Back, neck & spinal care in Suffolk

Improving patient experience

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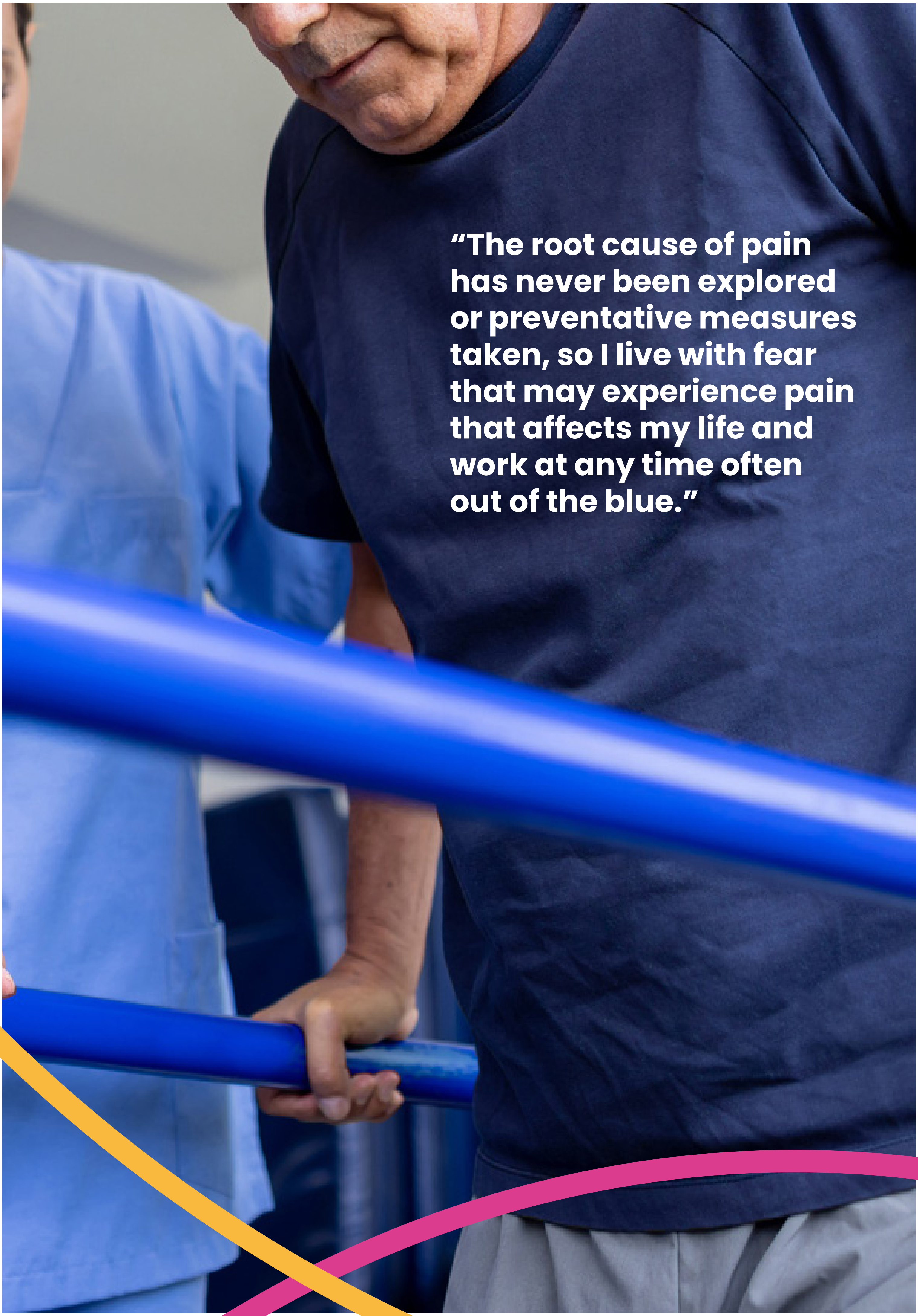


> “The root cause of pain has never been explored or preventative measures taken, so I live with fear that may experience pain that affects my life and work at any time often out of the blue.”

1. Introduction

About Healthwatch Suffolk CIC

Healthwatch Suffolk CIC (HWS) is a social enterprise delivering insight to shape local NHS and social care. We passionately believe that listening and responding to people's lived experiences is vital to create health and care services that work for everyone.

We collect and share lived experience to improve standards of health and social care in Suffolk, regionally and nationally. Our independent role is enshrined in law, supported by trusted data and embedded in local integrated care systems by established relationships with partners.

Our core purpose is to...

collect and share lived experience to influence better standards of health and social care.

We live and breathe...

co-production in everything possible. We are inclusive, transparent, accessible, and accountable. We believe passionately that listening and responding to lived experience is vital to create health and care services that meet people's needs.

www.healthwatchsuffolk.co.uk

Learn more about us and find our insights by visiting our website. You can also call us free on 0800 448 8234 or email info@healthwatchsuffolk.co.uk with enquiries.

About this report

The East of England Spinal Surgery Clinical Network commissioned Healthwatch Suffolk (HWS) CIC to include people and professionals in shaping patient experience of back, neck and spinal care locally. The project is helping the network to prioritise actions to improve people's experiences across services and consider how people's feedback could be collected and shared in the future.

Specifically, the project aimed to address three key objectives:

1. To gather feedback from patients across the spinal network on various pathways to ensure their feedback is included in the shaping of the network's work plan;
2. To establish where patients are already engaged in services, and how this can be further utilised and improved;
3. To consider how feedback could be regularly captured within the network, and to understand how this can contribute to service development.

Each one of these key aims is related directly to the following report sections:

1. The results from the patient engagement survey are presented in section one, which details patient feedback about the pathway;
2. Section two details current efforts within the spinal network to elicit feedback from patients and carers, as well as factors identified as perceived barriers and enablers of patient engagement work. It includes responses from:
    I. Interviews and focus groups with ten staff and professionals working in key services, focussed on common themes in patient experience and their view on the key barriers and enablers to patient feedback and engagement work;
    II. Ten short interviews with patients, focussed on their view of how patients would like to be involved in patient engagement and feedback work;
    III. Two detailed interviews with spinal cord injury patients about their experience.
3. Section three functions as the recommendations for the report, reflecting on how spinal services and the network could consider capturing feedback more regularly in the future. It provides broad principles to guide patient engagement and feedback work and ensure such activities are meaningful and achieve change.

How people's experiences were gathered

The project was completed in two phases.

The first phase sought to informally engage staff and stakeholders across the network in discussions about how people's experiences were already being gathered by services. This enabled staff to reflect upon some of the enablers of patient engagement in services, as well as key challenges and perceived barriers. Professionals were also able to inform and influence this project by sharing a perspective on their understanding of key patient experience issues people were likely to reflect in their feedback.

Staff engaged during this phase of the project included:

- Nursing staff at the East Suffolk and North Essex Foundation Trust (ESNEFT);
- A representative for the Spinal Injuries Association;
- A representative for Allied Health Professionals Suffolk Back and Neck Service (AHPS);

- A representative for MRI services at West Suffolk Hospital.

During this initial phase of the project, HWS CIC staff also undertook specific activities that would help us to engage patients appropriately in the research. This included a dedicated session with local charity Survivors in Transition (SIT) regarding trauma-informed practice in engagement. Informative conversations were also arranged with colleagues in Healthwatch Essex, which has completed considerable focussed work on trauma.

From this activity, we were able to embed and check engagement plans against specific resources provided by SIT and recommended best practice. Specific principles of trauma informed practice were embedded into our approach and the way in which engagement of patients was planned and carried out by HWS staff.

The second phase of the research aimed to gather the experiences of people who have used back, neck or spinal services across Suffolk.

A mixed-methods approach was adopted to ensure people could participate accessibly in the project. This included both digital and face-to-face methods of collecting feedback, including:

- A patient engagement survey hosted on the Healthwatch Suffolk website and available in alternative formats (such as easy read or large print);
- Hard copy surveys distributed in communities by Healthwatch Suffolk staff as well as back, neck and spinal service providers;
- Interviews and follow-up conversations completed in person or by digital means;
- Engagement by HWS Engagement and Community Officers in service environments and communities.

It was not feasible to design a single survey that could ask detailed questions about each service across the spinal care pathway due to the variety of services people may access. Therefore, a general survey was adopted to gather people's experiences. This ensured people had flexibility to describe what they viewed as the most important aspects of their experience, whilst avoiding the need for a lengthy routed survey that would have hindered response rates within the project. People could also indicate their consent to participate in further interviews or follow-up phone calls with HWS CIC researchers to explore the nuances of their experiences.

Beyond the report

It is encouraging that the spinal network has sought to bring independence into its decision-making regarding patient experience priorities and has committed support to local Healthwatch in the process. This shows a level of determination to embed a positive culture of listening to patients and carers into the network and to ensure services provide care on a foundation of lived experience.

Ultimately, listening and responding to patients and carers is the only way to truly ensure services are meeting people's needs effectively, and not just the needs of the services or systems within which they operate. It will require an ongoing commitment to co-production, engagement and meaningful patient experience across the network. The commitment of professionals in the network to support this project is certainly a positive indication of a willingness to account for people's experiences in delivering the highest possible standards of NHS care.

It is hoped that this report will help to inspire the development of further patient experience initiatives, both locally and regionally. The recommendations and principles discussed represent useful learning for services across the network. However, it is important to note that the volume of experiences gathered is unlikely to be fully representative of all back, neck or spinal patients. Nevertheless, the themes explored may resonate with those of patients accessing services in other areas.

Healthwatch Suffolk CIC hopes to maintain a proactive relationship with the network and to communicate its response to this report.

With thanks to the East of England Spinal Surgery Clinical Network and every person who has participated in, or supported, this project.

2. Patient engagement survey results

This section summarises the key findings from the engagement survey, which gathered 126 responses between September 2024 and January 2025.

While the survey included both quantitative and qualitative elements, the primary insights are drawn from the free-text responses. In them, patients shared detailed accounts of their experiences. These narratives provide a deeper understanding of what patients perceive as the challenges, concerns, and positive aspects of their care.

Therefore, this section aims to answer the following key questions using survey data:

- What are people's current experiences of spinal services?
    - What might be a priority for future engagement?
    - What are people's experiences across the whole pathway, and are there any gaps between services?

Demographic (in brief)

Of the 91 respondents who provided their gender, 73% (66) were female and 25 were male.

Of the 81 respondents who provided their age:

- 11% (9) were aged between 20 and 39.
- 35% (28) were aged between 40 and 59.
- 43% (35) were aged between 60 and 79.
- 11% (9) were aged between 80 and 89.

All 74 respondents who provided their ethnicity identified as white/ white British.

Services accessed/ timeframe

Respondents were asked:

1. 'Which spinal services or care would you like to tell us about?' with a drop-down list of options, as well as a free-text box, and;
2. 'Roughly, when did the main part of this experience take place?'

However, it should be noted that their selections did not always align with the more detailed insights provided in their free-text feedback.

Respondents said they had contact with the following key services:

- 74 had accessed physiotherapy through either AHPS or ESNEFT;
- 35 had experience of surgery at ESNEFT;
- Four had an experience of spinal cord injury;
- 29 had experience of outpatient appointments at ESNEFT;
- Other services included diagnostics or scans at ESNEFT (20) or West Suffolk Hospital (15).

Most experiences (67%) had occurred within the last year. Respondents to the survey said their experiences had taken place within the following time frames:

- Very recently [Less than six months ago] - (63, 51%)
- Recently [Six to 11 months ago] - (20, 16%)
- A long time ago [One to two years ago] - (17, 14%)
- A very long time ago [More than two years ago] - (22, 18%)
- I don't know - (2, 2%)

67% of respondents said they were commenting about a recent experience that took place within a year of completing the survey.

Services used	Count
Physiotherapy (AHPS & ESNEFT)	74
Surgery at ESNEFT	35
Spinal cord injury	4
ESNEFT outpatient appointments	29
Diagnostic scans (ESNEFT)	20
Diagnostic scans (WSFT)	15

Table: Responses reflected on a broad range of services involved in people's care.

Interpreting the findings

Comments and experiences were extremely diverse and, in many cases, complex. Overall, the aim was to engage patients about their experiences across the whole pathway and, as such, comments tended to refer to multiple services and multiple issues.

Experiences were analysed using a process of qualitative coding, which involved organising and labelling written (free-text) information into key themes and sub-themes. The first step involved thoroughly reviewing all comments multiple times to identify recurring patterns. Similar ideas or concepts were grouped into 'sub-themes' and further grouped into broader 'main themes', describing overarching concepts.

Comments were also assigned a sentiment code, based on whether the respondent was expressing a positive, negative or mixed attitude or opinion on a topic.

Three main themes emerged from the data, incorporating multiple sub-themes (shown in the theming framework diagram overleaf and summary table below). The three main themes were:

1. Engagement* and involvement
2. Access and referrals
3. Treatment and care

*Note that 'engagement' in this context means the patient being an active participant in their treatment and care. It does not refer to taking part in 'patient engagement' or feedback activity.

There is limited independent feedback on patients' experiences of the spinal care pathway. This report aims to address that gap by summarising how patients described their experiences to inform future approaches to patient feedback and engagement.

Theme/Sub-theme table summary

Overall, 120 patients commented about their experiences. The table summarises the total number of positive, negative or mixed sentiment mentions of each sub-theme in the coding framework.

Theme / Sub-theme	Positive	Mixed	Negative	Total
Engagement and involvement				
Staff attitudes	26	1	1	28
Listened to, understood & involved in decisions	41	3	10	54
Access and referral				
Understanding pathways & referrals	14	2	23	39
Waiting times	6	0	13	19
Treatment and care				
Effectiveness of treatment and care	37	6	17	60
Receiving accurate or expected diagnosis	1	0	16	17
Ongoing care after an operation & inpatient care	11	1	5	17
Long-term impact or outcomes	10	0	18	28

Key theming questions

Three main themes emerged from the first stage of qualitative coding, inclusive of multiple sub-themes. These key questions guided the interpretation of people's comments.

Did the treatment they received meet expectations?

Did they receive a diagnosis they were happy with?

What was the long-term impact on them of their experience? Do they mention any other impacts on aspects such as their health, mobility, or work?

Did they receive adequate support post-operation or during an inpatient stay?

How have staff engaged and involved them in their treatment and care?

Did they feel staff held positive attitudes? Were they friendly, professional, or reassuring?

Were they directly involved in making decisions about their care? Did they feel listened to, or understood?

What was their experience of the process of accessing or being referred between services?

Did they feel that their wait time was appropriate?

Did they understand what services were available to them and how to access them?

Have they been able to access the services or treatment they expected?

Theme one: Engagement and involvement

Overall, people's opinions of being engaged and involved in their care were largely positive.

A total of 63 people made references to engagement and involvement in their feedback, with comments falling into two main sub-themes:

- The attitude of staff and professionals involved in their treatment (28 mentions);
- Feeling listened to, understood and involved in decision making about their care (54 mentions).

Note: some respondents left comments that fit into both sub-themes, hence the total count of the sub-themes (82) is greater than the number of respondents who referenced the theme of engagement and involvement within their feedback (63).

Sub-theme: Staff Attitudes

Twenty-six patients were positive about the attitude of staff involved in their care.

Fifteen of these comments were about staff attitudes during an experience of surgery at ESNEFT. Eight of these comments referred to Allied Health Professionals Suffolk (AHPS). There were also two comments about a pre-operation consultation and one about receiving a spinal injection at ESNEFT.

These comments referred to a wide range of professionals, including consultants, physiotherapists, spinal nurses, receptionists and ward staff.

- Patients often described staff involved in their care as 'friendly', 'professional', 'kind', or as having treated them with 'respect'.
- Some felt staff were 'reassuring', 'patient', or made them feel 'relaxed' when providing their care.
- Other common descriptions included staff being 'helpful' and treating people with 'compassion'. Some simply said staff and professionals had been 'excellent' or 'outstanding'.

It was clear that many respondents had been grateful for the treatment they had received.

Examples of positive quotes from patients about staff attitudes included:

> *"My experience was excellent. They looked after me very well, no complaints. Super team. They work very very very hard around the clock, non-stop... They care about their patients and take time. With a lot of responsibility, they do a fantastic job."*

> *"Respectful and reassuring. Took time didn't feel rushed."*

> *"Friendly receptionist at the appointment and modern, clean facilities. Professional clinicians, and very reassuring during detailed appointment. I was seen by someone who was in training but had full support of a fully trained colleague. I was given exercises, and also had the option to revisit if the problems persisted. Overall, an excellent service."*

There were two negative or mixed comments about staff attitudes. Both comments were about inpatient care at ESNEFT. They referred to staff being 'uncaring', 'rude', or their 'bedside manner'.

> *"Mixed review of care in Ipswich hospital. Some sadly uncaring, and very rude, staff."*

> *"Poor experience overall. Staff lacking in care, compassion, and bedside manner."*

"The staff were incredibly kind, caring and patient. They could not do enough to help. I will be forever grateful for their kindness and compassion."

Sub-theme: Feeling listened to, understood, and involved in decision making

Forty-one patients were positive about being meaningfully involved in their care. This included that they had felt listened to and understood.

- Seventeen respondents received good 'explanations' or had their treatment explained by staff. Several felt well 'informed' or mentioned staff had been 'informative'. A couple of respondents said staff followed-up and did what they said they were going to do.
- A small number felt 'listened to' or said they had been treated with 'understanding'.
- Some people gave direct examples of how they had been enabled to make decisions about their care, such as whether to proceed with surgery.
- One spinal cord injury patient emphasised their continued involvement in decision-making and felt their family had been updated about their care during their stay at ESNEFT. They credited multiple professionals for providing them with good care. However, they did note that they had felt 'rushed' during their discharge and had worried about how they might cope at home because of this. Their comments are shown in the highlight box below.

There were positive comments about feeling engaged, involved, listened to and understood across both AHPS and ESNEFT services.

Some examples are shown below.

> *"Awesome experience. Every nurse, doctor and receptionist I have met has been friendly, helpful and welcoming. I have always been fully informed at each stage of my treatment, always had any questions answered in detail and have come away feeling positive about my upcoming surgery. I have been under spinal care since 2021, and have been treated with the utmost care. I understand the time constraints as the NHS as a whole is just so busy, but because I've been kept informed, I've been happy (with pain relief!) to wait. I really can't praise the spinal department enough. I saw a male nurse today, he was very thorough in taking me through what happens next and answered all of my questions in such a knowledgeable, friendly manner."*

> *"Had a lovely physio from Allied Health Professionals. 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, and I also now understand what I was doing that was making things worse. I wish I'd had the appointment earlier. She was knowledgeable, kind and considerate. I also didn't have to wait long to see her, which was a big plus."*

Some (13) respondents offered a negative, or mixed, experience of being listened to, engaged or involved in their care:

- General comments about not feeling listened to and understood most often related to whether patients felt able to access the treatment they expected or which met their needs. For example, some patients referred to feeling 'ignored' or told 'nothing was wrong'. These comments related to both ESNEFT and AHPS services.

For more information about access to services, see the section on access and referrals, on **page 16.**

- One respondent (see right highlight) felt their treatment had not been effectively tailored to address their individual needs. They had received advice from AHPS and their GP surgery to do strength work for their lower back pain. However, they had found this 'generic' and not tailored to what they felt they needed specifically. This patient sought private treatment for their lower back pain and the subsequent advice they had received conflicted with that received from the NHS.

> "I have suffered with central lower back and left hip pain since December 2022… I've felt that with the GP and Allied Health Professionals, 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."

> "I was initially treated within A&E and then transferred and admitted to the trauma ward in Ipswich to be treated and cared for by the spinal team, due to severe injury to my back, neck, ribs and spinal cord. I was pretty poorly at this time, but when conscious I was updated, and my partner was very much involved in any decisions and updates provided.
>
> "I spent eight weeks in hospital to be stabilised and to ensure I was well enough for planned surgery to my neck and back. The care I received from multiple professionals within the spinal team and ward was incredible. I knew day-to-day what was happening, and the only time this was challenging was due to staffing shortages. I never felt like my care suffered because of this.
>
> "When I was readmitted to hospital for planned surgery to my neck, the support, communication and care was exceptional. The only issue I had was how quickly they wanted to discharge me post-surgery. It felt a little rushed, and although I could go home, I was very worried I may not be well enough or able to cope.
>
> "I know I can contact the team with any concerns if needed. Overall, I have been very happy with the care provided by ESNEFT and specifically the spinal team."

- One respondent described how the system of referral into AHPS had impacted their feeling of being listened to and understood. They felt that they would have liked the opportunity to speak to a professional about their issues when they were self-referring.

  They also noted feeling that the system required them to focus on one issue, preventing them from effectively explaining three interconnected problems to the service.

Quotes from patients about a negative experience of being engaged or involved in their care are shown below.

> *"Had to push to get scans as kept being told nothing was wrong, turns out got disc degeneration neck and lower back. Just left to adjust life myself."*

> *"I felt ignored and not taken seriously by AHP."*

> *"I have hurt my back and have a sore hip. I completed the self-referral form and have been given some useful information and exercises to complete for two weeks. If I am still in pain (I am) at the end of two weeks I can see someone. Whilst I understand the need to triage… I was disappointed that I did not have the opportunity to speak to, or see, someone. The system is also quite rigid in that it wants you to only deal with one problem… I think I have three different issues that may or may not be interconnected. It would have felt more empowering to have had a conversation."*

Watch: Jaime's views

Jaime had a horse riding accident, resulting in serious injury to her back, neck, and spinal cord. In this video, she reflects on just some of her experiences of long-term spinal care and things that could improve her experiences.

Jaime has spent many weeks receiving acute hospital care, with support from a range of services (e.g., physiotherapy, radiography and more). Her experience is complex, but she feels there are things that could improve experiences for people facing similar trauma in the future.

Short highlights (4 minutes)

Full video (8 minutes 20 seconds)

Theme two: Access and referrals

Patients were often negative about their access to care and processes for referral.

Overall, 52 people made references to access and referrals in their feedback, with comments falling into two main sub-themes:

- Patients' understanding of the pathway and systems for referral (39 mentions);
- Waiting times (24 mentions).

Note: some respondents left comments that applied to both sub-themes, hence the total count of the sub-themes (63) is greater than the number of respondents who referenced the theme of access and referrals within their feedback (52).

Sub-theme: Understanding the pathway and systems for referral

Within this theme, there were twenty-three negative comments about people's understanding of the pathway and how to access treatment and care. Comments generally focussed on two issues:

1. Some respondents felt unable to access the diagnosis or treatment they wanted or expected;
2. Some respondents had experienced issues or breakdowns in communication on referral between services.

Positive comments about understanding and accessing the pathway were most often related to experiences of quickly and easily accessing an MRI or other diagnostic scan, or described a positive experience of self-referral to AHPS.

1. Patient expectations and criteria for accessing treatment

Sixteen patients reflected that they had not understood the criteria to access further treatment or care, or had expectations for their treatment that were not met by services. Some felt they had not met the 'threshold' or were not 'bad enough' for treatment or referral.

Many of these experiences of accessing services were complex, with some spanning multiple years and various contacts with different professionals and services. Some felt services had missed opportunities to address or investigate symptoms, leading to what they have viewed as poor management of their condition and deconditioning that could have been avoided.

- Nine patients felt their needs were not adequately met due to a lack of onward referral or limited access to specialist care. This feedback did not just refer to one stage of the pathway.
- Two respondents had never received any onward referral from their treatment with AHPS to the spinal team. One said they were currently under pain management but emphasised the amount of pain they were still experiencing. Another had chosen to see a chiropractor and been prescribed gabapentin by their GP.
- One person said they experienced 'multiple missed opportunities to act sooner' and that there was a 'lack of neuro physiotherapy'.
- One person was accessing pain management services following a 'failed spinal fusion'40 years ago. They said referrals were 'historically hit and miss or looking at the wrong problem' and that they had received 'no onward referrals to spine specialist services'.
- One person had received an operation ten years previously, but their condition had recently worsened. They felt

there was 'no chance of a hospital appointment' and suggested no more options for treatment were available.

- One person said they had been trying to access treatment for scoliosis and kyphosis over a ten-year period and felt 'dismissed', 'ignored' and not 'bad enough' for treatment. They had received treatment from AHPS and pain management services, however they felt it had been ineffective. They were offered a 'corrective operation' when they attended Addenbrookes and felt 'neglected' and 'disappointed' about the offer from NHS services in Suffolk.
- One person had a negative experience of accessing support from their GP practice for a spinal condition. They said an Advanced Nurse Practitioner at their GP surgery had not taken them seriously and had not made any referral for further treatment or diagnostics. They had accessed an MRI privately. Although GP surgeries are not part of the spinal pathway, the patient felt that this was the key barrier preventing them from accessing spinal care.

Examples of quotes from patients about a negative experience of being able to access a referral or treatment which met their needs included:

> *"The whole system. I'm 29, I've been suffering with back pain for three years. I'm in agony every day, and no one knows what's causing it. I'm being told to pace myself and deep breathe. I can't even walk straight; it keeps me awake at night. I can't do anything. I don't think I'll ever be able to carry a child through pregnancy or afterward. I spent a year under Allied and they never gave me any physio. I've never even seen a spinal expert in Ipswich Hospital, just a senior allied health professional in Eye. I'm now under pain management, which has also been no help. My pain is constant 24/7 and never subsides."*

> *"My experience spanned over 10 years, trying to get treatment for a scoliosis and kyphosis. Overall, I was very disappointed with how I was treated. I felt dismissed, ignored and like I wasn't 'bad enough' for treatment. I was required to jump through so many hoops to be let down at every turn. My last resort was visiting Addenbrookes, where I was offered a corrective operation in my very first consultation - after 10 years of neglect in Suffolk. The services I used in Suffolk included: Physiotherapy (Allied)- the physiotherapist never even touched me or manipulated anything. All they did was simply give me a piece of paper with exercises. Pain Management Clinic - where they told me pain was all in my head and if I controlled my mind my pain would stop."*

> *"Visited my GP Surgery due to new symptoms I believed to be due to a deterioration in an existing spinal condition and was concerned about the particular way the spine may have deteriorated. Did not get to see a GP, only an 'Advanced Nurse Practitioner' who said they did not think it was anything related and, as I could still walk, didn't believe any further assessment was needed. I asked for a private referral for MRI to assess the deterioration. It resulted in an additional diagnosis to the original condition, which itself has brought the need to manage my back pain in a more considered way than previously. Had I not had this MRI, I could have caused my spine more damage than necessary and resulted in the need for a more frequent pain medication or worse. I did not feel like my GP surgery took anything seriously, or that I might have some knowledge about how my back pain had changed. I did not get to experience NHS services beyond this, despite it actually being quite crucial to understand the changes and how to manage the two conditions I now have."*

> "I have suffered with back pain for around 15 years. During this time, I have been seen at pain management and been offered and taken up various procedures including nerve ablation, root blocks etc. None of these have been successful.
>
> "Despite me asking many times about having an MRI, I was never offered one until about two years ago when I saw a different consultant who listened to what I was saying and suggested I may have a spinal stenosis. An MRI then confirmed this and I was referred to the spinal team, which I am now under. Moving forward, it looks like at some point I will need surgery…
>
> "My thoughts are though, around the 12 years that I was not offered an MRI, my back has declined over the years to the point I can now only walk a few yards without needing to stop. I cannot stand for more than two minutes. Also, the cost of the procedures I had, which I have now been told would not have made any difference to the stenosis. If I had been offered an MRI during that 12-year period then would I be as bad as I am now?"

Seven patients raised concerns specifically about their understanding of how to access an MRI scan on the pathway.

- One person, who had accessed multiple services (including pain management) over 15 years, had not been offered an MRI until two years ago. The MRI indicated they may have spinal stenosis, and they were subsequently referred for surgery. However, they felt their condition had declined due to this delay in accessing treatment.
- One patient talked about experiences of accessing services across 15 years (see highlight box above). Until recently, they had not felt involved in their care from physiotherapy services and the ESNEFT pain management service. Since they were offered an MRI scan within the last two years, this had changed and their consultant had now indicated they may require surgery. Their view was that if they had been 'included and listened to' sooner, they may have accessed an MRI earlier and may not have suffered as much pain or decline in function. Their comment is shown below.
- One person was told during their treatment at AHPS that scans were 'not on the pathway'. Another had experienced both AHPS and outpatient treatment at ESNEFT and felt they had needed to 'push' to access an MRI.
- One person commented that they had attended appointments with three different physiotherapists before receiving a referral for an MRI.
- One person was negative about the wait time to access MRI and to get a diagnosis that met their expectations. Their MRI was completed in three months from referral from the AHPS Back and Neck Service (BANS). However, they noted that 'within a day' they were then booked in for an urgent nerve root block. They said that the nurse at pre-assessment had been 'amazed' at the delay in their diagnosis.
- One person had a fall and said the West Suffolk orthopaedic clinic had 'taken months to acknowledge [their] pain'.

They received an MRI and were referred to the ESNEFT MDT. They required further nerve conduction tests. When they attended a follow-up appointment for their nerve conduction, their consultant showed them their MRI and informed them that they would require surgery to 'prevent progression of SCI'. This highlights a lack of consistency in advice and interpretation of MRI that the patient received across multiple services.

Negative quotes about access to an MRI scan are shown below:

> *"It took a very long time to get the scan required to get a correct diagnosis. I was told at the time that X-rays and scans were not on the pathway. This inevitably led to increased pain for me, three sets of exercises that made the condition worse."*

> *"Initial diagnosis at West Suffolk orthopaedic clinics following a fall and shoulder injury. They took months to acknowledge my pain. When they finally offered an MRI, I was called back the same week for a C spine MRI. I wasn't told much and referred to spinal back and neck service. I was seen by a specialist physio who took my symptoms and reported/presented my case, I believe at Ipswich MDT. Months later, I finally have an appointment to see a spinal surgeon… Months later, I am seen again. Greeted by same physio. She asked about symptoms, unchanged in great deal of pain still between shoulder blades and left arm. Immediately said I think we need an x-ray of your back, but that she would speak to a consultant. Within a few minutes, she returned and proceeded to explain I needed major surgery. I asked to speak to a consultant. He told me not to fall over as I could become paralysed. He showed me my MRI and explained about the surgery he could offer. My choice about going ahead. No guarantee of pain relief, but would hopefully prevent progression of SCI."*

2. Patient expectations and criteria for accessing treatment

Eleven comments were negative or mixed about their experience or understanding of the communication between services and the process for referrals. In some cases, it appeared that a referral had broken down or not been followed up, resulting in a negative experience.

This has been highlighted as a common problem by the Healthwatch network, which has called for national change and improvements to NHS administration. Healthwatch England's recommendations for the NHS about referral communication for patients includes:

- Communications must meet the requirements of the NHS Accessible Information Standard – This is to make

> "I never felt very involved (except for now under the spinal team). I felt that I had to follow a system and was told what was happening and what could be offered. If I had been included and listened to, I would have had an MRI scan way before I did. I felt on a conveyor belt where everybody was treated in the same way, physio first, then pain management, then usual procedures, then told nothing more can be done from pain management, referred to spinal team."

sure communications are not missed and are understood by people living with a disability or sensory impairment;

- Communications must be transparent - All parties should have access to the same centralised information about which stage of the referral process the person has progressed to;
- Communications must be collaborative - As well as improving channels for the NHS to update patients about their referral, patients must also have access to care navigators in general practice and a single point of contact at their hospital (or another referral setting). This is so patients can give feedback about their condition while waiting for care, including whether they need to cancel or reschedule appointments or quickly chase up a referral if they have not received information about its progress.

Learn more about this national research at https://www.healthwatch.co.uk/blog/2023-02-16/referrals-black-hole-new-findings-peoples-experiences-gp-referrals.

Problems with referrals highlighted by our respondents included that:

- One person had not heard back from the pain management service for two years following a referral by AHPS. It was not clear whether they were referring to WSFT or ESNEFT pain management services;
- One said their request for an X-ray had been lost when they were referred from physiotherapy to WSFT;
- One had received no contact from the spinal team at ESNEFT following an MRI, despite having been referred by AHPS;
- One had received treatment from AHPS. When their sessions ended, they had been referred for further treatment and did not receive an appointment. They chased, and were told that someone would call them back, however ‘gave up’ when they did not receive a response;

> **“I was referred for physiotherapy for my severe back pain... I was told that I would be referred to a pain clinic, that was over two years ago, still waiting so I am not impressed at all.”**

- Two comments made negative observations about the referral system to ESNEFT between their GP and AHPS. They said a referral to the hospital from AHPS required them to go back to their GP, who would then refer them back to AHPS, who would then refer them to the hospital. Both noted the unnecessary duplication of appointments and the potential impact on capacity or cost to the system;
- Three people implied that, despite presenting at their GP surgery with a back neck, or spinal issue, they had not received a referral or signposting to AHPS.

Examples of quotes from patients about issues regarding referral, or problems with communication and processes for referral, are shown below.

> *“Request for X-ray lost, so delay. Long wait to see hip surgeon. Lack of coordination between hip and spinal specialists. Agreed no surgery but problem not resolved.”*
>
> *“I was advised by Allied Health physiotherapist that I would receive contact from the spinal team but have not received any contact following MRI scans*

> *and results. I only had a conversation with physiotherapist who has been very supportive but would have liked to have received a consultation from the spinal team as to whether anything further could be done for my continued downward spiral in discomfort since I was last reviewed by the team."*

> *"The need for repeated referrals back and forth between the physiotherapy provider and the patient's GP appears to be a real barrier to a more efficient and effective service! Any process that requires a patient at a physiotherapy appointment - who requires a hospital referral - to have to go back to the GP and that GP to then refer the patient back to the physio provider in order that the referral can then be extended to the hospital is clearly broken. Indeed, it creates more demand on the doctors' time and of course duplicated appointments at both the GP and the physio - I guess someone is being paid by the number of appointments undertaken…."*

> *"I did not have confidence in the GP's ability to deal with my back and hip problems, although they did agree to an x-ray being done. They spoke to me about needing strong painkillers, which I refused as I wanted to understand and treat the back problem, not simply medicate it. The GP did not signpost me to self-refer for physio. A colleague at work told me I could do this."*

Positive comments about understanding the pathway and referral process

Fourteen respondents were positive about being able to quickly and easily access services on the pathway. These included:

- Ten comments about being able to quickly access MRI services or other diagnostic scans like an X-ray. These included being referred from AHPS and one from WSFT Accident and Emergency department;
- Three were positive about the process for booking appointments or self-referral to AHPS. This included that appointments were easy to book and that people had been seen quickly after their initial referral. One person said they had found their appointments with AHPS easy to book and access online, and that their appointment had been conveniently local to them;
- One person was positive about their referral to a spinal specialist because their consultant had read and understood their notes and history.

Examples of positive quotes from patients about their understanding of the pathway and referral process are shown below.

> *"AHP referred me to the Spinal Unit where examined me thoroughly and following useful discussion arranged for me to have an MRI scan of my spine soon afterwards. The scan only showed age related degeneration of my spine and the issues I'd had which could have been related to my spine had diminished somewhat since I'd stopped physio exercises related to arthritic knees so 'no further action' was required."*

> *"Physiotherapy from Allied Healthcare was excellent as well… The appointments were easy to book at a time and local location suitable for myself… The second stint of physio and the GP intervention was instigated by me and was easy to access online."*

> *"Speedy appointment from online form and friendly staff booked appointment. I would have liked to be seen locally in Haverhill but had to travel to Bury St Edmunds instead…hence four-star rating only for this reason."*

Sub-theme: Waiting for services

Thirteen respondents were negative about their wait for spinal services. Comments referred to waits at all stages of the pathway.

- Five were negative about a wait for surgery. Two cited long waits of one to two years. One said their operation had been cancelled three times due to strikes. Two had been aware that their consultant had a 'backlog' of patients. As a result, one person had decided to have their surgery privately due to extreme pain. However, many of these patients were otherwise positive about the care they had received, or their outcomes from surgery.
- Three respondents faced long waits in other areas of the pathway, for example for injections prior to surgery, for x-ray results, or an initial appointment.
- Three specifically said they had faced a long wait for an initial appointment, or that their appointment was 'overdue'. One said their MRI was considered out of date because of a long wait to see a consultant. This meant they had required another scan before being able to access their appointment.
- Two people had waited longer than expected for an injection. One 'had to wait so long for the appointment date that the sciatica recovered on its own' a week before their injection was due.
- Two comments about waiting times for physiotherapy were negative. One mentioned the wait time for AHPS, while another had faced a wait both to be referred to the Back and Neck Services (BANS), as well as for a spinal injection.

"I was seen by specialist physio… Months later I finally have an appointment to see a Spinal surgeon. [Consultant] showed me my MRI and explained about the surgery he could offer. My choice about going ahead. No guarantee of pain relief but would hopefully prevent the progression of SCI. I was given a leaflet and told I'd be added to the waiting list. Again, months passed and finally got surgery date."

"My longest bout of sciatica was 18 months. After about 8 months I was booked in for a back injection at Ipswich hospital… I had to wait so long for the appointment date that the sciatica recovered on its own a week before my injection was due, so again, that service was useless like the physio."

"Physiotherapy services generally have been poor, with long waits for an appointment (even using self-referral)."

There were six positive comments about wait times to access physiotherapy. These comments referred to receiving quick appointments post referral from their GP or completing an online self-referral form. One said there had been a quick referral time from AHPS physiotherapy services to the BANS. One was positive about their wait for a spinal injection.

"Relatively quick referral GP to physio."

"Was having physio, but on a visit to GP mentioned new symptoms pain in hands and increasing pain in neck. Was referred immediately to back & neck service. Waited only two weeks."

"Quite a quick time between seeing the physio to being referred to BANS. Clearly explained by physio referred for scan."

“I was disappointed with the Spinal team at the hospital. I was referred for an urgent appointment… and was supposed to be seen within 12 weeks. However, the hospital didn’t get an appointment arranged… by this time my MRI was out of date [and] I had to wait for a second one to be done. I am now waiting for a second appointment with the spinal consultant to follow-up.”

Theme three: Treatment and care

Feedback about treatment and care across the spinal pathway was mixed.

A total of 58 people made references to treatment and care in their feedback, with comments falling into four main sub-themes:

- Effectiveness of treatment and care (60 mentions);
- Ongoing care after an operation and inpatient care (18 mentions);
- Receiving an accurate or expected diagnosis (17 mentions);
- Long-term impact or outcomes from treatment and care (28 mentions).

Note: Some respondents left comments that fit into more than one sub-theme, hence the total count of the sub-themes (123) is greater than the number of respondents who referenced the theme of access and referrals within their feedback (58).

Sub-theme: Effectiveness of treatment and care

Positive experiences

Patients were generally positive about the treatment interventions they had received (for example surgery, an injection, physiotherapy advice and exercises). Some more general comments referring to good 'care' were also included within this sub-theme.

In total, 37 respondents made positive comments about this sub-theme.

Physiotherapy services

There were 12 positive comments about an experience of receiving treatment and care from physiotherapy services:

- Some comments were quite general, indicating they had received physiotherapy for general back pain, and their condition improved;
- Positive experiences were also noted by people with more complex needs. For example, one person said the pace of treatment during rehabilitation from a spinal fracture had suited them. Another had received ongoing support with a clear route to contact AHPS for support with spinal stenosis. They said AHPS were '100% supportive';
- Two respondents were positive about exercises they had been prescribed. The first felt they were listened to and given guidance on how to complete exercises, commenting that 'the difference has been amazing'. They now understood more about how they were making their pain worse. Another respondent felt exercises had 'much improved' their movement;
- One said their physiotherapist has been helpful in making suggestions and recommending adaptations (such as lumbar support) for them.

Examples of positive quotes about the effectiveness of treatment from physiotherapy services are shown below.

> *"Lower back concern - self referred and seen by physio within three weeks. Advice was given and then followed up by an appointment four weeks later, I'm now better."*

> *"I visited the physio twice within a 10-week period. The physio knew me as had previously given me treatment for something else one year ago. I felt involved in what she recommended and at the first appointment I was asked in detail about what I had tried before accessing physio. I was given clear guidance and an indication of what my recovery period could be. She also suggested adaptations I could make such as using a lumber support or advising how I could make time to do the stretches she suggested."*

> "Physiotherapy from Allied Healthcare was excellent as well. I received physio as part of my rehabilitation at the time of the fracture and again later on to deal with secondary issues with nerves. The appointments were easy to book at a time and local location suitable for myself. The pace of the treatment suited me as I was keen to get back to full function ASAP."

> *"Allied Health Professionals Suffolk were very caring and supportive. They gave me exercises to do, we discussed that there will never be a cure for my condition Spinal Stenosis and in time things will get a lot worse. Keeping my gentle exercises up will hopefully help me to be more comfortable and upright. They've kept my appointment as an open one so that I'm able to contact them and not have to start from the beginning again. They can discuss with me any further problems/questions and see me for a further consultation. They were 100% supportive."*

East Suffolk and North Essex Foundation Trust (ESNEFT)

There were 26 positive comments about an experience of treatment and care at ESNEFT. Most referred directly to an experience of receiving a surgery or procedure.

Many comments were quite general. For example, six referred to receiving broadly 'good', or 'excellent', care from staff. Many responses also featured positive comments about staff attitudes (for more detail on staff attitudes see **page 12**).

People also discussed positive outcomes from surgery. For example, one person said, ''It went smoothly'. Some simply expressed gratitude for their treatment or procedure.

- Two respondents were positive about the treatment they had received at ESNEFT following a spinal cord injury.
- One respondent was positive about their outpatient consultation at ESNEFT. An MRI showed they needed 'no further action', but they had found their discussion and appointment useful.
- One patient was positive about their experience of pain management. They had a complex experience, having been 'under the care of Ipswich hospital for 23 years'. Their ongoing and current care was from the pain management service, including receiving a spinal cord stimulator. They had experienced 'limited success' from their treatment, but mentioned seminars they had received had been 'incredibly helpful'.

Quotes about positive experiences of treatment and care at ESNEFT are shown below.

> *"From the consultant intervention to the end of my treatment, I received excellent care. The consultant took the time to explain my fracture and how long it would take to heal."*

> *"[Consultant] was excellent, supported by a very dedicated team including the specialist spinal nurse and his secretary. Whilst I had a delay to access surgery, due to backlog, the care given was excellent."*

> *"Needed two discs replaced. Care of the medical team is amazing. Wards clean and all staff friendly and patient. I have been very well looked after from start to finish - physios, doctors, nurses, pre-op, surgeon - everyone!!"*

> *"I was under the care of Ipswich Hospital*

> *for 23 years. I have been under the care of the pain clinic at Ipswich Hospital. Spinal injections were followed by the insertion of a spinal cord stimulator in August 2019. There has been very limited success, but the nurse specialist has been incredibly helpful with pain seminars and the device... [The] team couldn't have done more to help and involve me. The pain clinic has tried to help but have had COVID, extremely long waiting lists, surgical delays, staff shortages to contend with. I was quickly referred to the spinal team with neck issues."*

Negative and mixed experiences

There were seventeen negative, and six mixed, comments about the quality and effectiveness of their treatment and care. Where patients had negative experiences, these most often related to the effectiveness of the exercises they had received from community physiotherapy, and support from the pain management service.

Physiotherapy services

Thirteen patients were negative or mixed about the effectiveness of the exercises they had received from community physiotherapy. These patients often perceived being given exercises as unhelpful, or that doing their exercises had not resolved their symptoms.

Common reasons why patients felt their exercises were unhelpful included:

- Exercises received had a mixed or minimal impact on people's pain or symptoms;
- A smaller number of respondents felt the exercises were not targeted at the right diagnosis or symptoms. Some patients referred to receiving a later diagnosis or treatment from another service or private care that was different to their initial treatment through physiotherapy services;
- Three respondents wanted to receive 'hands on' treatment or care, or had sought private treatment to access this type of care;
- Two respondents had found the exercises they had received 'generic' or had been able to find the same exercises provided by their physiotherapist online.

Negative quotes from patients about the effectiveness of their exercises from community physiotherapy services are shown below.

> *"The Physiotherapy was useless. I had spent 5 minutes looking at exercises online*

"Whilst I am very grateful for the operation I had in the past, I felt at the time the aftercare was very poor and in spite of my difficulties was just pushed aside to get on with it, which I have been doing for the past ten years. Recently, though my condition has worsened, suggestion is that the spinal stenosis may be responsible. I know there is no chance of a hospital appointment, I have done 'the exercises' religiously every day to no avail.

"I am concerned that with the advancement of medical science we are all living longer but it is a painful life to live."

> *before going to Physiotherapy and what they showed me was what I had already found online in 5 minutes."*
>
> *"No long-term solutions given. I have been seeing a private Chiropractor for a number of years but when the back pain is more muscular, I was told by GP to refer to Physio - very basic exercises given that didn't really offer any long term help - no alternative options like deep muscle massage to help loosen the muscles were offered - all this has to be done privately at a cost."*
>
> *"I was referred for physiotherapy re my severe back pain. The exercises given did not help at all."*
>
> *"Minimal help for neck but keep doing the exercises taught. Still experiencing a lot of pain."*

Pain management services

Five comments were negative about the effectiveness of support from pain management services. A couple of comments suggested people had found the information basic or that it did not meet their needs. For example, one person had not found a PowerPoint presentation helpful, and said information about techniques for relaxation and sleep had not helped them. One person was more positive about having received treatment from the service, however they noted that 'nothing more could be done' to alleviate their pain or symptoms.

> *"I have suffered with back pain for around 15 years, during this time I have been seen at pain management and been offered and taken up various procedures including nerve ablation, root blocks etc. none of these have been successful."*
>
> *"The Pain Management Service leaves a lot to be desired and the wait for treatment is far too long. Offering relaxation and sleep advice is helpful to a point but a poor substitute for treatment."*

"The pain clinic doesn't exist and the options for effective pain management are now nil - unless you want to be sent on a pointless course where you sit and watch a power point presentation about your pain. Which I hate to say is simply pathetic and a totally ridiculous form of treatment."

Sub-theme: Ongoing care after an operation and inpatient stays

In addition to comments about the direct intervention patients had received, several people also made comments about the follow-up care they received after their surgery. Eleven comments were positive about experiences of an inpatient stay or ongoing care following an operation. These included:

- Several positive comments about care from nursing and physiotherapy staff at ESNEFT during an inpatient stay. Many of these comments were also favourable about treatment and care provided by the service (see page 24 above);
- One respondent reflected positively on how community physiotherapy had supported their rehabilitation following a spinal cord injury.

Examples of positive comments about care following and operation or during an inpatient stay are shown below.

> *"The spinal nurses and physiotherapy team are excellent. They always had time*

> *for me, I felt listened to and they always came up with solutions for any issues I was facing. They all saw me daily throughout the week to check in and make sure I was OK. I felt cared for and really appreciate what they have done for me. Thank you."*

> *"Too early to assess but the treatment has been excellent all the nurses and physio were very helpful with the caring nature the food in general has been very good as exceeded my expectation of hospital food. A very good hospital thank you to an excellent surgeon."*

> *"Everyone I came into contact with was professional, kind and caring. When I asked for help, I was not kept waiting. The nursing staff were kind and reassuring and did what they said they would do. I cannot in anyway fault my inpatient stay at Ipswich hospital."*

Six respondents experienced a lack of support following an operation. This included that people were unable to access community physiotherapy or further appointments at the hospital. Feedback included:

- Five comments related specifically to support during an inpatient stay at ESNEFT:
    - Two were negative about their access to pain relief as an inpatient following surgery;
    - Four participants shared an experience related to their discharge from the hospital. One felt they were discharged before they were ready, while another felt pressured to get up and walk sooner than expected after surgery. One person wished they had stayed an extra day, and another was unsure if they were ready for discharge.
- Two respondents mentioned follow-up support from community physiotherapy or as an outpatient. Some mentioned both support during their stay as an inpatient as well as in the community or as an outpatient following surgery. One said that they felt their aftercare had been 'poor' and they had to 'get on with it'.

Examples of quotes from patients about a negative experience of support following surgery are shown below.

> *"Once they found how grotty the discs were, I was referred for surgery quite urgently and had the discs replaced and fused. However, post-op support and care was non-existent. The Allied physio services were utterly useless, they made so many mistakes and forgot about me several times."*

> *"Poor post-operative care. Very few follow-ups or routine scans to continue post-op care. Poor experience overall, staff lacking in care, compassion and bedside manner. Pain relief requests ignored as an inpatient. Being denied pain relief for a scan despite attempting to get this in place well before the scan date as an outpatient."*

> *"I don't think I can fault my treatment pre, during and post-op, but I would like to mention I found the physiotherapists who came to see me less than 12 hours after my operation very upsetting. I was in pain as I explained to them, but they insisted I got up and walked about. I was unable to stand up, let alone walk about. They kept insisting I got up. In the end, other patients who witnessed this because the curtains were open asked them to leave me alone as I was upset and in pain. They left saying we will come back later. I understand the importance of getting up and moving after an operation, but I feel this was a little over the top."*

Sub-theme: Receiving an accurate or expected diagnosis

Sixteen comments framed their experience around having difficulty accessing a diagnosis or receiving the diagnosis they expected. These comments included:

- Seven about the consistency of advice offered by various professionals involved in people's care. For example, some received differing or conflicting advice from AHPS physiotherapists. Others mentioned receiving inconsistent diagnoses or advice across different services in the pathway. This included comments about professionals not having access to the correct information or notes, or interpreting scans differently;
- Five comments reflected that services had been unable to provide a diagnosis or help them to understand what was causing their symptoms. Some said they had not been given a clear diagnosis, for example that an MRI scan 'did not reveal anything', or that 'no one knows' what was causing their pain;
- Three respondents said delays in accessing an MRI had contributed to them not being able to access the diagnosis they expected;
- A couple of respondents received a diagnosis that met their expectations after seeking private treatment;
- Many of these comments reflected other themes, particularly access to treatment. This may suggest that patients frame their expectations of the pathway and their care around receiving the correct diagnosis. Once a diagnosis is given, this may affect patient's interpretation of their previous care.

"I had issues with my back many years ago, left hip X-ray taken, paid for chiropractic, podiatrist treatment. More recently, consulted AHP for arthritic knee and hip and spinal issues. They told me there was no curvature issues. More recently, a private physio as well as an osteopath confirmed that I had scoliosis."

"By the time physio appointment arrived pain was reduced but has flared several times since with no particular cause and I have paid privately to be treated by osteotherapist the cost of this causes financial difficulties. The root cause of pain has never been explored or preventative measures taken so I live with fear that may experience pain that affects my life and work at any time often out of the blue."

"Referral to the spinal team and I was shown an image from my previous treatment that wasn't the image I was shown at the time and told it was so insignificant it was nothing. Had a CAT scan which I was told was an MRI and they said there was nothing there, that my apparent ruptured discs had disappeared."

"The physio was excellent although I felt I shouldn't continue with it after my scan they couldn't see what was causing my pain, so decided just to put up with the pain as I felt if they couldn't find out why they wouldn't be able to stop it."

Sub-theme: Long-term impact or outcomes from treatment and care

Some patients also shared a perspective on the long-term outcomes from their treatment and care. Eighteen comments were negative. Negative comments about long-term outcomes from treatment included:

- A few respondents reflected a feeling that they no longer had any options for treatment that would resolve their pain or symptoms. Some mentioned feeling that they just had to 'live with' or 'put up' with their pain. Other comments highlighted a lack of support, including that patients now 'self-manage' or that they were 'left to adjust' by themselves;

- A couple of respondents implied that they were unsure what support was available if they had chosen not to have surgery;
- A small number of people described high levels of impact from their condition on their quality of life. For example, sharing how their mobility had been affected or other aspects of their lives (such as their ability to carry out daily tasks, engage in family planning and how their condition was affecting their mental health and emotional wellbeing);
- A couple of comments reflected on how treatment had not fully addressed their symptoms. For example, one person had thought receiving spinal injections would mean they would be pain-free. However, this had not been the case.

Examples of negative comments about long-term outcomes from treatment and care are shown below.

> *"I now have permanent nerve damage in my spine that is progressing because I was misdiagnosed for so long by so many and pumped full of drugs I now have no stomach left either. If I had been seen on time, and accurately diagnosed I would never have ended up permanently disabled and unable to find work or take care of myself. And because of how long it took them to correctly treat me (a fact I'm not entirely unconvinced wasn't deliberate!) I couldn't seek compensation for medical negligence or any other help due to the time period that had lapsed. They ruined my life and made my quality of life unbearably miserable."*

> *"I have gone to the physio team multiple times and am now about to re refer myself. I have the exercises but apparently have to sign to say that I will have any treatment they say is applicable without exception... as I have no wish for back surgery without full understanding of the issues it may bring, I am not keen to do this - but this is where the support ends ... until the pain becomes too much and I go back for someone to 'look' give same advice and I'm still in pain."*

> *"It took quite a while to be eventually referred to Back & Neck service. Then a wait before treatment was carried out in March 2024. (Injections into base of spine). I had hoped I would be relatively pain free following this procedure, but that is not the case. I am currently waiting for further advice/session in pain management."*

Whilst comments about long-term outcomes tended to be negative, this may reflect a bias in our data that people who experienced positive outcomes from their treatment were less likely to describe any long-term impact.

However, ten respondents did reflect on positive benefits of their treatment. This includes that, for example, their surgery had enabled them to walk again or live pain free. Positive comments about long-term outcomes from treatment and care included:

- Three respondents generally included that their concerns had been resolved effectively by physiotherapy services;
- Two were positive about the outcomes of spinal stenosis surgery;
- Two noted that their treatment had enabled them to walk again or to keep walking, and one said they could now work full-time, dance and engage in activities they were unable to carry out before their operation;
- One said their treatment had been 'life changing'.

Examples of positive comments about long term outcomes from treatment and care are shown below.

> *"At my appointments with Allied Health Professionals... two consultants fully explained what my issues were and how*

> "I was in extreme pain and needed this spinal operation. I was in a wheelchair, in constant pain, so this operation has been life changing [and] has given me my life back. I'm one year on since my op, I'm back to full-time work, and I can do everything again. Mostly dance and enjoying the things I wasn't able to do without this operation. So, it's been life changing."

they could be treated. An MRI Scan was organised at West Suffolk Hospital within a matter of days of one of my appointments. I looked at my scans and they were fully explained to me. The severe pain I was experiencing in my hips has been greatly alleviated and I am able to walk for essential exercise once again, for both myself and my dog."

"Very satisfied with the treatment I received, and I believe that so far, my surgery has been successful. I also had a bilateral decompression in November 2020 which has also given me relief and enabled me to keep walking."

3. Developing spinal engagement

The following section of the report addresses the project's key objective to:

- **Establish where patients are already engaged, and how this can be further utilised and improved.**

To do this, this section covers two key questions:

1. How do spinal services currently seek feedback from patients?
2. What are the barriers and enablers for services trying to capture feedback?

To answer these key questions, this section considers the feedback gathered in:

- interviews and focus groups with staff and professionals across the spinal network;
- follow-up phone calls and interviews with patients for their views on engagement and feedback across spinal services.

Professionals in the following roles and organisations took part in an interview or focus group:

- Spinal Consultants at ESNEFT;
- Allied Health Professionals Suffolk;
- Nursing, physiotherapy and other staff from ESNEFT.

In total, ten professionals directly contributed their views in a conversation with HWS. To protect participant anonymity, the report refers to 'interviewees', rather than identifying individuals or groups by their job title.
In addition to the interviews, several professionals contributed to the initial co-production and set the context for the project. These conversations are not formally reported, but did play a key role in shaping the project and informing our understanding of patient engagement and feedback across the network.

Professionals who contributed to the initial co-production conversations included:

- Nursing staff at ESNEFT;
- A representative for the Spinal Injuries Association;

- A representative for Allied Health Professionals Suffolk Back and Neck Service;
- A representative for MRI services at West Suffolk Hospital.

How do professionals say spinal services currently seek feedback from patients?

Allied Health Professionals Suffolk (AHPS)

Gathering a large volume of Friends and Family Test (FFT) data: One interviewee emphasised that patient feedback and experience was a key indicator of clinical quality for AHPS. They said AHPS's main approach to gathering feedback was to use FFT, including capturing a free-text comment alongside the raw scores.

AHPS capture this at multiple points in the patient's journey, for example during treatment and after discharge. The form is also available on the AHPS website. They noted they captured a lot of these responses, more than other similar services in the region.

Challenges with FFT: However, they acknowledged that the data from FFT offered a 'very limited' view of patient experience.

> *"Lots of patients will complete feedback, perhaps several times during their journey, which is nice… The problem is that it's very limited. I think it offers you a very limited view of the patient experience. And the comments are always much, much more insightful. I think even those, however, are quite limited."*

They also noted that it was difficult to interpret a change in average FFT score across the organisation. For example, there had been an eight per cent increase in average FFT score over the last year. However, the interviewee felt that AHPS had delivered a 'significantly better' service over the same period in response to a large volume of feedback.

To address the limitations of the data captured using the FFT, AHPS had also previously used semi-structured interviews to capture patient stories, which they said they had found 'a lot more insightful'.

> *"We have a sort of semi-structured interview… where we'll say you should tell us about your treatment, what was it like, how did you find the clinician, how did you find environment, and those are a lot more insightful."*

Other methods AHPS uses to seek feedback: In addition to FFT, AHPS used patient feedback from several other methods. These included:

- A feedback questionnaire sent to patients, via email, following a referral;
- One-to-one peer reviews and case-based discussions with their team. This involved reviewing patient feedback with clinicians and team leads, looking at 'whether there's a variance between how the clinician felt that went and the patient felt it [their contact] went';
- AHPS also review complaints and use these as part of training;
- One interviewee noted that AHPS physiotherapists also receive informal feedback as part of their role which is passed on to clinical leads.

East Suffolk and North Essex Foundation Trust

Limited opportunities currently: One interviewee said that patients often wanted to get involved in providing feedback to services, but there was currently no clear way for them to do so. They said that patients had often given them feedback verbally about what they thought could be improved about their experiences. However, the only existing channel they were aware of for patients to give feedback was through making a complaint. They felt, however, that many spinal patients might not want to make a complaint about their care, due to not wanting to seem 'unappreciative' of the care they had received. They said:

> *"It would be nice to know how people can feedback - in a way other than going down the complaint route. People are really grateful for the care they receive, but also simultaneously also really upset and in some cases traumatised by the worst cases they see. People don't want to feed into channels that make them seem unappreciative."*

Collecting objective outcome measures: Another interviewee reflected that engagement with patients at ESNEFT was limited. They said that the service collected some 'objective' data, for example, 'functional outcome measures', such as Patient Reported Outcome Measures [PROMs] and 'pain assessments'. However, they felt that the Trust currently did not capture patients' subjective experience of spinal services at all.

Buy-in from frontline staff to hear about patients' experiences: Despite a perception of a lack of opportunities for patients to feedback, one interviewee said that they felt that staff and professionals were interested in hearing about patients' subjective experience and outcomes. They said:

> *"I think the people who are directly involved in patient care day-to-day actually are interested in how they've actually had an effect with that patient and what the patient's experience is. Whereas it would kind of seem that when you're more on the peripheral, you're more interested in the actual outcome measures of the treatment and bits and pieces, whereas we are interested in the subjective, which is what we don't capture at the minute and we're kind of as soon as they leave our care, we don't know what happens."*

FFT data is already collected by ESNEFT, but there are questions about how this is used: One interviewee noted that the hospital patient engagement team should be collecting Friends and Family Test [FFT] data about the experience of spinal patients and that capturing this data was part of the 'accountability framework' for ESNEFT. However, they also noted that this information was not ever 'seen' by spinal consultants.

The interviewee also noted that consultants did receive informal feedback from patients during their conversations. They felt that the 'internal governance' systems for feeding information about patient needs did 'work', however, it was not 'formally documented'.

> *"I think firstly we should use what is already available - so if we are not using Friends and Family appropriately, we should be using it within the Trust. It's a recognised national system, it's recognised to give standardised feedback, so we should be using that… so it would be useful to know what percentage of our patients fill it in or have been offered to fill it in."*

> *"The other aspect to this, we do speak to patients, we see patients… they often do come and speak to us about their experiences… We do feed that back, it's just not formally documented very often… This happens on an ongoing basis based on how the service is running and the things that aren't there for patients, are the things that we then raise as legitimate concerns and risks on behalf of patients. The internal governance I think works, if you know what I mean."*

Highlight: Feedback from Regional Spinal Network Event

In September 2024, Healthwatch Suffolk attended the East of England Spinal Network Regional Clinical Meeting to seek professionals' views on patient engagement and feedback in spinal services. The HWS team gave a presentation, and invited attendees to complete a short survey.

Of the seventeen professionals who returned the form, ten respondents were from services in Norfolk, four from Essex and three from Suffolk. The first question on the short survey asked what methods the service they worked for used to gather feedback from patients and professionals.

Professionals told us that they used:

- FTT (Friends and Family Test) (4)
- PROMS (Patient-Reported Outcome Measures) (4)
- Paper Feedback Forms (3)
- Face-to-face contact (3)
- PALS (Patient Advice and Liaison Service) (2)
- British Spinal Registry (BSR) (2)
- Text messages (2)
- Surveys (1)
- Emails and anecdotes (1)

What do professionals say are the barriers and enablers for services trying capture feedback?

Throughout the interviews with staff, HWS asked about what they perceive to be the key barriers to doing more patient engagement and feedback work within services. They were also asked for their thoughts on how patient engagement could be further promoted and improved.

Feedback from professionals about the barriers and enablers to patient engagement work are summarised into four key themes:

1. Time and capacity
2. Methodology and communication strategy
3. Feedback culture
4. Accessibility

1. Time and capacity

Capacity with services, particularly elective care: One of the barriers which staff and professionals across services emphasised, was time and capacity to carry out patient engagement and feedback work.

For example, one interviewee stated that elective services were under a lot of pressure. They felt that teams might require support from an administrator or other colleagues to be able to capture feedback from patients. They noted that for a member of staff or professional to engage with patients on the ward takes time, which can impact on the service they are able to provide. Furthermore, they felt the planning and preparation needed to set up a process for capturing feedback from patients was a barrier. However, once a 'protocol' was in place and data was able to be collected from patients on admission and discharge, they felt it would be easier to continue to manage.

Prioritising feedback alongside clinical roles: Another interviewee noted that most clinicians would not identify seeking feedback

Highlight: Feedback from Regional Spinal Network Event

Respondents at the Spinal Regional Clinical Meeting were also asked to reflect on whether there were any challenges they faced gathering feedback form patients. Common challenges they listed were:

- Patient response (two): Patients sometimes do not provide feedback through text messages, surveys or forms;
- Resource and time constraints (two): Limited by funding, time, human resources, and IT systems;
- Feedback culture (two): Including engagement from management or prioritisation by leaders;
- Limited follow-up on feedback (one): One noted there was often little action on the results of patient engagement or feedback;
- Patients' digital ability (one): To complete an online survey or feedback form.

as a key responsibility of their job role. They said that clinicians often did not have time to prioritise seeking feedback over their clinical role. In addition, they said that clinicians would often not know the 'processes' or 'boundaries' to plan for how patients can give their feedback. They said:

> *"There is no one particular clinician who would think: 'That is my job. I'm going to do that'. All clinicians have to prioritise clinical stuff… [But] service development… always falls to the bottom of the pile. It [also] gets into the world of management… What are the processes and what are the boundaries and what are you allowed to do?… I wouldn't know where to start with that kind of stuff."*

2. Methodology and communication strategy

Rapport and buy in from patients of ESNEFT: One interviewee talked about their contact points with patients, and the opportunities they had to build up rapport to get patients involved in giving feedback.

For example, they noted there were important differences between seeking feedback from spinal cord injury patients, and elective care patients at ESNEFT. They reflected that spinal cord injury patients stay in hospital for a longer time, allowing staff to build a rapport with them. One interviewee remarked that they found most spinal injury patients were happy to give them feedback about their experiences, due to their length of stay and high impact of their injury and the care they received. They felt that seeking feedback was a powerful way to 'empower' this group of patients.

> *"People often have the feeling when they've had a spinal cord injury, they're reduced to this person in a gown who looks the same as everyone else… Nobody asks them anything. To just basically be told you have a voice and we're interested in what's happening to you… that alone will be huge for people."*

In contrast, for elective patients, the interviewee felt the 'turnaround' was faster, with less opportunity to build up rapport. In addition, they had less 'touch points' to seek feedback from elective patients. This could depend on the surgery the individual patient had received. For example, some patients would attend for further outpatient appointments after their surgery, giving services and opportunity to follow up for feedback. However, those who had more minor surgery may not attend a follow-up appointment.

Rapport and buy in from patients of AHPS: One interviewee noted similar challenges in collecting feedback from patients of AHPS services. For example, they noted that the service did not have a standing Patient Participation Group. The interviewee felt that one of the main barriers to developing a group was that patients were in contact with AHPS for a shorter amount of time in comparison to other services (three to four months in most cases). This meant that they did not build up a relationship with the service in the same way as they might with their GP surgery or hospital.

The interviewee felt that previous attempts by AHPS to form a Patient Participation Group had failed to engage a representative sample of patients. They said about setting up a Patient Participation Group:

> *"For some patients, they see us just the one time… and actually they're happy to manage it from there because most MSK conditions are transient…"*
>
> *"When we have spun up [a participation group], and we have had people come to it, they normally come with a certain agenda, so we don't find that it's really representative of the whole."*

Improving general engagement at ESNEFT through using existing FFT resources: One interviewee suggested that there was an opportunity to improve engagement through linking with the Patient Experience Team at

ESNEFT. They noted that the Patient Experience Team would likely already hold data about spinal patients, such as FFT data. They felt it was important not to duplicate work by designing other methods for patients to feedback. They said:

> *"Have a word with the patient experience team to see whether it is already being gathered, as they should be able to break it down into where those patients come from, as they may be doing it already."*

Furthermore, they noted that one of the key challenges to increasing patient engagement and feedback work was the difficulty with identifying patients to speak to. They went on to explain that patients already receive a lot of information, for example, about their conditions, from ESNEFT. It therefore needed to be easy for patients to feed back. They suggested adding a contact method or consent to contact patients at the bottom of clinic letters, or the existing FFT could do this. They said:

> *"You want to make it easy for the system to identify and push these patients onto your website or to give feedback in the way that they want to… There's already too much stuff out there, all good stuff, but there's a lot of stuff out there for patients to try and get their head around. And so you don't want to bombard them. We give them lots of information already for their condition, so you want something easy for them to do to push them in the direction of feedback… Is it just on the bottom of a clinic letter or the bottom of the normal letter they get sent out?"*

Data protection and consent to contact: One interviewee said professionals at ESNEFT had considered options for how they could contact patients with a survey, post-discharge, to find out more about their experience. However, a critical barrier was having the right consent from patients to follow up. They had worked on a consent form for patients to sign when they were admitted; however, at the time of the interview, this process needed approval from the Trust before it could be put in place. They reflected that they did have an opportunity to contact patients for feedback at outpatient clinics. However, they may not be able to capture all patients through this route.

Avoiding selection bias: One interviewee talked about the importance of communicating about opportunities to feed back in ways that did not introduce bias into the results. They gave an example of a previous survey distributed by AHPS, which they felt had some limitations. They felt that this survey may have been distributed 'selectively', leading to bias in the results. They said this limited the usefulness of the data they received, and meant that nothing had changed as a result of it:

> *"In previous periods, I think we have selectively surveyed people more and the information we got back was useless… because if you're at the top, you're at the top. You're the best and of the best. It's much more difficult to get better from that point."*

Another interviewee expressed concern about the possibility of selection bias when staff promote opportunities to feed back to patients. They explained, that if staff found some patients 'problematic' or challenging, they may be less likely to be offered the opportunity to feed back. However, they also felt that these patients might offer the most valuable insight. They said:

> *"Based on other services I've been in as well, sometimes who is asked… their feedback can be a bit self-selective, and sometimes it's the people who are excluded who probably would have given some insightful feedback."*

The challenge of separating feedback about different parts of the pathway: One interviewee said that it was important to try to separate feedback about the different parts of the pathway. They noted that people's overall experiences of care could be complex, and span multiple services; for example, mental health and social care. To understand the feedback about patient experience of ESNEFT, it would be necessary to have some way to separate this out. They reflected that people's experience of the pathway could impact their expectations of the care they would receive. They said:

> *"Because of patients' journeys they come in with different expectations and they come in from different sources so the feedback they get from visiting a spinal service is different because of their experience throughout that journey. The gateway for us is via our community triage pathway our single point of access so really, you've got patients that go into that, and they get spat out in a number of various directions depending on that threshold… You've already got a ready pool that I guess you can interrogate everything that comes from that single point of access. And then I guess you are going to have to do a massive data gather, because you are going to have mental health issues, you are going to have social care issues, all of this multiple stuff, and some of it will be us [ESNEFT]."*

Another interviewee had similar feedback. They wanted to know more about whether patients might experience frustration with other areas of the pathway, and how that might impact their experience or feedback about their treatment at ESNEFT. One specific area they talked about was patients who were fast-tracked through the pathway. They reflected that some patients are seen a short time before their surgery and therefore may not get as much support. They said:

> *"We see a lot of patients that we're getting through the system quite fast, which I can think obviously has negative sides and also positive sides and just try and understand how patients feel about that and how we can make the process, even when it is sort of fast tracked, the best experience it can be."*

Some staff and professionals felt that there was a gap in engaging spinal cord injury patients: Two professional interviewees noted in separate conversations that there were specific gaps in seeking feedback from spinal cord injury patients. Both interviewees reflected that spinal trauma patients were now often staying longer in ESNEFT.

They felt that there was a need to know about this experience and how it could be improved for patients. They also felt that there was a gap in understanding patients' experiences after they had been discharged to a national rehabilitation centre, such as Sheffield or Stoke Mandeville. They felt that knowing about people's experiences at these centres would also help them prepare patients, as they can explain what the service is like.

One interviewee felt that considering the 'timing' of when to seek feedback from injury patients was important. They stated that patients required sufficient time following their injury before it was appropriate to engage them in conversations or feedback. Conversely, they also needed to have been on a ward at ESNEFT long enough to be able to give meaningful insights about their experience. The interviewee suggested that after about four weeks patients 'know what is going on' with their care and on the ward and would be able to give informed feedback. They also recommended that ward staff would likely be able to guide engagement activities to patients who are willing and able to talk about their experiences.

The interviewee also suggested it would be valuable to seek feedback from patients while they were on the ward, rather than waiting until their transfer to a specialist rehabilitation centre. They questioned how much people would remember about 'what they were bothered by' during their time in Ipswich, and whether they might 'gloss over' some details once they had left.

Other staff and professionals felt that engagement with spinal cord injury patients should already be covered by partner organisations such as the Spinal Injuries Association: Two other interviewees questioned whether engagement with spinal cord injury patients was already well covered by the activities of the various support organisations including the Spinal Injuries Association [SIA], Backup and Aspire. They advised caution about when the best time was to engage spinal injury patients, saying:

> *"I would not approach any patient while they were acutely injured."*

Overall, their recommendation was to not 'reinvent the wheel' on how to engage with spinal cord injury patients. Their feedback included:

> *"They're already being picked up by the SIA, so it might be better for you to liaise directly with the engagement team at Spinal Injuries Association so that you're not duplicating or misjudging when you should approach these vulnerable patients. So, the SIA may be able to give you that cohort and say, 'No, this is how you should do this, and this is what we collect already'. Because if the data is already collected… then you can use that information that's already been collected by them and just having it directed to the spinal network area."*

> *"I think you have to go back to looking at what is already collected and who is collecting what. So, a lot of patients for example, the data is collected by the Spinal Injuries Association, who tend to actually speak to all those patients with various questionnaires, various patient satisfaction scales, much, much more in-depth assessments."*

3. Feedback Culture

It was clear across the conversations that organisational culture impacted professionals' views on patient engagement and feedback work, as well as patients' feedback and willingness to engage.

Achieving impact from patient engagement and feedback work: One interviewee said that there needed to be impact from feedback and engagement work. To achieve this, they said it was important that capturing, and acting on, patient feedback should be a whole team responsibility, rather than just single members of staff.

They felt that improving services with patients' needs in mind could ultimately lead to cost saving in the long term. They felt evidence of potential cost savings could encourage leaders at ESNEFT to support further patient feedback work, but without this evidence, gaining initial support might be difficult.

Differing perceptions between patients and staff on appointments or interactions: One interviewee noted that one of the challenges to seeking feedback was the relative power imbalance between patients and professionals.

This meant that a patient might find it difficult to speak up or challenge a clinician whilst in an appointment and may only acknowledge later on that they were unhappy with their consultation. This meant that a clinician might feel that their consultation had gone well but might later receive negative feedback. They said:

> *"Often times [clinicians will] think that an interaction went really well with the patient because often the patient might say that at the time. [But] they might reflect on it later and change their mind… I think it's very difficult for patients to feel very empowered to speak up against the clinician who from their point of view, is an expert…"*

AHPS addresses this by fostering a 'no blame culture' when approaching conversations about patient feedback and in case reviews. They said that 'in time they [clinicians] come to learn that it's quite a positive thing'.

Setting realistic aims and expectations: One interviewee felt there was a need to set realistic expectations within services about the volume of positive feedback they should receive. Setting an ambition for 100% of patient feedback to be positive was 'unreasonable' to expect and created an incentive not to utilise negative feedback. They said:

> *"I don't think we should be aiming for every person to have a positive experience… that's unreasonable for us to expect… When you're matching… thousands of tens of thousands of people to hundreds of clinicians, there's always going to be a mismatch…. I think as long as we're getting it right 97%, 98% of the time, I would be really happy with that. I don't think we'll ever get to 100%… if you're looking for 100% perfect all the time, then that's an incentive to not acknowledge where you could make improvements."*

4. Accessibility

Ensuring that methods to feedback do not rely solely on access to digital technology: One interviewee reflected on barriers related to accessibility and communication when seeking feedback from patients. They noted that not everyone would be able to access digital communication. Because of this, they felt that email was often not the most effective way to reach people. They suggest engaging patients face- to- face might lead to a more productive conversation.

Top tip: Healthwatch Suffolk has co-produced key resources considering digital communication in health and care. You can view Healthwatch Suffolk's Guiding Principles for digital service delivery and development at: https://healthwatchsuffolk.co.uk/digitalhealthandcare/

Critically, these note that a 'digital first' approach should not mean 'digital only', and that services must meet their statutory requirements under the NHS Accessible Information Standard for recording and meeting patients' communication needs.

Ensuring that engagement is accessible to people with a range of communication needs, particularly spinal cord injury patients: Two separate interviewees highlighted that spinal cord injury patients might face challenges with communication which might impact their ability to get involved in giving feedback.

They explained that some patients with a spinal cord injury may have speech difficulties, problems with mobility, or hand function, to use electronic devices. They suggested that paper forms or online surveys may be unsuitable for spinal cord injury patients without some sort of assistive technology. The interviewee felt that, in practice, many would have to rely on someone else to give feedback on their behalf, for example a family carer. Overall, interviewees emphasised the need for careful planning to ensure feedback processes did not unintentionally exclude anyone.

What do patients say about their opportunities to take part in engagement and feedback currently, and what would they like to see in the future?

HWS conducted follow-up telephone calls with a small sample of people (nine) who had responded to the engagement survey.

The purpose of these phone calls was to gather more information about people's experiences of giving feedback about spinal services. Respondents were also asked what they felt would be the most effective ways of gathering feedback from spinal patients.

Six people reflected on their experience of being asked for or giving feedback about spinal services. Their responses highlighted several of the issues already mentioned by professionals.

Staff do not always have the time or resources for gathering or acting upon patient feedback.

One respondent said that as far as she could recall she had 'not really' had the opportunity to provide feedback about her experiences while staying on the Trauma ward at Ipswich Hospital. They said in addition to the ward staff who she saw daily, they also saw two spinal nurses throughout the week. They said that, if they had any issues, they would raise them with the spinal nurses. They felt there was no point in raising issues with the ward staff as there was little they could change about the situation. They did not view this as being 'due to a lack of caring, they were simply run off their feet and were massively understaffed'.

Consideration should be given to the appropriate time to seek feedback from patients.

One respondent 'vaguely' recalled having been given a tick box form in hospital, soon after surgery. They felt giving the form out just after the operation was the wrong time. They said, 'Sometimes it is hard to judge what is happening to you at the time it is happening. Sometimes you need time and space to look back on the experience and judge how you felt about it'

Another respondent reflected, 'I think it is helpful to have a gap between accessing the service and then asking for feedback. When you are in the middle of being treated and you are in pain, that's not the best time to ask for feedback'.

While both these respondents felt they had been asked for feedback 'too soon', another respondent highlighted that leaving too much of a gap between intervention and seeking feedback may mean patients have 'moved on' with their lives and may dismiss issues that, at the time, had been of importance to them.

This respondent said that, while they had not been formally offered the opportunity to feedback about spinal services, they had written a letter to the physiotherapist at AHPS to explain how they felt about the treatment and service they had received.

The physiotherapist had replied, acknowledging her letter and saying they would discuss it when they next met. However, the next contact this person had with the service was a phone call with the results of their MRI which indicated that they did not require physiotherapy anymore. They could have followed up on the issues raised in the letter, but as their current issue was resolved they 'couldn't be bothered', saying 'I've got lots of health issues which are more important for me to focus on'.

> "Ipswich Hospital do telephone surveys, and I always respond to those. However, they have a lot of multiple-choice questions and answers and there is little opportunity to share the detail of your experience."

Consideration should be given to the type of feedback being sought, as this will affect the type of questions that need to be asked.

Another respondent reported that they had been asked for feedback at every stage of their treatment, 'anytime I saw anyone I was asked to give feedback'. Sometimes, this was in the form of a survey or a feedback form. They had filled in forms about the physiotherapy service, and had given good feedback. However, this was not 'a reflection of my whole journey, just a reflection of that particular service on that particular day'.

Some people are more inclined to take the time and give feedback to services.

This is an important consideration when gathering feedback to mitigate any bias in the results. Another respondent thought they had been given a form or survey by AHPS to fill in at the time they were accessing their service, but could not recall what it was. When asked whether they had any understanding of what would happen to the feedback, or how the service would use it, they said they had 'no idea', but felt that 'gathering feedback is important and I will always take the time to give my feedback'.

When asked about the most effective methods for gathering feedback from patients, most respondents reflected that one method would not suit everyone, and that a mixture of methods would be required.

> *"I would not be interested in focus groups. I'm too much of a loner for that."*
>
> *"You have caught me at a quiet time today so I am able to take the call but, if I had been busy, I wouldn't have answered."*
>
> *"I think asking people for some feedback using a short form, and then allowing for the options of a follow-up call would work well."*
>
> *"While receiving a call today had been fine because I'm in hospital and have little else to do, when I'm back in my 'normal' life' I would probably be too busy to answer a call… I think a mixture of methods would work best."*
>
> *"Not many people have time for a phone call, and not everyone does email. You could text message people with a survey."*
>
> *"I think people are unlikely to bother with surveys… Service user groups could work."*
>
> *"I'd fill in a survey if it was emailed to me. I wouldn't be keen on a focus group, especially if it meant travelling. I might consider something online, like a zoom group or something."*

Two respondents reflected on the limitations of surveys in gathering feedback. Specifically, they highlighted that a survey with only multiple-choice questions will not gather the nuances of people's experiences.

> *"Ipswich Hospital do telephone surveys, and I always respond to those. However, they have a lot of multiple-choice questions and answers and there is little opportunity to share the detail of your experience. For example, they ask how satisfied were you with x - very, quite, not very, not at all. There is no opportunity to say 'well for this I was very satisfied, but for that I was not' etc."*
>
> *"Surveys are useful if there is the*

> *opportunity to provide free text comments, not just a tick box exercise."*

Respondents also highlighted that, whatever method for gathering feedback is used, it needs to be easy for people to access and complete.

> *"It would need to be something easy to do that isn't too time consuming. Something I could do on my mobile phone, mobile phone friendly. I wouldn't want to be sent an email and then have to click a link to take me to a website where I have to scroll to find the relevant bit."*

Finally, a couple of respondents highlighted the importance of people feeling confident that their feedback would be read and acted upon.

> *"I was concerned whether my feedback form had been received by anyone and whether anything was being done with it, so I'm grateful you called."*

> *"It is important to feel that your comments are actually looked at and acted upon."*

> *"...feedback can be a bit self-selective. Sometimes, it's the people who are excluded who probably would have given some insightful feedback."*

In Focus: In-depth interviews (patients with experience of a spinal cord injury)

Professionals highlighted in their feedback that there may be gaps in engagement and feedback work with spinal cord injury patients. To gather further insight in this area, Healthwatch Suffolk also conducted two in-depth interviews with patients who had experience of spinal cord injury services at ESNEFT. Key highlights from these interviews are summarised below.

There was limited feedback from spinal cord injury patients in the public engagement survey. Four responses were received which feature in the survey findings on page 8.

Interviewee One

The first interviewee had a historic experience of spinal cord injury in 2012. They were currently receiving care from a pain management service and their GP surgery. However, their experience spanned multiple services and contacts with professionals, including receiving a spinal cord stimulator (TENS machine). They noted that:

- Immediately following their injury, these patients would be adjusting to a 'new normal' and often had a range of 'worries' about the impact of their injury on their lives. They felt that health and care services needed to offer comprehensive support for these needs. This included not just 'counselling and therapy' but also practical support and advice about employment, disability benefit, the impact on families, ongoing care needs;
- The interviewee also recommended engaging with family members and carers to understand their experiences. Specifically, they highlighted the importance of knowing if carers felt involved in the patient's care, and had access to information they needed. This was also mentioned by one professional interviewee who reflected that patients with spinal injury, can be 'so reliant on their families', who were often 'very, very heavily involved in care'. Although this was not a specific deliverable for the project, this could be considered by the network in the future;
- They felt it would be useful to engage spinal cord injury patients after discharge to understand if they felt adequately supported. They mentioned a feeling of 'safety' on the hospital ward. However, once they had left the ward, that patients could face other challenges with outpatient services, follow-up operations, or waiting to receive equipment or housing adaptations;
- They suggested that small, specific changes to the ward environment, such as lighting or colour, could impact spinal cord injury patients' experience of staying at the hospital;
- Finally, they noted that patients with spinal cord injury might find it challenging to participate in engagement due to the emotional impact of their injury or trauma. They recommended clearly communicating that patients could take a break at any time from an engagement conversation or interview. They also suggested safeguards should be in place for staff conducting these conversations, as some of the topics discussed could be distressing.

Examples of quotes from the first interviewee included:

> *"It could be as simple as I don't like the colour of the curtains or something like that, and actually something like that could be really important to someone. I think so… please paint something on the ceiling, so that when we're lying flat on our back, we've got something to look at…. or the light is flickering, or the light is too*

> *harsh, because I bet it is those really harsh lights that they've got."*
>
> *"Family members might say, well actually this happened, and we come to the ward and we're not involved and we don't know. But actually, we need to know because, you know, we need to be sorting out this other stuff at home, but we're not involved in that decision making."*
>
> *"I would hope, particularly for that sort of ward, that specific service where people have spinal cord injuries that... the service that they offer is all-encompassing. So, I don't just mean psychologists who will give them counselling or therapy but is it that sort of holistic service that then allows them to think about, 'OK, so I can't go back to my job, so what can I do? What are the sorts of jobs that I can do?'. You might also hear about benefits... for some of those people on that ward, it might be their first foray into that... I'm not sure that that's what they offer, but those are the sorts of things that people are going to be worried about."*

> **"I would hope, particularly for that sort of ward, that specific service where people have spinal cord injuries that... the service that they offer is all-encompassing. So, I don't just mean psychologists who will give them counselling or therapy, but is it that sort of holistic service that then allows them to think about, 'OK, so I can't go back to my job, so what can I do? What are the sorts of jobs that I can do?'"**

Interviewee Two

The second interviewee's injury and experience of inpatient care were more recent (within the last two years). They had an initial inpatient stay of eight weeks to stabilise after their injury, as well as a follow-up operation. They said:

- That, like the first interviewee, they reflected on the process coming to terms with what their spinal cord injury would mean for them. They noted that at the beginning of their experience, they 'didn't know if [they] would walk again'. They were positive about receiving psychological support early in their journey;
- The second interviewee was positive about being involved in decision-making by their consultant. The said they had been given a choice of whether to proceed with surgery on their back;
- Their main suggestion was that patients recovering from spinal cord injuries should be cared for separately, rather than sharing a trauma ward with patients who had different needs. They explained that sharing a ward with people experiencing dementia or mental health issues could lead to disturbances, and that other patients would sometimes try to talk to them while they were trying to rest. Although staff emphasised the importance of rest to improve their recovery, their sleep was often interrupted at night by lights and conversations when other patients were brought onto the ward. A family member had brought them some headphones and an eye mask to help them rest.

Examples of quotes from the second interviewee included:

> *"First of all, I didn't know if I would walk again. You know, I couldn't... feel my*

arms, my hands, I can't do anything at that point. I can't move. I was staring at some wonderful ceiling for quite a long time. And you, you need, you absolutely need someone every day to kind of give you that 'OK, you've done this today. That's amazing. Tomorrow you're going to do this'. And I think the side, the kind of psychological support, which they plug in very, very early is really important... but my mental health could have very, very quickly taken a dive. I mean, it did. I'm not going to like glamour. I've been to some quite dark places in the last year. But they, but they did plug in some of that support early on. So that was really positive."

"They were just genuinely like they wanted to do the best for me... That's how I felt when I was there. I can't think of anything that any point where I kind of questioned anything that they were suggesting or was worried about anything... Yeah, it was really kind of a two way."

"I know space in acutes is incredibly difficult... But my personal view is that if someone is recovering from a spinal injury. They should be separated out. I do. I think it's very different to someone who has broken a leg and going for an operation and coming back, and then they're going to be out in the next two days. Even if you're mobile, it's different because you can get away. You can have a walk down to the shop... I just think it didn't work at all."

"They kept saying, 'Oh, you know, you need to rest. It's really important because it's the only way your body's going to fight and get better'. And all I'm thinking is, 'I can't. I can't, actually'... and in the end, so I had headphones on. I had noise on my phone that would be next to my ear, and someone brought me an eye mask and that's how I had to sleep. Of course, I was woken every four hours for meds so and blood pressure... That's the only way I could block everything, out so we quickly kind of thought of ways that we could get around it, but that was all on us. That wasn't them suggesting that, that was me thinking, how am I how am I going to block this out?"

"I know space in acutes is incredibly difficult... But my personal view is that if someone is recovering from a spinal injury, they should be separated out [to have their own ward or space]. I think it's very different to someone who has broken a leg. It's different because you can get away... I just think it didn't work at all."

4. Key learning from this project

What do patients say about their opportunities to take part in engagement and feedback currently, and what would they like to see in the future?

This section is a summary of key learning or actions the East of England Spinal Network could progress to respond to this project. Specifically, this part of the report aims to address the key ambition of the project to:

- Consider how feedback could be regularly captured within the network, and understanding how this can contribute to service development.

This section has been created with due consideration to a combination of insights from:

- Patient interviews and surveys;
- Professional's interviews;
- Learning from Healthwatch Suffolk's research team conducting patient engagement and feedback work within the network;
- Experience of the Healthwatch Suffolk research team from delivering previous projects across health and social care.

These recommendations aim to inform key areas for the development of patient experience work within the network. However, some examples offer further detail as to how they might apply to specific services across the pathway.

The broad principles of the recommendations could also be utilised by services as suggestions to further develop their patient engagement and feedback practices. Overall, the recommendations should act as a resource for staff and professionals within services, and the wider network, to improve their own patient engagement and feedback mechanisms.

Recommendation one: Design engagement and feedback work with a clear aim in mind. Focus on specific areas in which patient feedback can evidence a need for change and lead to meaningful action and impact.

A key learning point from the project was the need for the spinal network to engage in focussed and specific patient engagement activities.

To drive meaningful service improvement, engagement and feedback must connect with clear aims and ambitions. Furthermore, there must be an ongoing commitment from services to action change, to respond to feedback from patients and carers.

Professionals leading the development of patient engagement across the network should consider their current understanding of patient experience (including the themes in this report) and identify key strengths and challenges for the services. Crucially, to make the most of patient engagement and experience work, there is a need to determine how gathering further information from patients could address knowledge gaps and inform service development.

Having a clear purpose should inform the planning and delivery of patient engagement or feedback work by services, or within the network. It will also help to define specific phases of any project, including, but not limited to:

- Identifying key stakeholders in the project. For example, which patients is the work aiming to hear from, and who are the staff, professionals, or leaders able to influence change from the findings?
- The targeting and timing of communications about the project. For example, at what stage of the patient pathway is it most relevant to hear about people's experiences? For instance, could patient experience work target referrals to ESNEFT, or focus on the ongoing support people receive post-discharge, or something else?
- The methods used to involve people in a project. This includes selecting the key methods for people to give their feedback, such as a survey or interviews, and the design of the key questions that will be asked. This is explored in more detail below.

How the aims for patient engagement and feedback work can guide the methods used

The engagement and feedback methods chosen should be related specifically to the aims and objectives for developing the work. This includes the type of data capture that can best meet key information needs, or that will be useful to inform service change.
For example:

- If a large number of responses, or more objective data, will be more likely to influence change, short surveys or simple forms are more suitable. Surveys can quickly and easily capture a large volume of data. They work well for broad feedback or understanding of an issue or patient experience. An example could be a targeted questionnaire about patients' experience of referral from AHPS to ESNEFT.
- If a deeper understanding is needed (e.g. if patient experiences are complex, or not much is known about patient experiences) and the information required is more exploratory, qualitative methods (such as interviews or conversations with patients), are a more appropriate method. Examples could be understanding more about the experience of spinal cord injury patients, or understanding more about how patients' beliefs or expectations impact their levels of activation and adherence to physiotherapy or pain management.

- These methods can be combined. This was the approach taken to patient engagement within this project. For instance, a survey can gather initial data and consent to contact from patients, which can then be followed up with a more detailed qualitative method.

Choosing a focus for patient engagement and feedback work, and ensuring that this leads to change

A critical consideration for patient feedback is how the information gathered will be used. Understanding the intended outcomes and expected impact from any engagement or feedback initiative should guide the development of the methodology. This can help to ensure that limited resources, such as staff time, are used effectively by eliminating unnecessary data capture, as well as making the analysis of patient data easier and more targeted to specific issues.

For example, a key point of learning from this project was the difficulty in identifying feedback about specific services or areas out of more general feedback about the pathway. Professionals also highlighted this challenge, noting that people's cumulative experiences of services can retrospectively impact their feedback about specific services. Furthermore, because of the relative complexity of some patient's experiences, they often touched on other areas, such as mental health and social care, which are not directly attributable to spinal services.

Giving projects a more targeted focus may help to reduce the time and capacity needed to analyse the data, and provide more actionable feedback, by making the data captured more manageable.

This requires developing an awareness and prioritisation of the specific aspects of patient experience that could be improved through targeted feedback and engagement work. Priorities can be developed in several ways, including through co-production with patients and families, from intelligence captured using existing patient feedback mechanisms, or through the informal feedback heard by staff and professionals.

Service patient experience leads may also consider the feedback captured in this report, and the themes generated from it, to help decide what areas to develop for further patient engagement and feedback.

A key priority identified by professionals and patients was developing patient engagement work to capture information about the experience of spinal cord injury patients. While this project has captured some insights from this group, relatively few spinal cord injury patients have participated. This likely reflects the smaller number of patients who access this type of care, compared to other services such as elective care or physiotherapy.

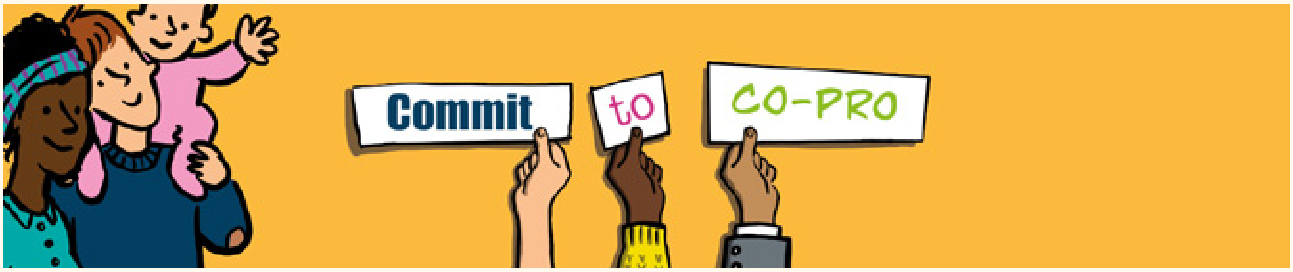
To address this gap, feedback and engagement work may need to adopt a long-term approach, capturing data from spinal cord injury patients over time. This could include following up with patients at regular intervals after discharge to assess how their needs are being met over time.

The following further suggestions for future patient experience work within the network are based on feedback from patients and professionals in this project. Consider:

- What are people's experiences of referral from community services to ESNEFT? What works well, and could aspects of patient experiences be improved?
- What are spinal cord injury patients' experiences of national spinal rehabilitation services, such as Sheffield and Stoke Mandeville, and how are these shared with patients in Suffolk to help them know what to expect from these services?
- How do experiences with GP services impact patient expectations of the

pathway, and are people signposted to the correct services from primary care (e.g. self-referral to AHPS)?

- What are spinal cord injury patients' experiences of recovery on a single trauma ward at ESNEFT, and how could this be improved?
- How can physiotherapy services further develop their tools and communication to help patients feel exercises are effective/helpful?
- How can patients be better supported to feel that pain management services are effective?
- How do patients feel about the support they receive following an operation (whether for spinal cord injury or elective care)?
- How can services ensure people receive holistic support following elective procedures or spinal trauma, including consideration of mental health needs and non-medical factors, such as support for caring responsibilities, employment or benefits?
- What are patient experiences of accessing a diagnosis, including MRI scans? What are their expectations, and how can services communicate better with patients about what they should expect from the pathway?
- What are family carers' views on their experiences with spinal services?



Make a commitment to co-production – we can help

In addition to seeking patient experiences, services should work in co-production when developing new aspects of service delivery. It ensures services are designed with patient's needs in mind and is the most proactive approach to patient involvement.

Our team offers support to embed co-production into services, and to understand the benefits it can bring. They offer a free of charge session to understand what people and services would like to achieve and provide guidance on how co-production can maximise the potential of any service or project.

Our offer is tailored to support professionals, partners, and people using their services, to develop a shared understanding of co-production, and to:

1. Explore the challenges that are hindering a truly co-productive approach.
2. Define an achievable approach.
3. Together, plan and design working-tools to support and embed the culture and learning required.

To learn more about how you can make a commitment to co-production, please visit https://healthwatchsuffolk.co.uk/coproduction-your-journey/

Recommendation two: Continue to use existing patient engagement and feedback resources, such as Friends and Family Test (FFT), but supplement this with focussed projects to support service development.

Professionals from ESNEFT and AHPS noted that both organisations already collect FFT (Friends and Family Test) data from patients. However, there were differences in how this information was used.

Professionals from AHPS reflected that the organisation generally received good levels of response from patients to the FFT. They were clear that this information was used for service development. However, professionals from AHPS also reflected on the limitations from the data gathered from FFT. Specifically, they highlighted the lack of detail of free-text feedback in this format, and the challenges with interpreting changes in FFT scores. They suggested AHPS could enhance this existing method by adding further detailed qualitative data capture alongside it.

Both interviewees from AHPS highlighted potential opportunities to have more detailed conversations with patients, for example by gathering consent to contact and calling a random sample of patients to find out more about their experience. This could directly target key areas of interest for the service, for example, exercise adherence, patient beliefs or expectations, and patient activation.

Friends and Family Test (FFT) data was only mentioned in one of the focus groups with staff at ESNEFT. The professionals who discussed FFT were uncertain about how this information was gathered and did not reflect that they had access to the results or findings from the data. Outside of this group, several staff at ESNEFT felt there were limited opportunities for patients to provide feedback about their subjective experiences. Professionals in the focus group that discussed FFT suggested there could be an improved link between spinal services and the Patient Experience Team to find out more about what was already captured from spinal patients using FFT. This suggests there could be consideration given to how information from the FFT about spinal services is disseminated to professionals and staff, as well as how this is actioned. This included whether FFT data is gathered at the correct 'level' to be able to identify experiences specific to spinal patients. If data is gathered at hospital ward level, it may currently be difficult for services to differentiate between feedback received regarding spinal care and feedback from patients located on the same ward for different reasons.

Overall, a single generic tool, such as FFT alone, is unlikely to be sufficient for patient engagement to be meaningful and have an influence on service delivery. While there is value in general feedback, it is unlikely that a single feedback tool (such as FFT or even the patient survey delivered as part of this project) will effectively address key issues for all services and patient groups.

For example, in the patient feedback, short experiences of AHPS or community physiotherapy services differed greatly from experiences of complex spinal care across multiple years. The critical consideration for services is whether this type of feedback can be effectively broken down and actioned, and whether the evidence gathered from such general engagement is enough to be confident in making decisions about service development. A combination of targeted qualitative and quantitative methods, tailored to the specific needs of the service and patient group, is more likely to result in actionable patient feedback.

Recommendation three: Build and maintain a culture that prioritises seeking and acting on patient feedback.

Having an organisational culture that

prioritises seeking and responding to feedback is crucial to increasing patient engagement and feedback work. Healthwatch Suffolk has found staff and professionals across services to be engaged and supportive of this project. They have enabled the successful delivery of engagement work by giving up their time to participate in focus groups and interviews, and to co-ordinate the promotion of key project materials to patients.

Frontline staff showed a genuine interest in knowing about the difference they were making for their patients and how they could better meet patient need. This is reflected also in the generally positive feedback from patients about involvement in their treatment. Spinal services can build on these strengths to facilitate further patient feedback and engagement work.

Promoting a culture around patient engagement and feedback requires commitment from professionals across multiple roles, such as communications leads, patient experience teams, leaders, clinical staff and administrators. There is a key role here for leadership within services to facilitate the development of a culture of feedback. This should include managing practical barriers that might otherwise prevent patient engagement and feedback work from being developed. Examples include allocating staff capacity to seeking patient feedback, issues around data protection, or prioritising space on clinical letters for communications about patient engagement and feedback.

The aims and objectives for seeking patient feedback should be realistic. There should be an acknowledgement that not all feedback will be positive, and setting unrealistic ambitions may provide a disincentive to respond to any suggestions for improvement. In addition, patient feedback and engagement should not just be a one-off event but something services seek to capture and monitor on an ongoing basis. The purpose of seeking feedback should be to enable continual, small improvements to patient experience.

Recommendation four: Ensure there is a clear plan for communicating the opportunity to give feedback and communicate directly with patients whenever possible.

Several staff and professionals noted that identifying and encouraging patients to respond to opportunities for engagement or feedback could be challenging. Not all patients will want to engage in giving their feedback to services, for many reasons including time, trust and motivation.

Direct communication from services with patients is always more likely to get a response than general communications, such as through social media. One additional way in which staff and professionals suggested feedback opportunities could be communicated to patients was through their existing appointment letters, or at the bottom of communication about FFT (Friends and Family Test).

It is likely that the best way to gather a large volume of patient feedback data would be to use multiple methods. This could include promoting opportunities to feed back in appointments, on letters, via direct calls to patients, as well as indirect methods such as social media, posters and leaflets. It is also important to use multiple methods to avoid selection bias, rather than relying solely on staff in services to promote a project to patients directly.

Services should communicate about what has changed because of staff and patient feedback. This can promote a better response from patients to feedback mechanisms in the future. If patients feel that their feedback will be used and heard, they will be more likely to respond. Services can also utilise engaging methods of communicating with patients, such as sharing video case studies from patients.

Recommendation five: Ensure that methods for engagement and feedback are accessible to patients with a wide range of communication needs.

Accessibility is a key consideration when promoting any patient engagement and feedback work. This is particularly true of any project seeking to address health or care inequality in systems or across pathways.

Information about the opportunity to feedback, as well as the tools used for engagement, such as surveys, must be tailored to the needs of the patients they are intended to reach. This includes offering a wide range of ways to provide feedback to ensure projects do not unintentionally exclude certain groups. Supplementing written or online data collection, such as surveys, with other methods, such as face-to-face conversations or telephone interviews, can help to increase the accessibility of any project.

Important factors to consider include ensuring that feedback materials are available in languages other than English if required, accessible to people with visual impairment, and do not solely rely on access to digital technology or skills. Services should ensure they are meeting their responsibilities under the Accessible Information Standard, which includes providing information in multiple languages and formats.

There are specific considerations for spinal patients, particularly if they have difficulty giving feedback verbally or in writing because of the level of their injury. In these cases, it is crucial to have some way to identify, record and meet these communication needs. For some patients, it may be more appropriate to speak to them with the support of a trusted friend, relative or carer.

Recommendation six: Consider what resources are available or required to develop patient engagement and feedback work. Consider how partner organisations or secondary data can support gathering data.

Doing meaningful patient engagement and feedback work requires dedicated resources, including time, staff capacity and, in many cases, funding to make the most of the opportunities to hear from patients. It is not enough to simply invest in patient experience tools without having resources dedicated to processing, reporting, and acting on key themes or issues.

Services may be able to strengthen their approach by assigning responsibility to specific staff to ensure feedback is captured and reported to decision-makers. However, it should be noted that in-depth qualitative methodologies and free-text feedback require significantly more time to analyse and interpret meaningfully.

Services can also consider what other skills and resources are available locally to be able to support patient engagement work. For example, services could direct patients to feed back independently to Healthwatch Suffolk by hosting a widget for the HWS Feedback Centre on websites. Moderated feedback is available for services to respond to on the HWS website at https://healthwatchsuffolk.co.uk/services. Service listings are monitored by hospital patient experience leads who can respond to comments and flag them to appropriate staff and service leads, who can help to address specific comments or issues; potentially avoiding the need for formal complaints. Healthwatch Suffolk can also help services to communicate about opportunities for patients to give feedback.

In addition, staff and professionals suggested that national organisations or charities supporting spinal patients may be able to assist with efforts to gather feedback or share intelligence from their engagement with patients.

Recommendation seven: Consider the role of the East of England spinal network in supporting services to improve patient engagement and feedback mechanisms.

Finally, staff and professionals throughout the project appeared to have a limited understanding of how the East of England Spinal Network could support services in improving patient feedback or engagement. The network should consider its role in responding to, or driving forward, patient experience issues or priorities. This is an important part of determining the purpose of any future patient engagement across the network.

The network should consider the opportunities it has to adopt an active role in supporting services on the pathway. This could include facilitating collaboration between stakeholders or leadership in services to address key barriers, providing strategic vision or direction, or helping services to overcome issues that prevent services from being able to address feedback from patients and families.

The network could also have a key role when considering and sharing best practice in patient experience work across the region; highlighting clear examples of where patient experience has led to service change, and the potential to replicate such improvements across the region.

In addition, the network could consider how patient representation might feed into its future work plan. For example, the Spinal Network could consider whether it would be appropriate to have patient representation at Board or Clinical meetings as well as its role in addressing some of the themes explored in this report.

We will be making this report publicly available by publishing it on the Healthwatch Suffolk website.

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