP and they managed to get me a scan which revealed a secondary fracture. He apologised, I had asked many times before this point.”

“Repeatedly requested referral for guided injections in thumb joints. They took over four months to send referral.”

“The GP was very responsive and their referral was spot on. They are excellent and I feel well cared for.”

Good support

Positively, **five** people described feeling well-supported by their GP in relation to pain management. This included GPs being quick to respond and offer appointments, organising medication quickly and efficiently, feeling listened to and supported, and receiving good information and advice.

“I visited for a post-surgery check with a nurse yesterday and they’ve arranged another appointment for me to be seen again today. Pain medication was arranged on Friday when I was struggling with pain and the staff were helpful and understanding. Everything has been dealt with very quickly.”

“The GP I’ve seen recently has been great, very supportive and has pushed with the hospital when needed too. They’ve done a referral to physio and addressed the pain I was in.”

Other comments

- **One** person felt their GP made every effort to help but was ultimately unable to identify effective pain relief.
- **Two** people reported misdiagnoses, including one case where cancer was initially diagnosed as a hernia.
- **One** person was prescribed a medication

they later discovered was inappropriate for them.

- **One** person experienced difficulties with the supply of their pain medication.
- **One** person encountered administrative issues related to moving from abroad, which disrupted access to pain medication and resulted in ongoing, severe pain.

Community-based services

Allied Health Professionals Suffolk (AHPS)

Seven of the **13** comments addressed the effectiveness of the treatment provided by AHPS. **Four** people gave positive feedback about the effectiveness of treatment, reporting a reduction or improvement in pain following advice from the service.

“They gave me exercises and an elastic material and I think it seems to have done the trick, I’m feeling much better with it.”

“The exercises I have been given have been easy enough to follow and so far have helped.”

One person provided mixed feedback, noting while they would prefer hands-on treatment, the prescribed exercises have provided some improvement.

“I prefer hands on treatment, but they have never offered it. Exercises have helped a bit, but it is slow progress.”

Two people reported negative experiences, stating that the exercises have not had any positive impact on their pain.

“Sadly I feel it’s a waste of time for me. After their exercises I feel in agony.”

Other comments included:

- **Two** people were pleased with the information and advice they were receiving from the service.

“I’ve been surprised by the great support and advice I’ve received.”

- **Two** people were generally positive about the treatment and care they are receiving, describing that they are doing what they can to help them manage the pain.

“The staff are doing all they can to regain as much movement as I can.”

- **One** person was positive about the wait times after a referral.
- **One** person noted that the referral only focuses on one issue, whereas the patient experiences multiple areas of pain.

Other services

One comment was about community midwives. A patient had remained in daily pain a year after their birth experienced. They described difficulty in getting NHS services to listen and take their concerns seriously.



From our research

Key projects

The following insights are taken from research completed by Knowing Works CIC, or its Healthwatch Suffolk service.

Waiting for elective care in Suffolk (2024/25)

In 2021/22 Healthwatch Suffolk conducted a project to gather the views and experiences of people waiting for hospital care.

The findings revealed the devastating impact of waiting on people's lives and made recommendations to health and care leaders about holistic management of those waiting, communication with patients, and inequalities.

In 2024/25 Healthwatch Suffolk revisited the topic and again asked patients what it was like to wait for elective care and how this wait had impacted their lives. A total of **1,144** people provided comments.

The research highlighted the interconnected nature of the impacts people experienced. For example, how pain can restrict mobility, which can affect ability to work and financial stability, increasing stress on individuals and families.

A third (**34%**) of all respondents who left a comment wrote about the pain or discomfort they experienced whilst waiting for elective care. Experiences ranged from 'general discomfort and inconvenience' through to those who described their pain as 'excruciating', 'debilitating' and 'unmanageable'.

Some experienced occasional pain, while others spoke of being in constant or persistent pain and several respondents reported that their levels of pain had either increased or that they

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“Waiting for a new hip. Full time carer to a disabled son and another son who has just had heart surgery. Pain level is unbearable by middle of the day. Disabled son has cerebral palsy and autism, and he is a big 19-year-old. My daughter has had to step up and help around her job and family as I can't drive to shop, can't weight bear my son anymore.”

“In constant tears.”

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were experiencing pain more frequently.

Pain was often identified as the primary cause of other impacts on people's lives, affecting their ability to work, socialise, and move around. Furthermore, living with constant pain had a significant impact on some people's mental health and wellbeing, as well as disrupting their ability to get quality sleep.

Many relied on pain relief to manage their symptoms, with some reporting an increasing dependence on medication to enable them to cope with daily life. Some respondents however reported pain medication to be less effective

Shrinking worlds? Hundreds of people said their wait for care was leading to poorer health and reduced mobility.



over time, while others highlighted side effects of prolonged use of pain killers. This included constipation, nausea and weight gain. Concern was expressed by some about the long-term health impacts of constant use of pain relief.

Ultimately, this research has shown clearly how, over time, pain can be a significant drain on emotional and physical energy. It can lead to an increasingly isolated life and, at its worst, leave people bed-bound or afraid to move.

Pain can also affect things like relationships and impact on caring responsibilities – both creating new family carers supporting those living in daily pain, and simultaneously disabling those who already have caring responsibilities at home.

Back, neck, and spinal care in Suffolk

In 2024/2025, Knowing Works CIC conducted a project to gather feedback from patients across the spinal network on various pathways to understand experiences of back, neck and spinal care in Suffolk and identify priorities for service improvement.

The survey gathered **126** responses.

Many respondents reported living with long-term pain, sometimes over many years. Several felt the root cause of their pain had not been properly investigated, especially where access to MRI scans had been delayed. In some cases, patients believed earlier imaging or specialist input might have prevented deterioration. A recurring theme was that people were moved through a standard pathway without feeling that their individual pain experience was fully explored.

Some described that interventions (e.g., nerve ablation, root blocks, or spinal injections) had limited to no lasting benefit. Others described long waits for appointments or treatment.

Several people reported that pain management programmes focused heavily on coping strategies (e.g. relaxation techniques, sleep advice, seminars, PowerPoint-based sessions) rather than providing meaningful symptom relief.

There were a number of positive experiences reported, particularly where specialist nurses provided ongoing support, education, or access to devices such as spinal cord stimulators. Despite pain relief being limited, some appreciated being involved and supported.

While many people improved with community physiotherapy, a few felt the exercises were generic, repetitive or ineffective, especially for severe or complex pain. Some reported that exercises worsened their symptoms or did not address the underlying problem. A few accessed private treatment for more ‘hands on’ therapies.

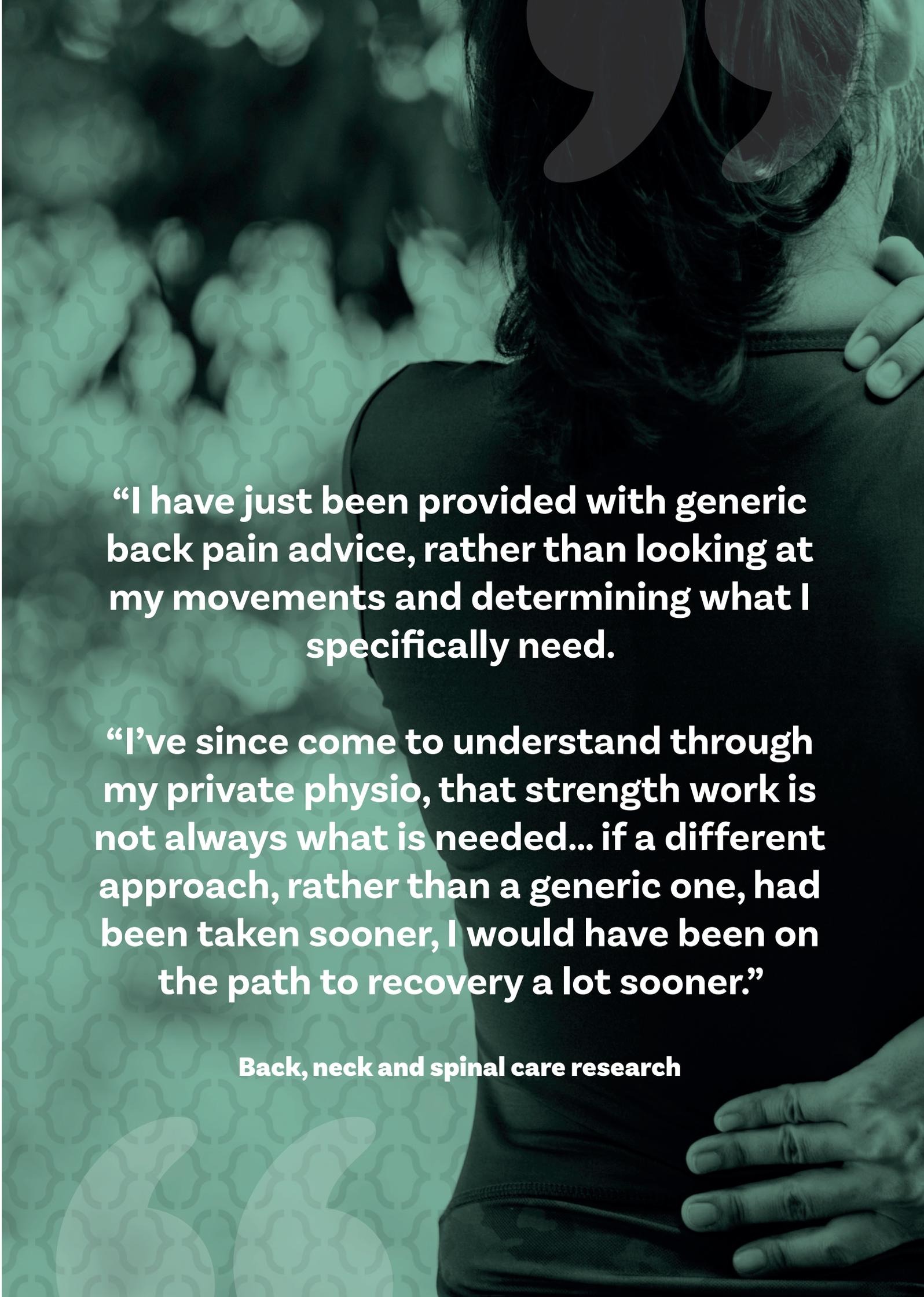
After surgery, experiences of pain control were mixed. Many praised surgical care, but some reported difficulties accessing adequate pain relief during inpatient stays. A small number felt pain relief requests were ignored or poorly managed. Concerns were also raised about being discharged while still in significant pain.

Unmanaged or persistent pain had an emotional and functional impact. People described fear of flare-ups, sleep disruption, reduced mobility, financial strain from private treatment, and anxiety about it getting worse.

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“Had a lovely physio from AHPS. She properly listened to the problems I had been experiencing with my neck for some time, and was the first person to give me proper exercises with guidance on how to do them. I then had a follow-up appointment where she gave me further exercises. The difference has been amazing.”

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“I have just been provided with generic back pain advice, rather than looking at my movements and determining what I specifically need.

“I’ve since come to understand through my private physio, that strength work is not always what is needed.. if a different approach, rather than a generic one, had been taken sooner, I would have been on the path to recovery a lot sooner.”

Back, neck and spinal care research

Key learning from our insights

In systems and services under significant pressure, and with so many people waiting for treatment, pain is an increasing concern and a significant public health issue.

In fact, chronic pain is thought to affect between one-third and one-half of the population of the UK, corresponding to just under 28 million adults and millions of GP appointments each year.

It may therefore be important to view pain as a silent epidemic; a growing concern resulting from increased need and reducing capacity in our health and care systems.

Taken together, the combination of insights from the Healthwatch Suffolk Feedback Centre and research projects by Knowing Works CIC offers some useful points worthy of further reflection by commissioners and decision-makers in NHS services.

Notable trends are outlined below.

Pain can affect all aspects of people's lives

People in pain need holistic treatment that can support them in all aspects of their lives.

Systems and services need to recognise that pain is not something that exists on the peripheral of people's lives – instead, it can be a constant depriver of factors that enrich lives and contribute to positive wellbeing.

This includes that it isolates people from friends, family and vital community support, reduces mobility and therefore access to green spaces and exercise, and can force people into

financial uncertainty. It can deprive people of sleep, influence eating habits, and have severe consequences for people's mental health (generating anxiety and, in some cases, suicidal ideation where pain may be particularly extreme and relentless).

Addressing the impacts of long-term pain requires systems to consider holistic approaches that support people in their lives. Those in pain need to be guided to support for all aspects of their lives that may be deeply impacted by their wait for treatment or long-term pain.

Pain can make caring for others unbearably difficult

Family carers are a population group that show vulnerability to the impacts of pain on all aspects of their lives.

Our elective care research has shown that elective care backlogs are both creating new family carers supporting those living in daily pain, and simultaneously disabling those who already have caring responsibilities at home.

Pain affects everyone differently and requires personalised support using a variety of different approaches

People need access to a range of different solutions to manage pain.

A recurring theme in our back, neck, and spinal care research was that people were moved through a standard pathway without feeling that their individual pain experience was fully explored. While many people did improve with physiotherapy, a few felt the exercises were generic, repetitive or ineffective, especially for severe or complex pain.

Some people reported that exercises worsened their symptoms or did not address the underlying problem. A few felt they needed to access private treatment for more ‘hands on’ therapies.

In our research about elective care backlogs, people wanted improved access to pain management support. This was particularly important for those who had experienced multiple cancellations or prolonged delays during their wait. Findings highlighted that people wanted access to alternative pain management techniques alongside traditional medication.

Many respondents were concerned about the long-term health implications of pro-longed reliance on pain medication, while others reported experiencing side effects that limited its effectiveness or suitability.

Pain should be acknowledged and taken seriously

Pain can be a leading cause of disability, but the invisibility of pain may also lead professionals in services to doubt people’s concerns. People want to feel that their long-term pain has been acknowledged and should expect to receive compassionate advice and guidance instead of dismissal.

There is evidence that people feel their pain is sometimes dismissed by professionals working in services. In several cases, people had needed to actively pursue action by services to open pathways to further treatment, or they

experienced variation in the responsiveness of clinicians.

In our research exploring the experiences of people who had used back, neck, or spinal services, several respondents felt the root cause of their pain had not been properly investigated, especially where access to MRI scans had been delayed. In some cases, patients believed earlier imaging or specialist input might have prevented deterioration if their concerns had been acknowledged or acted on.

A number of comments related to maternity and gynaecological services, reflecting informal feedback from our staff in communities that women can often feel dismissed about symptoms, such as pain, in primary care and other services. These are sentiments that are evident in [our report about experiences accessing support for women’s health](#) published in 2024.

Further focus in systems is needed on improving the experiences of women seeking support for gynaecological issues and related pain. We know from our elective care research that this is a group of patients that are at most risk of detrimental impacts to their lives.

Where clinicians feel further treatment or investigation is not warranted, there should be clear information provided about the reasoning for this. Furthermore, people should know when they might reasonably expect a response from services if their symptoms persist – precisely what may be defined as ‘long-term’ pain requiring treatment.

Clinicians should also be equipped with resources to ensure people leave their appointment with adequate signposting to further information and support related to pain and pain management. No pain-related contact with services should complete with an entirely dismissive response.



**Knowing
Works®**

**Because guessing is an
expensive waste**

This report has been created by Knowing Works CIC to shape and influence standards of services and care, and to support delivery of the Healthwatch service in Suffolk.

For more information about Knowing Works CIC, our services, or to make an enquiry of our team, please visit www.knowingworks.co.uk, call **0800 448 8234**, or email info@knowingworks.co.uk.

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