Healthwatch Insight Report

What people across West Yorkshire are telling us about their experience of health and care services

August 2022

West Yorkshire Health and Care Partnership

healthwatch working together in West Yorkshire

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Introduction

In January 2019 the NHS in England published a 10-year plan for the NHS to improve the quality of patient care and health outcomes. The plan set out the areas the NHS wanted to make better.

West Yorkshire and Harrogate (WYH) Health and Care Partnership were asked to formulate a local plan in response, specifically a 5-year strategy. To ensure this reflected what local people wanted, the six Healthwatch organisations, (Leeds, Bradford, Kirklees, Calderdale, Wakefield, and North Yorkshire) across West Yorkshire were commissioned by Healthwatch England to find out local people's views. Over 1800 people told Healthwatch about their views and experiences, over the course of 2 months and a report of the findings with recommendations was written and shared with WYH Health and Care Partnership. This report fed into the development of the 5-year strategy, Better health and wellbeing for everyone which was published in February 2020.

With the passage of the Health and Care Act 2022 and the new statutory arrangements to support integration, all ICSs across England are required to refresh their five-year strategies during 22/23. A key part of the refresh is to take an open and inclusive approach to strategy development and leadership, involving partners, stakeholders and communities, and utilising local data and insights. To ensure local insight and voices are central to the strategy refresh Healthwatch across West Yorkshire were asked to provide a report about people's current experiences of the health and care system. The aim of this work was to pull together current insight across the area and identify any key gaps in insight.

What are we hearing?

This report is a summary of the key messages that Healthwatch across West Yorkshire are hearing from people in their areas. This data comes from a range of sources including engagement work undertaken, enquiries received by Healthwatch, and reports produced by West Yorkshire Health and Care Partnership, local places and third sector partners, over the last 12 to 18 months.

GP access

Access to GPs remains one of the key areas that people are talking to us about. People see GPs as the front door to the wider health and care service, and many feel let down when they can't access their GP in a way that works for them. There have been significant changes made to the way people can access GPs as a result of the covid 19 pandemic. We have heard of a lack of communication and confusion around the changes.

Some comments also reflect a view that people's perception is that while other services have returned to normal after the pandemic, they feel the same has not happened with GP services.

For some, the result of a lack of access to their GP has had a detrimental impact on their health and wellbeing.

“Being unable to access a doctor has led to my health failing further and has affected my mental health.”

People have highlighted several key challenges around access to GPs.

Booking appointments

Many people told us about their frustrations around the challenges of booking an appointment, whether online or on the phone. The issue of having to call on the same day, is a long-standing concern that we continue to hear about. People have also told us about challenges with call systems where they are having to wait in long queues or sometimes being cut off without the option of waiting in a queue. In terms of booking an appointment online, people have talked to us about not understanding how to do this, there being multiple options for booking causing confusion and online systems not being consistently available to people. This is resulting in long waits, not being able to get an appointment on the same day or when they feel they need it, or people just giving up and not booking an appointment at all. The result of this is potentially minor issues are being left untreated and escalate into major concerns that require more interventions. People told us about having to keep calling back to try and get an appointment. Having English as a second language acts as a barrier at some surgeries.

“Getting through on the phone [is the problem]. Being told there are no appointments left. Same situation all year round covid or not.”

“People (who don’t speak English) rely on families to help make the appointments, sometimes after a long wait they are told to call back the next day as no appointments are available.”

There have also been instances where people have been unable to get through at all and this resulted in them giving up or seeking help elsewhere.

“Didn't get through I was on call waiting for over two hours.”

“Had to go to walk in centre - couldn’t get through to surgery.”

“If you’re elderly or have a child and can’t get to see a doctor you go to A&E don’t you.”

From what we have heard ringing the surgery is sometimes the only option for making an appointment and when other options are available, they are not always accessible or effective.

“For so long doctors weren’t working or if they were didn’t answer the phone. My mum was stood in the reception of the surgery and was told couldn’t book an appointment had to be over the phone. So, she went outside and rang them and could see the receptionist and they took the booking. Unbelievable.”

“Can’t get through to surgery on phone. Can’t get appointment. Wait hours for a telephone diagnosis. Very stressful for older people not getting an answer on phone…. When people are ill, they can’t wait hours for a telephone response. In fact, I have felt like crying because I had no idea how to get a response. Only alternative to go to A and E and wait four hours to be seen.”

Face to face appointments

While some people have welcomed the convenience of a move to online and phone appointments, many people still want the option of face-to-face appointments and have reported difficulties making appointments to see GPs face-to-face.

“Don't understand why I cannot be SEEN by a doctor. I have heart issues, sciatica and arthritis and telephone appointments do not satisfy my needs.”

“I spoke to the receptionist about a face-to-face appointment, she said get used to it over the phone and video calling is the new way.”

The issue of face-to-face contact is especially highlighted by people with different communication needs and those who may not be able to get online and are digitally excluded. It is important to note that phone appointments work for some but not for everyone and are better suited to certain types of appointments and issues but not to others.

“My partner – who is in his eighties – was told to send them photographs of his private parts. He wouldn’t; you don’t know where those pictures might go.”

“I think GP’s need to return to seeing people. People need that one-to-one contact not a phone call. In the initial outbreak it was excellent, but it has become way too prolonged.”

Variation

One of the key themes that has emerged is the lack of consistency and variation between different practices. While surgeries are seeing people face to face this does seem to be easier to do in some practices than others. We have heard of variation in terms of communication, access, booking appointments and access to additional support through the GP.

> **"I have not been seen by a GP since before the pandemic, only phone consultation."**

We have heard of positive experiences where people have been able to access the support they need from their GP. However, for others this remains a challenge and clearly highlights the variation across the system.

> **"Never had an issue with my surgery answering the phone even during COVID - other people seem to have problems getting through to theirs but not me."**

> **"My GP surgery is very good I can get a face-to-face appt to check my blood pressure and weight and if I'm told a GP will ring me back, they do. I rang once on a Friday and was offered an appt on Monday but when I explained it was for my mental health she said, 'oh no we can't leave it until Monday' and she got me a GP appt for the same day. I can't praise my surgery enough."**

Triage

People told us about their confusion and discomfort around the triage questions that they are asked by reception staff and online booking systems. People either do not understand the reason for these questions or feel uncomfortable about sharing personal information with the reception staff – whether that be health information or other private matters.

> **“They [receptionists] shouldn’t be allowed to ask medical questions.”**

> **“They don’t tell you why they are asking questions.”**

> **“At one time if you said, ‘it’s personal’ they’d leave it and get the doctor to ring you but for the last 3 years they won’t give you an appointment unless you tell them.”**

There was also dissatisfaction about the outcomes people had following the triage questions. Some people felt they did not get what they needed, and the questions asked had been an unnecessary obstruction to getting an appointment with the GP.

Staff Attitudes

The issue of staff attitudes was another theme that we have heard about. Much of this related to reception staff and linked in with the triage questions. However, there were also concerns that reception staff were not always kind, compassionate and flexible in their approach and in many cases acted as gatekeepers.

> **“I feel they (reception staff) treat you like rubbish.”**

> **“Impossible, can’t access GP, can’t get past receptionist….”**

> **“Getting past the receptionist is the problem. When I ring up there's a message which says, 'Please be kind to the receptionist', they should be telling the receptionists to Please be kind to the patients.”**

People felt that the reception area should be welcoming and private staffed by a kind, compassionate and non-judgemental team.

> **“Since the front of house staff such as GP receptionists are often the first point of contact in any health service, it is important that they be non-judgemental and sensitive to a range if complex needs. A discreet reception area that is safe and inviting and allows for privacy while speaking to staff about health issues would also be very valuable.”**

Routine checks

We have also heard about regular reviews and check-ups moving to phone appointments or not happening at all. Some people told us about the deterioration in their conditions due to not being seen for routine checks.

> **“I have not had an annual check-up since 2019, I have two health conditions which were monitored annually.”**

> **“My family/friend was hospitalised due to the complications from her diabetes.”**

Accessible Information Standard (AIS)

The AIS is a fundamental mechanism to ensure access for specific communities, many of whom are facing the greatest health inequalities. Feedback has identified that the AIS is not being adhered to in many health and care settings.

From a GP perspective, we have consistently heard that people with sensory and other impairments sometimes find it difficult to access GP surgeries. There is evidence that the AIS is not being applied routinely across all surgeries, with people not always being asked about their communication preferences, and those preferences not always being acted upon. People with sensory impairments and other disabilities have told us it would be helpful if information about their needs was flagged within and across services.

Some GP practices use an electronic banner display to notify patients in the waiting area when they can go in to see their medical practitioner, but it was pointed out that some people cannot see this display and others are unable to read it.

We heard from people with learning disabilities and their carers about medical forms not being properly understood. The issue of staff not always taking the time to ensure things were explained and people understood what was happening was also highlighted. Medical staff may not see that people with a learning disability need to be treated any differently, but reasonable adjustments still need to be made when appropriate.

> **"Simple reasonable adjustments to help people with learning disabilities include having receptionists speaking to them kindly and patiently, surely something every patient should be entitled to, and giving them extra time."**

NHS Dentistry

Waiting lists

The issue of access to NHS dentists has been raised across all Healthwatch, including for both adults and children. People have told us that they simply cannot find an NHS dentist taking on patients.

> **"I moved here 6 months before the pandemic, and I have been unable to find an NHS dentist taking on patients."**

People have told us about the difficulties of registering with and seeing an NHS dentist, or even getting on to a waiting list. When people have managed to get on to a waiting list many have reported not knowing how long they will need to wait before being seen or being told the wait will be years.

> **"My teeth are in a terrible state, and I cannot access treatment."**

> **"I needed to ring several dental surgeries to get on the waiting list."**

> **“I registered with a dentist and was told I will be contacted; this was just before the pandemic; I am still waiting (over 2 years later).”**

We have heard reports of people being taken off lists without being aware of why, or how, that happened, or thinking they were on a waiting list to only be told that this is not the case.

From the information shared with Healthwatch over the last few months the situation has become worse, and it is becoming increasingly challenging to find an NHS dentist with a waiting list that people can join.

> **“I have rung 40+ dentists today to be told there is a 3+ year waiting list. I just don’t know where to go, I’m in pain cannot afford the thousands of pounds it would be to go private.”**

We have also heard about the challenges people are facing to find up to date information online about which dentists are taking on patients and how they can register. People have also told us that individual dental practice websites can be confusing about what they offer, for example, saying treatment is available but when contact is made this is only for private patients.

The only way to get the information is having to make many phone calls to dentists across the region.

Emergency Dental Care

Access to urgent dental treatment and care has also been highlighted as an issue. People are contacting NHS 111 for support when they need emergency care and are finding the service to be busy and not as responsive as they would expect.

> **"NHS 111 took up to 3 days to get back to me about a dental appointment."**

We have also heard about people contacting local dental practices for urgent treatment as per NHS England guidance but in reality, not being able to access this support due to not being registered with the practice.

People have told us about the impact that not getting dental treatment has had on them. This has led to obvious oral health issues and people having to live with extreme pain and broken teeth. This in turn has had an impact on people's mental health and wellbeing and is leading to greater health inequalities as those unable to pay for private treatment are suffering the most.

“I am feeling defeated… I am 6 years on waiting lists... I have effectively contacted every dentist in York, Selby & Leeds/Bradford. I have attended Leeds emergency dental care for antibiotics more times than I can count. After 6 years I have only been given antibiotics by the dental system. I am 24 years old and am due to lose all my teeth by the failings on the NHS to provide access to these services… I need to be referred to the dental hospital, but I can't be referred unless I have a dentist, which is quite ironic. I have broken teeth below the gum line which is potentially very dangerous and I'm at risk of septicaemia due to having to take antibiotics constantly, as I have open pockets in my gums... If I could afford private care, it would have been sorted by now.”

Children’s Orthodontics

Following the recent re-commissioning of children’s orthodontic services across West Yorkshire we have seen an increase in enquiries around this issue. We have also heard anecdotally that both the old and new providers of orthodontic treatment have been receiving high numbers of calls and complaints from patients.

One of the key issues people have been telling us about is around a lack of communication of changes with existing patients and those on the waiting list. People have told us that despite from being told their current provider was going to cease providing treatment at the end of March 2022, there has been no further communication about who will be providing future treatment or what to do/who to contact in the interim if treatment and advice is needed.

> **"She is in pain and distress, but there seems to be no way of securing her an appointment. When I ring 111, all they can say is "go to the GP". When I go to the GP, the GP says it's nothing to do with them and we have to go to the provider – but there appears to be no provider actually offering a service at present."**

For those on the waiting list, we have had reports of people receiving an email asking if they would still like to be on the waiting list in February but state that they have received no further communication.

> **"I am really worried she will have to be referred again and be at the back of the waiting list, having already spent 3 years waiting."**

We have also heard about the issues people have faced due to the gap in provision from the old service ceasing in March and the new contract beginning on 1 June.

Cost of living

We are hearing about the cost-of-living crisis and the impact of this on people's lives. People's access to services and support can be affected if they do not have money to travel to appointments, do not have access to or cannot use smart devices, or are unable to pay for private care if NHS care is not available (e.g., NHS dentists).

We have heard from local organisations supporting people about the increase in the numbers of people seeking help and having to make difficult choices in their lives.

> **"Currently the cost of living is causing a lot of problems in the local area and we're seeing a dramatic increase in the number of members that come to us for support around bills, particularly utility bills. We have heard stories about people choosing whether they're heating or eating, which is really difficult. At the moment the sun is shining, so that will be less of a problem, but as the year goes on and the winter nights come in and things get colder, this is going to be more difficult for people."**

People and local organisations are also telling us about the impact of the cost-of-living crisis on people's health and the challenges that can bring for many groups such as people living with serious illness, addictions and carers.

> **"We're seeing the cost-of-living crisis affecting those people (with alcohol dependency) because they're having to make decisions between buying alcohol, which they need to essentially stay alive, and paying their rent or buying food or buying necessities for their children."**

> **"The cost-of-living crisis is a huge worry to an awful lot of carers about how they're going to manage. A lot of caring involves, people perhaps using taxis to get from A to B because the person they care for can't manage on public transport. With certain conditions, people with care needs need to live in an environment that perhaps is very warm, so they have and particularly, obviously over the winter, people very worried about having the heating on, having enough warm clothes to wear."**

We also heard from stroke survivors about the impact of the cost of living on their recovery. They talked about the importance of having access to physical activities to support their recovery and wellbeing, but this was becoming limited due to cost.

“I go to aqua aerobics once a week, I'm lucky as I have a discount card (apparently now discontinued) so I pay a reduced payment, but even then, I can only afford one session a week.”

“I attend a private rehab gym once a week but have to pay £34 for an hour, ideally, I would like to attend twice a week but am financially restricted.”

The issue of having access to exercise and leisure facilities to support health and wellbeing was highlighted through engagement work. However once again people commented that for some this was limited due to cost, especially when we factor in other expenses such as getting there.

“Consider how we can reduce health inequalities and increase exercise opportunities for people on lower incomes.”

We are beginning to hear about the impact of the cost-of-living crisis on the workforce, especially those working in the care sector. We have heard of instances of support workers declining work where they need to travel relatively long distances because they don’t get paid mileage. This is having an obvious impact on them and the people they support.

Mental Health

Mental health was a priority theme identified through the engagement work Healthwatch carried out for the NHS long-term plan. The themes identified then were around access, waiting times, crisis support, better community support, young people's mental health and access for those with additional needs. We have continued to hear about these issues, and many have been impacted further by the effects of the pandemic and the increase in people needing support with their mental health.

Access to help when needed

We continue to hear about the challenges of people trying to access support for their mental health in a timely manner.

> **"Mental health diagnosis and access to support needs to be significantly easier and faster. People need support at the time they reach out, not months or years later."**

> **"I personally have previously waited on a list for counselling for a year which is far too long."**

The pandemic has seen an increase in the numbers of people needing help and support and it has become increasingly difficult for people to access support.

We have also heard about people falling in between services when they are ‘too ill’ for one service but do not fulfil the criteria for another service.

> **“Having to refer myself to IAPT to be then told I'm not eligible for support there basically left suffering.”**

Others have told us about the need to have a varied range of services and community-based mental health support. People have told us about the importance of support being tailored to people’s needs and for people and their carers to feel involved in the care.

> **“Being person-centred, recognising that the service needs to be designed around the users and not the other way round.”**

> **“Involve carers in care planning and when making any decisions about care. Carers know best, they are the people who look out or after them day in day out.”**

People also talk about the need for more preventative and awareness-raising work around mental health.

> **“Needs to be embedding MH awareness earlier, i.e., in schools.”**

Young People’s Mental Health

We are hearing about significant issues around a lack of support for young people with their mental health. Again, there has been an impact of the pandemic on young people’s mental health with increased challenges around getting support when it is needed. This has consistently been a key theme that children and young people have identified as a priority for them.

We have also heard about a lack of support for children with autism and long waits for assessments for autism.

> **“No mental health appointments for a 9-year-old. All we got was a call from CAMHS after being referred from the first response team. CAMHS said to contact charities for counselling, but he is too young for them. I'm trying and trying but I can't seem to get him any mental health support. It's just impossible to get anything other than an ASD/ADHD diagnosis out of CAMHS. We're now waiting 1+ years for his ADHD medication appointment because they have no staff.”**

“Significant lack of staff for children's mental health services. Child started receiving weekly support from Community Psychiatric Nurse, but nurse kept changing, which was not easy for a child with autism to cope with. For several months now there has been no support at all. Now having to pay for private counselling to support autistic child with complex mental health needs and suicidal thoughts. Inability to support private care long term.”

Crisis Support

A lack of support for people in mental health crisis continues to be an issue that we are hearing about. People have told us about long waits and not getting the support they need when they need it. Some people report that crisis services are not working effectively for them.

“Mental health crisis help is far too long, when people are in crisis they need support there and the 6-8 weeks is a ridiculous long time to wait when people are in a desperately low situation and need help there and then.”

Delays in Treatment

We have heard about long delays people have faced as a result of the pandemic and the impact of delayed treatment on people's health and wellbeing.

> **"I was told I had diabetes just before the pandemic. I was told the nurse would be in touch, I am still waiting, and it is two years."**

People reported severe deterioration in their physical, mental and emotional health, with high levels of anxiety and worry amongst people, even more so where people were living with mental health conditions. Others had seen a financial impact or been unable to work.

People also talked about the 'knock on' effect on family members.

> **"I have young children. I was not able to entertain or attend to them. I felt frustrated and sad."**

There were comments around communication where people hadn't been kept informed of how long they could expect to wait and what was happening. This led to additional stress and people feeling 'forgotten about' and not knowing who to contact for information and/or support.

> **"I could only contact the GP; I don't know who else to contact but it is difficult to get a GP appointment."**

> **"I just need to know my treatment hasn't been forgotten about even if I had simply to wait in the queue."**

Digital Inclusion

The issue around information, appointments and support becoming less face to face was consistently raised by those who feel this excludes them. We found this was a key concern for those who are not able to use or do not have access to digital technology. However, it is also important to note that many people told us that even though they can access digital platforms this is not a suitable option for certain health and care appointments and people may prefer this at some points and not others. In many instances, this affects people and communities who face additional barriers such as older people, those who may not speak English and people with learning disabilities.

> **"We do not get information from the internet because we do not know how to use it."**

“We feel it’s really important to have face-to-face appointments to avoid miscommunication. Language is an issue as is using digital technology.”

The idea of appointments only being available via an app was highlighted as a huge issue by an organisation supporting people with learning disabilities.

“That would really work against people with learning disabilities and likely have the greatest impact on those most financially and digitally excluded, effectively adding to multiple disadvantages.”

While some people understand the different ways of accessing support from health professionals such as telephone and online there is a clear message that this doesn’t work for everyone, and people should have a choice.

“It doesn’t work for everyone; I do not have a smartphone so I cannot send my GP an image of my infected area.”

“Make sure digital access to services is good but provide hardcopy information too. Give people the choice of how they want to access support.”

We have heard of the positive impact on many people of moving to more online and telephone appointments, but this should not be at the exclusion of people who don't have access to technology. People are also clear that this should be one option and that it works better for some things and not others. There is a need to have different options to prevent a two-tier system developing with people who don't have technology worse off.

> **"Yes, [to using technology] for most things (e.g., one off appointments, prescriptions, bookings), but with a face-to-face option, particularly for mental health appointments."**

Quality of Care

We have recently started to hear about negative experiences of people staying in hospital. People have told us that staffing seems to be an issue, where staff are busy and overstretched and there appears to not be enough staff to deal with patients on the ward. This has resulted in people not always being treated with care and compassion and their dignity being compromised.

“I was given a commode to go to the toilet in however they didn’t empty it frequently, so I was left in a room in my own mess. They also blocked me into the bed by keeping the side barriers up so when I tried to get up to use the commode, I hurt my back and wet myself on the bed.”

Health Inequalities

We continue to hear about the increasing challenges faced by those communities who experience the greatest health inequalities. Through organisations supporting these communities, we have heard about barriers to access, issues around digital inclusion and the impact of poverty on accessing health and care.

“Services need interpreters and multilingual literature.”

From all the messages we have heard from these communities and organisations that support them, some key themes have emerged. While many of these messages mirror those raised by many other individuals and groups it is important to note that for those communities who experience the greatest health inequalities there will be additional and specific issues and challenges.

- The **key role of GP practices** in health and care – while this is true for everyone there is a particular emphasis on GPs being a central point of information and support and co-ordinator of care for particular communities.
- The **first experience** when they enter a health and care setting – This has been particularly highlighted in terms of how people are welcomed if staff take a person-centred approach and are sensitive to the needs of different groups and communities.

"It would be nice to see a welcome sign in practices."

"Staff should have some cultural awareness of how people might express their pain and trauma in different ways."

- **Barriers to accessing** health and care services – this focuses on the needs of specific communities around language and interpreters and offering information that adheres to the accessible information standard.

"Not all people with autism are flagged or asked about autism when talking about reasonable adjustments – so autistic people might not know to tell someone about it."

“My dad was waiting on the IAPT waiting list for a year and a half. He went to the first and second session but did not continue as he was unable able to understand all the things that were being said…”

- The need for more joined-up **working** – This is a challenge across the system, but when there are additional challenges with communication it becomes even more important that people are not having to repeat their stories and there is an understanding of their communication needs.

“Try to ensure people don’t have to keep repeating their story to different staff members, as it can be retraumatising.”

- **Impact of poverty** on accessing health and care – We have heard about the disproportionate impact poverty has on people trying to access health and care services.

“It is common that GP’s charge for letters. Not everyone can afford to pay.”

- **Digital inclusion –** We have heard of the bigger impact on certain communities with the move to digital, where many are being left behind. People stressed the importance of having a choice.

> **"Make sure access to digital services is good but provide hardcopy information about them too. Give people the choice of how they want to access support and find out how carers want to be communicated with..."**

- The importance of having **an inclusive workforce** – This has been highlighted as an issue for communities who feel it is crucial that the workforce understands their needs, is inclusive and reflects the communities that it serves.

> **"To make me feel welcome I would need to see people that look like me or I can feel comfortable with."**

- **Gaps in current service offer** – We have been told about gaps in provision for certain groups and communities that result in support not being appropriate and leading to poor outcomes. These include the need for extended appointment times to support those with additional communication needs.

> **“People aren’t being made aware that they can book a longer appointment if they don’t speak English as a first language.”**

Being able to see the same GP to ensure more person-centred care. Recognising and addressing the gaps in mental health support, specifically around culturally appropriate language and support and where people fall in between services.

> **“Lots of people with a learning disability also have a mental health diagnosis and tend to fall between services.”**

> **“Services should use a de-stigmatising approach towards mental health, using positive language about emotional wellbeing as opposed to mental health problems.”**

- **Partnership with trusted communities** – Many organisations talked about the strong relationships third sector and local organisations have with certain groups and communities. If there were stronger links between the health and care sector and these organisations this would lead to better outcomes for people and increased trust in services.

- **Do all this with people and communities** – some of the feedback received talked about the importance of involving people from those communities in co-producing services so that their voice is at the centre of decisions.

> **"Ask people's views about services before putting things in place. There is still a tendency to ask people too late, when a project's parameters are already very much in place…"**

> **"Services should be shaped and influenced by the lived experience of service users and carers of all ages."**

Hospital Discharge

We have been hearing about people's experiences of hospital discharge. People told us about their experience of being discharged too early from hospital and not feeling prepared. The reasons for this included not having been informed it was going to happen or that it felt rushed or happened at very short notice.

> **"In hospital they didn't speak about discharge. I didn't get any warning that I was going to be moved, no-one comes and tells you anything."**

Others talked about not feeling involved in the process and this is even more of an issue for family members and carers.

> **“I spoke to the desk when I visited and asked if there were any plans to discharge and for them to let me know. The next day my dad was discharged, nobody had let me know and he was just sent home, without a care plan just with a bag of tablets.”**

Where discharge had worked well, people cited good communication, feeling involved in the process, involvement of their family members where applicable, and good coordination and quality of after-care as key reasons for this.

> **“The transfer was a good experience. The hospital prepared her well and were helpful. She knows she is in the facility as she still isn't ready to go to independent living.”**

People discharged home were more likely to be dissatisfied than those sent to a community care or other residential setting. The reasons given for this were a lack of follow up and people feeling that they had been left to sort things out for themselves, sometimes with no contact details of who to call if they needed anything.

Communication about discharge was highlighted as a concern, especially for those people being discharged home. People spoke about wanting better communication with family carers and more accessible information on discharge papers which they could easily understand and use to inform the person’s ongoing care.

> **“My daughter asked what the procedure was for discharge and was told the ward did not know the date of his discharge, but we would be informed the day before. On Sunday we returned from church to find my husband sitting on a cold stone step in hospital pyjamas and the transport driver was asking my neighbours where I was. A message was on the landline answer machine from that morning saying he was already on his way home.”**

We also heard about people being discharged home without the necessary support being put in place.

> **“Poor discharge un-co-ordinated with ensuring there was a provision of district nurses for providing insulin injections and dressing of leg wound,” family member.”**

Hypermobility

People with hypermobility issues have told us that they continue to experience difficulties getting a diagnosis. This was particularly the case for people who ended up with a diagnosis of hypermobile Ehlers Danlos syndrome. Medical professionals are frequently not recognising that the complex and multifaceted symptoms being reported are linked and for many people this leads to significant delays, often spanning years, in the diagnosis of a hypermobility syndrome.

People experienced multiple referrals, inappropriate referrals and difficulty persuading their GPS to refer them to consultants, lengthy waiting times both pre-and post-diagnosis and an absence of follow-up appointments.

People have reported that they are often unable to access NHS professionals with knowledge of hypermobility syndromes/related comorbidities, outside their area, due to waiting lists being closed to patients living outside the locality in which the service was provided. This has resulted in people receiving inadequate or no NHS care for their condition.

There is a lack of understanding and recognition of the condition and its comorbidities amongst health professionals leading to wasted time and referrals to other services that are not able to offer the support needed.

Key Messages/Recommendations

Much of this insight highlights challenges faced by people across the area as we come out of the pandemic. Many issues are ones that we were hearing about before and have been further exacerbated by the pandemic and now the cost-of-living crisis. We are hearing of the additional challenges faced by those with the greatest health inequalities, those with additional communication needs and people living in poverty. The key themes of access to primary care, NHS dentistry, mental health support and getting the move to non-face to face delivery right, further highlights some of the inequalities and inconsistencies across the system.

Based on the insight we have been receiving over the past 18 months we have previously made recommendations to The West Yorkshire Health and Care Partnership on key themes (The move to online, NHS dentistry, access to routine care, care home residents, GP appointments, integrated care, cost of living)

Based on this insight and building on those previous recommendations we would add the following:

- **Access** – There should be clear and simple systems and effective communications that allow people to access primary care services/appointments when these are needed and in a way that works for them.

- The **availability and length of appointments** should reflect the needs of the population and steps should be taken to address the availability when there are increased demands on the system.

- **Information**- All services should provide clear and simple information in a variety of formats about what support/services are available and how these can be accessed.

- **Involvement -** People and their family/carers should be kept fully informed and involved at all stages of their journey from referral through treatment to discharge. This should be done in a way that works for them and respects their wishes.

- **Inequalities –** Implement specific measures that address the additional barriers faced by people and communities with the greatest health inequalities. Ensure the needs of these communities are central to the design of health and care service development and delivery.

- **Variation** – Consider how to tackle variation across the system; identify good practice and consider how this can be shared and duplicated. Ensure measures to address variation take into consideration the impact this has on inequalities. Identify solutions to address and reduce health inequalities caused by variation, especially when this disproportionality affects those with the greatest health inequalities.

- **Communication** – Good clear communication is key to delivering a person-centred approach to care. Good communication improves outcomes, reduces costs and minimises some of the harm caused to people waiting for treatment and care. Every organisation across the health and care system should be working towards improving effective communication. Good communication with people using health and care services should be:

  - Person-centred
  - Clear and jargon-free
  - Timely
  - Compassionate
  - Sensitive
  - Accessible
  - Not rushed
  - Informed, accurate and trusted

- **Compassion** is another essential part of person-centred care. Compassion, or lack of it, plays a vital role in shaping people's experience of care. There is a key link between compassionate care and people's confidence and trust in services and better outcomes. All organisations across the health and care system should create conditions for compassionate care.
  - There should be a culture of compassionate care – leaders lead by example and frontline staff receive good support and opportunities to develop more compassionate ways of working
  - There should be a recognition that compassion cannot be rushed and there needs to be flexibility and time to deliver good quality care
  - Staff should be supported to have 'time out' to reduce compassion fatigue
  - There needs to be a recognition that system and staffing pressures will have an impact on the consistent delivery of compassionate

care and changes in how the system works may need to be considered.

- **Co-ordination -** Good co-ordination of services to meet people’s needs is one of the key principles for delivering good person-centred care. Good co-ordination helps people have a positive experience and improves outcomes, especially for those that have multiple and interacting health conditions. It can lead to a positive impact on people’s wellbeing and make people feel safe and in control. All organisations across the health and care system should work together to ensure there is good co-ordination across the system. Good co-ordination should include:

- ➢ Timely and efficient interventions
- ➢ Clear communication
- ➢ One person co-ordinating
- ➢ Good information sharing systems
- ➢ Consideration for the person as a whole
- ➢ Involvement and consideration of family carers
- ➢ Involvement of the person in receipt of care at all stages
- ➢ Using digital services, platforms and infrastructure to enhance people’s experience

Next steps

This report will be shared with the West Yorkshire Health and Care Partnership and used to help inform the refresh of the 5-year strategy. Any gaps in engagement will be identified and a plan developed to address these gaps. The report will be available on the West Yorkshire Health and Care Partnership website and will include a formal response to the recommendations.

References

This report has been written using a range of reports and sources including information received through enquiries across local Healthwatch, engagement work undertaken or currently being carried out, feedback shared at a local level and reports from local places which can be summarised here West Yorkshire Health and Care Partnership - Involvement and consultation mapping report (May 2022)

All Healthwatch reports that have been used to support this report and are publicly available will be available on each Healthwatch website:

Healthwatch Leeds

Healthwatch Bradford and District

Healthwatch North Yorkshire

Healthwatch Wakefield

Healthwatch Calderdale

Healthwatch Kirklees

Previous Reports

Healthwatch Reports to System Oversight and Assurance Group (WYHCP)

Healthwatch Report on NHS Long Term Plan

Links

NHS England 10-year plan. https://www.longtermplan.nhs.uk/

West Yorkshire Health and Care Partnership 5-year plan - Better health and wellbeing for everyone. https://www.wypartnership.co.uk/publications/our-five-year-plan healthwatch

working together in West Yorkshire