healthwatch
Westmorland
and Furness

You Told Us

August 2024

You told us...

Based on August 2024, we've analysed the feedback we received to get an overview of the most common themes within health and social care in Westmorland and Furness. By encouraging people to share their experiences, it informs our future focus of engagement as well as highlighting any issues that we may need to escalate directly to the provider.

We also offer information and signposting if people need further support or want to make a complaint.

140 People were signposted to further assistance and help

We engaged with 700 people 256 members of the public, patients and charity sector

We reached 441 people through our social media and newsletter

We had the most feedback about...

- **Caring, kindness, respect and dignity**
- **Accessibility and reasonable adjustments**

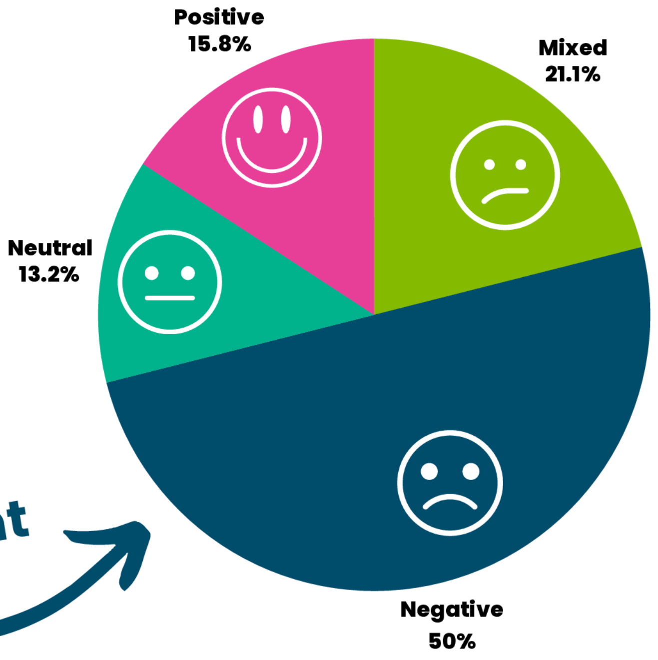
You told us...

- Acessibility and reasonable adjustments
- Caring, kindness, respect and dignity
- Quality of treatment

- Caring, kindness, respect and dignity
- Follow-on treatment and continuity of care
- Accessibility and reasonable adjustments
- Access to services
- Diagnosis
- Health inequalities
- Parking and transport
- Quality of treatment

- Consent, choice, user involvement and being listened to
- Parking and transport
- Accessibility and reasonable adjustments
- Caring, kindness, respect and dignity

Feedback sentiment



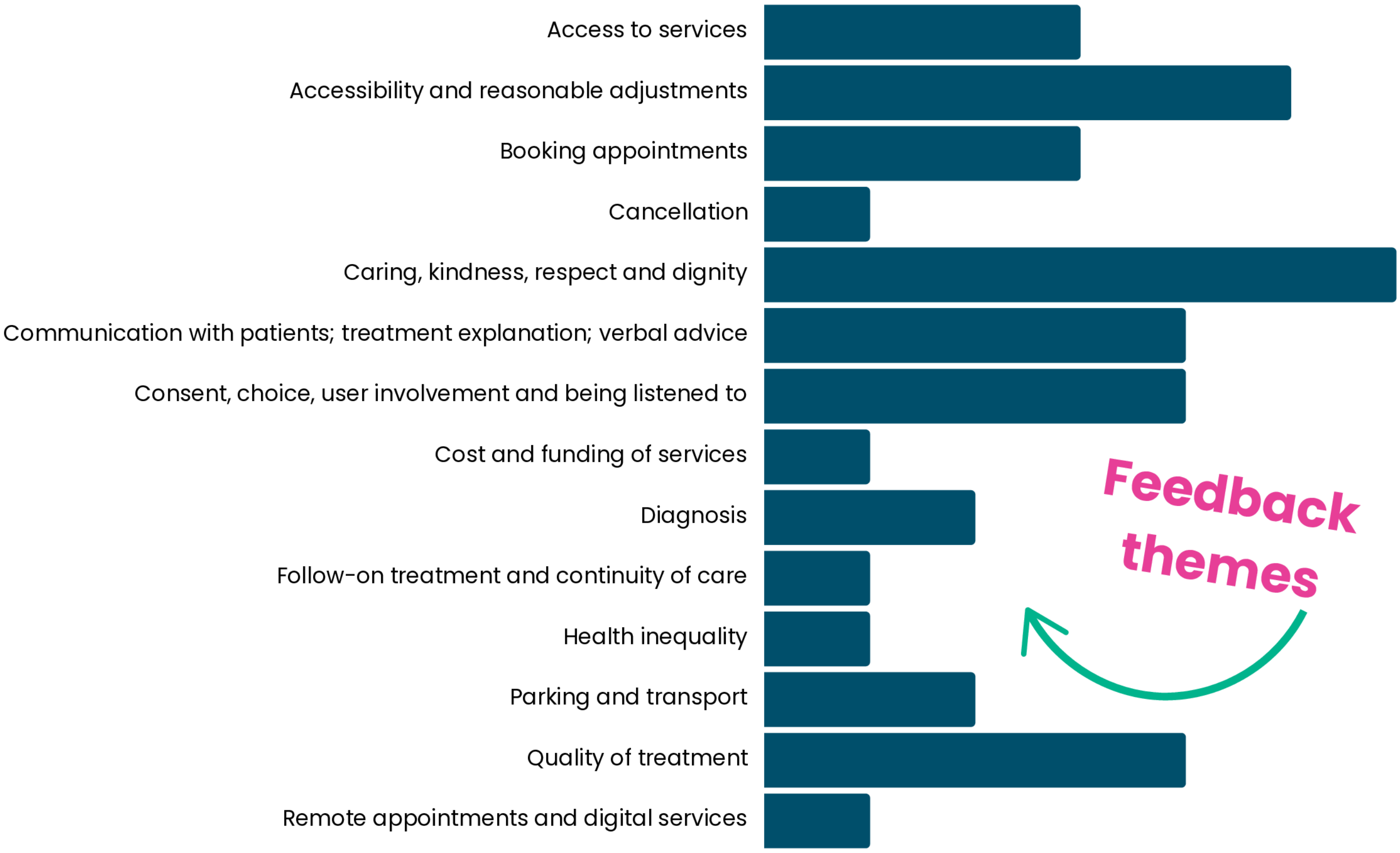
- Access to services
- Accessibility and reasonable
- Communication with patients, treatment explanation, advice
- Cancellations
- Diagnosis
- Remote appointments and digital services
- Quality of treatment
- Service cost / funding
- Consent, choice, user involvement and being listened to
- Follow -on treatment and continuity of
- Appointment booking

Domiciliary care
Member of the public has domiciliary care for one hour per day, six days per week and a two hour call on Tuesday. On Tuesday the carer helps with shopping and remainder of week they support with cleaning, cooking, changing bed and ensuring client is eating properly and has taken diabetic meds.

They are happy with carers as they help keep them healthy and 'it's company for me'. They have regular carers and they know each other well now. They help with form filling and other things if needed.

You told us...

We also heard about



This month we were out in the community across Barrow, Eden and South Lakes, hearing local peoples views of the health and social care. Some of the events and places we visited to talk to patients and the public were:

- **Penrith Hospital drop-in -** to hear patients' experience not just of outpatient and in-patient care but also dentistry and other issues.
- **Social Prescribing Health & Wellbeing Event, Barrow**
- **Appleby hub drop-in**
- **Lakeland carers afternoon tea**

Appleby Hub drop-in: Our great volunteer, Nigel, and Senior Engagement Officer Lisa

We did...

Report: Supporting patients with additional mobility needs to attend appointments

Earlier this year a member of the public contacted us regarding an issue getting physical access to his GP's surgery.

Restrictions had recently been imposed on a certain class of mobility scooters using the lifts at Alfred Barrow Health Centre, Barrow-in-Furness and, as a user of such a mobility vehicle, this limited his access to his GP, who is based on the first floor.

Under the Equality Act (2010) a legal duty for all health and care services to ensure that services are as accessible to people with disabilities as they are for everyone else. This duty recognises that disabled people might appear to have equal access to care and services but, without specific adjustments being made, that access may not be equitable.

We contacted the following services located on the first floor of the health centre directly to ask what alternative and reasonable adjustments were offered, and received constructive responses from the services.

healthwatch Westmorland and Furness

Alfred Barrow Health Centre, Duke St, Barrow

Supporting patients with additional mobility needs to attend appointments

August 2024

Read our report here

- Atkinson Health Centre (GP Practice)
- Abbey Road Surgery (GP practice)
- Diabetic eye screening services
- Cumbria Health (CHP)
- Talking Therapies
- Podiatry services

We took this opportunity to produce recommendations to all services at Alfred Barrow Health Centre to raise awareness of the reasonable adjustments needed by patients with additional needs. Our impact is improved communication and options for those patients.

We did...

We asked Eden women, 'What matters to you?'

Healthwatch Westmorland and Furness (HWW&F) worked with North East North Cumbria Integrated Care Board (NENC ICB) to find out what matters to women and girls in Eden when it comes to their health.

We promoted 'The BIG Conversation' survey across our social media channels, including a paid-for campaign in Eden. By taking part participants help to shape and improve future services for women and girls in Cumbria. We undertook the project as part of the North East North Cumbria Healthwatch Network, in partnership with NENC ICB.

We will follow this up with focus groups in September speaking to women with knowledge or experience of maternal mental health in small groups - a 'safe space' to share feedback. These conversations are so that we can gather additional information to the survey, which will help the ICB understand in what way the groups the Healthwatch network have spoken to have different needs. We will publish the results when they are made available by the ICB.

HWW&F will undertake the same survey across South Lakes and Barrow to build a comprehensive picture across Westmorland and Furness of what matters to women and girls in the local authority area. We need to do this work in two parts because South Lakes and Barrow fall under a different ICB (Lancashire and South Cumbria) than Eden.

Look out for our posters and take part!

We did...

We held our annual public Board of Trustees meeting

The value of listening

Healthwatch Westmorland and Furness

Annual Report 2023-2024

healthwatch Westmorland and Furness

Our Board of Trustees met this month at our Carlisle office. The meeting is transparent, and open to the public, who can ask questions about our work.

The board ensures that we deliver our statutory duties under the Health and Social Care Act 2012, and that we are acting with integrity and independence on behalf of the people of Westmorland and Furness.

The board meets every month and is kept informed by our CEO on the performance and delivery of our work programme. Trustees provide supportive challenge and critique as well as encouragement and acknowledgement of successes. This helps us to achieve results and impact for patients, the general public and our under-represented communities.

The Healthwatch Westmorland and Furness team are available to talk between 9am and 5pm, Monday to Friday. We're here to listen to your views and experiences, and we can help you find the health and care services you are looking for.

There are multiple ways you can share your feedback with us. If you have an inquiry, or want to share your general experiences, you can call the office on 300 373 2820 or email info@healthwatchwestfurn.co.uk.

ACTION

If you would like to leave feedback about a specific service, such as your GP Practice, care home or hospital the best place to do this is on our independent Feedback Centre at www.healthwatchwestfurn.co.uk

Personal story

Living with hypermobility spectrum disorder

'Anne' contacted Healthwatch Westmorland and Furness and asked if she could tell her story of living with the Ehlers-Danlos syndrome, Hypermobility Spectrum Disorder (HSD), one of 13 inheritable connective tissue disorders. A member of the team spoke to Anne to understand how the condition affects her day-to-day life, the lack of treatment pathways and what she would like to see change going forward.

Please note, for anonymity purposes, names have been changed.

Hypermobility spectrum disorders (HSD) are connective tissue disorders that cause joint hypermobility, instability, injury, and pain. Other problems such as fatigue, headaches, digestive problems, and autonomic dysfunction are often seen as part of HSD. (What is HSD? - The Ehlers Danlos Society (ehlers-danlos.com))

Anne is retired and lives in South Cumbria. Despite having the condition since birth Anne wasn't diagnosed correctly until she was in her early sixities, through an appointment with a rheumatologist.

HSD has several symptoms and not everyone experiences the condition in the same way. Growing up, Anne found she was double jointed and could do what she calls 'party tricks' with her body.

As she got older other symptoms began to manifest. Anne has particularly suffered over the years from elasticity of the joints and muscle and ligament weaknesses, which causes instability and makes it difficult to walk. She also cannot carry things such as shopping, and has issues with her back, neck and shoulders.

Anne explained it sometimes feels like joints are being "pulled out of their sockets". In retrospect, Anne admits the lack of diagnosis when she was

Personal story continued

younger may well have contributed to problems in later life, but there was little knowledge or awareness of HSD then.

Anne manages her condition through occasional use of crutches, electric chair and supports and braces to keep joints stable. She has had to purchase some of these herself. Her GP prescribes pain relief medication and she buys over-the-counter paracetamol but can’t take anti-inflammatory medication due to taking blood thinners. The condition means it is difficult for Anne to go out on her own and find ways to relieve the pain. Her partner helps where possible. She is, in effect, managing the condition herself as there is no treatment pathway.

Anne contacted us because she believes there is a “lack of knowledge, misdiagnosis and consequently support in this area (and nationally)” of HSD/ Ehlers Danlos syndrome. Principally, Anne is concerned with the lack of knowledge GPs and other health professionals have about the condition. She said of GPs: “I appreciate how pushed they are, but they treat symptoms individually not holistically. They need to join the dots up”. In Anne’s words, any treatment is “a bit piecemeal”.

Anne describes this as: “When you hear hoofbeats behind you, don’t expect to see a zebra. In other words, GPs look for the more common diagnosis, not the surprising diagnosis. The zebra became the symbol for those with HSD because they are the unexpected. Sometimes when you hear hoofbeats, it really is a zebra.”

A GP toolkit has been created but there needs to be better signposting to it. She would like GPs to think more laterally when assessing patients with potential HSD symptoms and not just treat each symptom in isolation.

Anne would be happy to volunteer her time to educate, inform and talk of her experiences with local GPs, Primary Care groups and any other relevant health professionals with a view to helping raise awareness, accelerate future diagnoses and potential treatment pathways.