



Self-management of health

What people across West Yorkshire told us helps, and what gets in the way of them managing their health

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healthwatch
working together in West Yorkshire

West Yorkshire

Making a difference in health and care

VOICE

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Summary

Introduction

Across the health and care system and policy, we are seeing an increasing move towards 'supported self-management', a term often used to mean increasing someone's knowledge, skills and confidence to manage their own health. (See ['background'](#) for further information).

To help bring people's voices into planning across West Yorkshire, we wanted to understand more about people's experience and views of the realities of 'supported self-management'.

Through an online survey and outreach, we heard from 155 people about their thoughts and experiences of self-management; what has helped and what the challenges are. This report draws on both data from the above engagement as well as previous engagements and wider sources (see [bibliography](#) for full references).

Key findings

- People already self-manage their health every day. This will be a bigger part of people's lives if they have one or more long-term conditions or disabilities.
- Successful self-management requires access to quality support on a needs-led and ongoing basis. This means shifting away from seeing self-management as solely led by individuals, towards understanding it as a shared responsibility between them and services.
- Supported self-management approaches need to look beyond simply influencing behaviour change and consider wider systemic barriers.
- There can be significant risks to people's health and wellbeing where self-management is promoted but not supported or overseen.
- There are lots of things that can be done to increase the chance of supported self-management being successful – these are outlined in the different sections of this report.

Key message

We want this report to be a useful and practical summary about people's experiences of self-management and how they can be better supported to look after their own health and wellbeing.

We have structured it around a series of themes that came out of what people told us.

- Cost of living and meeting basic needs.
- Existing conditions and disabilities.
- Accessible information and communication.
- Confidence and motivation,
- Family, carers and other support networks.

For each theme, we have explored the barriers and challenges that people are facing, as well as guidance around what people told us helps them to self-manage.

We would like service providers, teams and individual professionals to use this report, especially the 'what helps?' sections of it, to reflect on what more they can do to work with people to ensure the best chance of supported self-management being successful.

Background

This year, the government published the 10-Year Health Plan, which focuses on three 'shifts' towards:

- care being closer to home (“hospital to community”)
- making more use of digital (“analogue to digital”)
- prioritising prevention of poor health (“treatment to prevention”).

Within this, we are seeing an increase in conversations about the use of ‘supported self-management’ approaches. The [Fit for the Future: 10 Year Health Plan for England \(UK Govt, 2025, p34\)](#) and [West Yorkshire Integrated Neighbourhood Health Teams Blueprint \(West Yorkshire ICB, 2025, p.32\)](#) also described aims to support people to take greater care of and make decisions about their own health.

[NHS England](#) describes ‘supported self-management’ as increasing someone’s knowledge, skills and confidence around managing their own health.

The [Fit for the Future: 10 Year Health Plan for England \(UK Govt, 2025, p.34\)](#) also highlighted the impact of health inequalities on people’s ability to self-manage their health.

“To make self-management sustainable, we must also acknowledge the barriers people face, such as digital exclusion, cognitive decline, language and cultural differences, or social isolation. These factors can't be ignored in national strategies or local plans.” (Respondent to professional’s survey)

What we did

Between July and August 2025, we ran an online survey for the public and professionals, alongside a programme of outreach to groups across West Yorkshire. We also spoke to two professionals who run services that support people to self-manage (see [good practice examples](#)).

In both the survey and our in-person outreach, we asked people:

- What barriers they face to managing their own health?
- What they worry about when managing their health?
- What supports them to manage their health?
- Examples of good practice.

Focus Groups

We ran five group discussions with community members and one with professionals.

- **The Prince of Wales Hospice social group (in person).**

A social group held in Pontefract for people using Prince of Wales Hospice services, such as carers, bereaved carers and people who are facing social isolation (6 people).

- **Service User Network, SUN (online).**

A group of people with lived experience of using Leeds and York Partnership NHS Trust's mental health, learning disability and neurodiversity services or people who care about someone who does (14 people).

- **Healthy Living Group at Bradford People First (in person).**

A self-advocacy group in Bradford helping people with learning disabilities have their voices heard (4 people).

- **Inclusive Voices Group, part of the Accessible Calderdale Project (online).**

The group is made up of people with a wide range of impairments who meet regularly to share ideas, develop insight into genuine co-production and advocate for change and transformation. The group runs a variety of sessions that are welcoming and safe spaces to reach local disabled people in their communities. (4 people)

- **North Leeds Medical Practice Patient Participation Group (in person).**

A group of patients in Leeds who volunteer to act as a link between the practice and its patients, gathering feedback on experiences, discussing issues, and making suggestions for improvements to the healthcare they receive. (8 people).

- **Young Lives Consortium in Wakefield (in person).**

A network in Wakefield that brings together professionals across VCSE, NHS and local authority who support children and young people (24 people).

Survey responses

We completed 45 individual in-person surveys.

- **Kirklees in Recovery (in person).**

We attended the breakfast club in Dewsbury (Kirklees) for Kirklees in Recovery, which is an organisation that supports people with recovery from drug and alcohol addiction. (12 surveys)

- **Project Colt (in person).**

We attended the community cafe at Project Colt in Elland (Calderdale), which is an organisation that supports people with recovery from drug and alcohol addiction. The cafe is open to the public, so we spoke to people using services and wider members of the local community. (16 surveys)

- **Batley Multi Academy Trust**

We attended a summer fair at one of their eight schools, Field Lane Junior, Infant and Nursery School. We spoke to parents attending the summer fair with their children (16 surveys).

We had an additional 33 online responses to our public survey and 15 to our professionals' survey. You can find a breakdown of the demographics of survey respondents in Appendix 1.

What do we mean by 'self-management'?

When we asked people what helps and hinders them managing their own health, the feedback demonstrated the huge range of elements that people saw as being involved in self-management.

These included:

- **Ongoing management of overall health (not related to specific condition)**

For example, managing elements of a healthy lifestyle through factors such as diet, exercise and sleep.

- **Managing a specific condition on an ongoing basis**

For example, taking medication, monitoring or managing symptoms like pain and adapting their lifestyle.

- **Administrative and practical tasks which aid self-management**

For example, booking appointments for new concerns or arranging follow-up appointments, booking tests, ordering and collecting prescriptions, managing referrals, and managing travel.

- **Understanding symptoms and/ or conditions**

For example, recognising a health concern or a change in an existing condition and knowing when and where to reach out for support.

- **Accessing and understanding information**

Finding out information about a new or existing health concern and where to access support.

- **Decision making**

For example, deciding when and how to get support for a health concern or change in condition.

- **Having support**

For example, attending appointments, understanding information provided by health professionals, asking questions to professionals and following up on advice and signposting provided.

Therefore, we have used 'self-management' quite broadly to refer to any of the steps that people must take to manage their overall health and wellbeing as well as specific conditions and/ or disabilities.

Cost of living and basic needs

Barriers and challenges

While health services are free to access through the NHS, some people told us about the financial costs involved in certain elements of staying well and managing health conditions and/or disabilities.

In our public and professionals' surveys and outreach, people told us that the costs of exercising, using public transport and paying for private equipment or services has impacted their ability to self-manage. The role of money in supporting people to self-manage was a particular concern at a focus group with people experiencing mental health difficulties. A few survey responses from people with disabilities or long-term conditions also expressed worries about the potential health impact if they were to lose their benefits, especially with their health conditions making it difficult to work.

"If my benefits should be withdrawn. I will not survive. I could not afford my rent, electric or gas bills or any of the private services I currently use to keep me as mobile, mentally healthy and able to eat. I employ a cook, cleaner, shopper, driver, befriender, podiatrist, physiotherapist, reflexologist, and I purchase a variety of vitamins, minerals, electrolytes, gut help, and Fortisip. I have to wear a knee brace, use a walking stick and power wheelchair, all bought privately" (respondent to public survey).

When speaking to people from 'Inclusion Health Groups' about the 10-year health plan, we heard how health can often fall to the bottom of someone's priorities due to other, more pressing basic needs. For example, people spoke about the difficulties of managing multiple needs such as housing, benefits and employment, when leaving prison, and how health was often the lowest priority.

People with experience of sex work also highlighted that behaviours that may be considered detrimental or a risk to someone's health can form part of someone's basic needs. They gave examples of how both substances and involvement in sex work are important means for someone's survival.

Therefore, it's important that professionals approach any self-management discussions with compassion, curiosity and without judgement.

“Sometimes there are other appointments for non-health related things that clash with health appointments. It's about deciding what you prioritise. Most times, I'll knock my health back and go do something else” (respondent to public survey).

What helps?

- **Working with people to find affordable ways to manage their health**

It's important that professionals are mindful of different financial circumstances and how this might impact self-management. For example, some people told us that they would like to be able to access free or low-cost exercise options, and those struggling with their mental health highlighted the importance of low-cost counselling options.

This need for more financially inclusive signposting and information about staying healthy was echoed in various reports including: [‘Cost of living Check in’ \(Healthwatch Leeds, 2022\)](#), [‘Let’s hear it for women’s health and wellbeing’ \(Healthwatch Kirklees and Calderdale, 2024\)](#) and ‘Closing the Gap – Thinking Together to Act on our Financial Challenges’ (Bradford District and Craven Health and Care Partnership and QA Research, 2025). These reports highlighted examples such as the need to improve support and information about cooking on a low income, and where to find affordable places to exercise.

- **Reducing travel and the associated costs**

With travel costs being highlighted as a concern, people may benefit from care and wider health and wellbeing support which is closer to home. This may involve home visits or support and activities provided at local outreach venues or community hubs.

Where travel is necessary, support people to access low-cost or free options.

People on low incomes may be able to access the [Healthcare Travel Cost Scheme](#) for hospital appointments, and there are community transport options such as [Access Bus](#) to help people access local activities and other services.

- **Offering appointments alongside services that help meet basic needs**

In discussions around the 10-year health plan, people from 'Inclusion Health' groups (people in contact with the criminal justice system and sex workers), shared that it was helpful when appointments were offered at a location where they could also get other types of support. This could be a drop-in or community venue which also offers support such as hot meals, food parcels or housing advice.

- **Being curious if someone doesn't attend appointments/ 'engage'**

Some people from 'Inclusion Health' groups and supporting professionals, have told us that missed appointments should be approached with curiosity rather than judgement. This was echoed in a paper on ['Understanding the causes of missingness missed appts in primary care'](#) (Lindsay et Al., 2024), which found that those missing more than two GP appointments a year on average were those experiencing financial hardship. Therefore, it's important for professionals to consider why health may not be someone's main priority at a particular time due to their circumstances.

Existing health conditions and disabilities

Barriers and challenges

In the recent [‘Neighbourhood Health Report’ by Healthwatch Leeds \(2025, p.29-30\)](#), the most common barrier identified by people to looking after their health the way they would like to was their physical or mental health. This was echoed by our own findings, where people told us about the difficulties of self-managing health when living with one or more disabilities or long-term health conditions, particularly mental health conditions.

“I have CFS and am well at the moment but am always aware that a bad flare up could be round the corner despite my best efforts to stay well” (respondent to public survey).

A key message from one of the focus groups was that self-management is already a core part of daily life for those living with disabilities and something they are good at.

People’s answers in the survey and focus groups showed the physical and mental toll that self-management of existing conditions can have on people and the need for greater support.

“With PIP, I can avoid all the stressors that aggravate my condition and regulate my nervous system to some extent. But even when I have my plan of action and appointments in place and know I’m doing all I can to protect and sustain my life, my nervous system still remains overwhelmed in fight or flight, for my life has been a daily trial since infancy... So, life is oppressively lonely and isolating... an ordeal with no respite” (respondent to public survey).

Therefore, we heard about how symptoms and wider elements of existing conditions or their current health can make managing overall health and the administrative side of self-management more challenging. For example, people spoke about memory difficulties leading to forgotten medication, and someone expressed challenges with booking appointments early in the morning due to insomnia.

We also heard about the side effects of medication, making it harder for someone to lose weight, as well as examples of people's weight, making it difficult for them to exercise.

On top of these existing daily challenges, some people told us that managing their condition(s) was difficult due to services not being joined up. Several people in the survey spoke about their care for different conditions or symptoms being separate, without a holistic approach to their overall health and circumstances. This also included examples of people having to speak to different professionals and having to repeat themselves. We also heard examples of people struggling to access the support for self-managing their existing conditions due to not meeting the criteria of services or due to difficulties getting a diagnosis. For example, some people couldn't access mental health support due to other existing conditions and circumstances, such as having a learning disability or experiencing drug and alcohol dependence.

"Systems are too confusing. Having multiple long-term conditions means that medical professionals only consider their own speciality, and no one looks at me as a 'whole' person. Knowing who to contact when problems arise is a huge barrier, and I have been passed from person to person on a number of occasions, trying to speak to the right person...I also have fatigue and mind fog, so that can cause difficulty if I need to speak to a clinician, as I have to feel 'well' to do so" (respondent to public survey).

People also talked about the ways in which self-managing health can be made difficult, when necessary, services, activities and ways of accessing them do not consider different needs. For example, people shared examples of the difficulties of finding disability friendly or covid safe exercise spaces. We also heard in our focus groups that public transport can be a barrier for those with experiences of mental health and/ or trauma, and appointments at unfamiliar locations can be a challenge for people with a learning disability. When speaking to people about non-emergency patient transport earlier this year, we heard that people have experienced a lack of and a high cost for Wheelchair Accessible Vehicles (WAV) taxis.

We also heard about the difficulties of managing conditions and disabilities without the appropriate practical support in place. An example from one of our focus groups was the impact of long waiting times for wheelchair assessments, leading to sores and poor posture, which can affect someone's ability to move around. The impact of delays for occupational therapy assessments was also highlighted by a professional working with older age adults and in conversations about the 10-year health plan with people from Gypsy and Traveller communities.

“Without basic Occupational Therapy (OT) assessments, individuals may go without essential mobility aids or home adaptations, increasing the risk of falls, injury, and hospitalisation” (respondent to professional's survey).

The [2025 'Healthwatch Leeds Neighbourhood Health report' \(p.4; p.29-30\)](#) also found that multiple health conditions were more likely to be identified as a barrier to self-management by people living in lower-income areas (Indices of Multiple Deprivation 1 and 2).

Further, as highlighted by someone in our professionals' survey, we also know that poor housing conditions due to damp and mould or increased pollution can affect people's health, making it more difficult to self-manage their health, including existing conditions like asthma. This was shown in the ['Housing for Health' \(West Yorkshire and Harrogate Health and Care Partnership and Yorkshire and Humber Academic Health Science Network, 2020\)](#).

What helps?

- **Recognising the impact that long-term conditions can have on people's ability to self-manage and that this may fluctuate alongside their health.**

Professionals need to be understanding of the difficulties of self-managing when living with long-term and/ or multiple conditions. Some people told us about practical solutions which can help them to better navigate the inherent difficulties of managing one or more disabilities or long-term conditions, such as Dosette boxes and delivered medications.

Professionals shared tools they use to support older age adults who may struggle with memory such as hydration charts and memory clocks. These are just some examples of what some people find helpful, and it's important that any such solutions are still person-centred.

- **Recognising that people with multiple conditions may need ongoing, flexible self-management support that is tailored to their specific needs.**

Support needs to be personalised as everyone is different and needs different information, tools and support to help them self-manage.

Some people also said they would benefit from having a consistent named person that they could speak to about their conditions and who is easy to contact. This can help build trust and confidence through a better understanding of a person's individual needs and circumstances, and lead to more consistent communication and information. Some people also talked about the benefits of pre-planned contact with professionals, such as follow-ups, check-ins and reviews booked in advance.

“They [professionals] just said, “I seem to know what I am doing and am managing it well” and I was discharged. This was fine until I had no one to contact when things were not fine” (respondent to public survey).

“People are more likely to share health concerns and follow advice when it's coming from someone they feel safe with” (respondent to professional's survey).

- **Acknowledging people as experts in their own health.**

People with long-term conditions and disabilities (as well as others) want recognition for the ongoing self-management of their health that they do every day. A [briefing on 'Reducing emergency admissions \(The Health Foundation, p.1\)](#), revealed that people with long-term conditions spent under 1% of their time in contact with health professionals. This suggests that a large amount of health management is done outside of health appointments. People told us that they want the knowledge and experience they have built up through self-managing to be valued and included within any plans and decisions about their care.

"Most people manage their own health and sometimes need professional assistance too. It's very patronising to assume that most people don't do that" (respondent to public survey).

"Self-management is touted every few years, we become 'expert patients', then we get ignored or treated like the enemy because we dare know about our conditions. Support it or don't, but not just as a cheap substitute for actual care" (respondent to public survey).

"Ultimately, people tell us that managing their health feels easier when they are listened to, respected, and involved in their care decisions, rather than having plans imposed on them" (respondent to public survey).

Accessible information and communication

Barriers and challenges

Although there is a lot of information available about health and related services, some people told us they don't feel they have enough, or the right kind of information needed to manage their health. This theme was mentioned in each of our focus groups and throughout the public and professional surveys.

“I know that if I don't take my epilepsy medication every day, it would have serious consequences. Originally, when the medication was prescribed, they didn't tell me what it was for until I asked” (focus group participant).

In our focus groups and professionals survey, we heard that some people don't feel they have the information they need about what support is available. People expressed that they were unsure where to find information about specific health services and wider support services related to managing health and wellbeing. In one of the focus groups, people said that mixed communication from services and professionals can make it more difficult to choose the appropriate service.

“If you speak to a pharmacist, they might say go to GP anyway, if you ring 111, they send you to A&E/ hospital anyway. People end up in emergency departments anyway” (respondent to public survey).

Both the public and professionals survey also highlighted that some people also don't feel they have the information needed to understand and manage specific symptoms and conditions. Some people spoke about this in terms of not having clear or accessible communication from professionals. For example, some described communication as “rushed” or “full of jargon” and others said things weren't explained clearly, such as the reasons for medication or tests. We also heard examples of people being without important information while awaiting a referral to a specialist, such as a dietician, for diabetes. People and professionals also shared examples of the impact of not communicating clearly when something changes, such as a brand of medication, which could lead to uncertainty and confusion.

Unclear information or communication may affect someone's ability to follow up on advice, monitor and manage their symptoms and conditions or arrange further appointments.

[about a doctor's appointment] ... "lots of information given, which is hard to absorb, especially as it was such a new and upsetting scenario for me. I did scribble notes down, but would have been really useful to have had a written overview about next steps, i.e. blood test in a week, don't take meds, do take folic acid, etc. There is no way my mum could have taken any of that in without someone being there and I was struggling" (respondent to public survey).

A key concern that West Yorkshire Voice and Healthwatch across West Yorkshire regularly hear is people not having information in the format that is most accessible for them, or appropriate to their culture, identity or life circumstances. For example, we often hear that people who speak English as a second language and those with lower literacy levels are often not provided with accessible written or verbal information about health conditions and about their care, affecting their ability to self-manage.

In one of our focus groups, people with learning disabilities told us about examples of not understanding information they had been given relating to their health, particularly if an appointment is not in person. These included not being given clear explanations, not being given follow-up information and occasions where information was not presented in the required accessible format (e.g. 'easy read' format). One person told us that they attended a self-management course for diabetes, but due to their communication needs not being met, they only understood around half of it.

"Long letters are really hard. They don't make it easy for you; they make it ten times harder. They're doing it in a way that's easier for them but not thinking about how it will make it easier for me" (focus group participant).

With the 10-Year Health Plan shift towards greater use of digital, it's important to note that while some people told us that they find digital information and communication beneficial, others said they didn't have access to or lacked the confidence or skills to use digital technology. Barriers to using digital forms of information and communication were raised in most of our focus groups and in both surveys, particularly by professionals supporting older age adults.

People with learning disabilities also told us that digital approaches to self-management can be disempowering for those unable to use them, as people are forced to rely on support workers to help them.

Digital exclusion can both impact people's ability to find information about health as well as access appointments through platforms like the NHS app or PATCHS. More information about people's experiences and the barriers they face around digital exclusion can be found in reports such as ['Keeping every door open: Ensuring access beyond digital in health and care'](#) (Healthwatch Leeds, 2025) and ['Digital access to GP services'](#) (Healthwatch Kirklees and Calderdale, 2025).

What helps?

- **Explaining information and allowing enough time for questions.**

We heard that it helps if professionals share clear information and explanations about where to get support, how to manage their symptoms or conditions and any future care and treatment. People need enough time in appointments to ask questions. Some said it would be helpful to have a written record of discussions from appointments.

**“We would have really appreciated...being given clear instructions, ideally written, around the next steps/care plan for my mum”
(respondent to public survey).**

Several people shared that they would like to better understand basic self-management of their condition in terms of what to look out for (warning signs), when to seek support and how to manage overlapping conditions. Others spoke about wanting better information about what services are available, as well as when and how to access them.

“Proper education- not just online or leaflets once a year”
(respondent to public survey).

- **Making sure people are provided information about their health and care in a way that is appropriate and accessible to them.**
- This must be in line with the Accessible Information Standard (AIS).
- Information should be culturally appropriate.
- Information should avoid using or explain jargon and medical terms.
- It's helpful to consider how someone prefers to learn or understand information e.g. visual, verbal, written.
- People should have a choice between digital or non-digital information.
- **Supporting people to navigate the complex health system.**

Some people, including professionals working with older age adults, told us that it would be helpful to have more professional roles which are focused on supporting people to navigate the health and care system. For example, this could include support with booking appointments, ordering prescriptions, and explaining health information.

Where it is not possible to have a dedicated professional, services should consider how all staff can take responsibility for supporting people to navigate the complex health system, as reflected in the approach of **'Making Every Contact Count'**. Within this, it's important that this is not limited to basic signposting, such as handing out leaflets, but considers different communication needs and barriers people face to services.

- **Recognising the valuable role information and resources which are developed with or informed by people who have personal experiences of health conditions and/ or specific circumstances.**

Some people spoke about the value of information shared by peers with similar experiences to learn about ways to manage their health condition or disability.

People who live with health conditions and disabilities have a wealth of knowledge from their daily experiences. We have seen examples of these experiences being used to develop resources to support others, such as the [West Yorkshire Neurodiversity Programme](#).

"When I was first diagnosed [with CFS], I was given some information by a friend which helped me considerably when I was unable to access help via the NHS due to long waiting lists. It gave me an overview of the condition and ways to manage it which I've used ever since" (respondent to public survey).

- Tailoring approaches to information sharing and health education to meet the needs of individuals and communities.

Examples of this are:

- When speaking to people using Leeds GATE services about moving more care from hospitals into the community, people said they find it helpful when health professionals attend their drop-ins to share health information.
- A care company in Leeds told us that they match people with carers who speak their first language and understand their cultural needs. This has supported better communication with people about their health conditions and improved people's confidence and motivation to self-manage.
- A professional working in a Leeds-based neighbourhood network for the over-60s suggested having health advocates or link workers to help explain health information to people in person.
- A professional working in cancer care told us about examples of group and one-to-one sessions delivered after cancer treatment to provide advice on nutrition, physical activity, mental wellbeing and local services.

Confidence and motivation

Barriers and challenges

Some people expressed low confidence in their ability to self-manage their health (sometimes referred to as self-efficacy), and 'fear' and 'worry' of doing the wrong thing. This included worries about managing a new condition, how to manage multiple conditions or disabilities and how to live a healthy lifestyle.

"I currently have a child with allergies, and managing that is worrying, especially as I've not experienced it before" (respondent to public survey).

Some people expressed worry and low confidence in self-management while waiting for a GP or specialist appointment due to worries about their conditions or overall health getting worse. Similarly, low confidence was also expressed when people were discharged from a specialist service due to being unable to get the same level or type of support from their GP. People in recovery from drug or alcohol dependence also expressed worries about relapsing. People with learning disabilities and those experiencing mental health difficulties said they had low confidence in getting support from services due to previous negative experiences of care or being turned away for support.

"In my area of work, we often find that once people finish cancer treatment, it actually becomes harder for them to manage their own health. They can feel less supported and unsure about how to move forward. It would be really beneficial to explore how we can help people feel more confident in managing their health after treatment." (respondent to professional's survey)

Experiences of stigma and discrimination from professionals and/ or wider society (e.g. from media coverage or social media), can also lead to worries about accessing support. For example, a report called ['Let's hear it for women's health and wellbeing'](#) (Healthwatch Kirklees and Calderdale, 2023), showed examples of people experiencing judgment around drug use and weight loss, and the impact this had on someone's confidence and/ or motivation to seek help.

“My girlfriend refuses to go to see anyone about her health due to a bad experience a long time ago... She is too scared to go to the doctor. She shuts down when I talk about health to her, and she won't let anyone in. She hasn't been to see anyone for screenings, and she won't go to the GP if she has health worries. I don't know how to help her to be able to go to the doctor, and I worry about her getting ill” (respondent to public survey).

Motivation also came up as a theme relating to people's ability to self-manage their health. Some people told us they find themselves 'putting things off,' and some struggle with the energy and time required to be motivated. At a focus group with people living with disabilities, we also heard that long waiting times, such as for GP appointments, can put people off seeking support.

Motivation and confidence to self-manage can fluctuate along with existing health conditions, disabilities and other interacting life factors. Motivation, like confidence, can also be affected by long waiting times, past negative experiences of being passed around and having to repeat their medical history multiple times.

“[A barrier/challenge to self-management is] feeling it's not important if the Doctors/ Nurses don't want to see them- it can't matter or can't be that bad” (respondent to public survey).

What helps?

- **Being shown what to do and checking people are confident to do it.**

Professionals shared examples of where elements of self-management can be taught such as insulin administration, managing a catheter, checking for warning signs such as skin changes, shortness of breath and changes in blood sugar.

“People need time to be spent with them to ensure they understand their condition and how to manage it. Some people tell me that no-one has ever actually explained their condition - just given them treatment.” (respondent to professional's survey).

You can read examples of this approach in the first [good practice example of Locala](#).

- **Positive and encouraging approach from professionals.**

The '[Supported self-management: summary guide](#)' (NHS England, 2020, p.5) discusses the importance of recognising the "skills, strengths and attributes" that a person brings to managing their health. It's important to recognise and praise progress, as well as being empathetic to the challenges faced. Using positive language can help build confidence and trust.

At a focus group with disabilities, people also shared that it is really helpful when they feel confident that a professional is listening to them.

"A positive attitude and gentle encouragement from carers or family members makes a big difference. Some individuals lack motivation or feel overwhelmed, and small, regular prompts help them build confidence in managing their daily health needs" (respondent to professional's survey).

- **Making sure that support is non-judgemental, compassionate and trauma-informed.**

Staff should be supported to develop awareness of how the way people behave or communicate may be affected by past experiences. This may include anger, frustration or defensiveness. We have heard from people from 'inclusion health' groups, and those who work with them, that supported self-management needs to be adaptable and accessible, taking past adversity and trauma into account.

Family, carers and other support networks

Barriers and challenges

Several people told us that having supportive social networks, such as family, carers and friends, can be beneficial for self-management of their physical and mental health.

We heard about their importance in providing social and emotional support as well as practical support with things like travel, food shopping and organising appointments. People with disabilities shared the importance of having people around you who can notice when things aren't quite right and offer support. Where people didn't have such support networks, people said it can be more difficult to self-manage their health and can have a negative impact on their mental health, particularly on older people or people with disabilities.

Equally, even where people have support networks or caring support, there are often limitations to when this support is available. In our public survey, unpaid carers highlighted the challenges of supporting a loved one with self-management, whilst juggling work or other commitments and responsibilities. At a focus group with people with learning disabilities, we heard about the challenges of managing all the different elements of self-management when support workers and carers are only available during certain hours. For example, asking people who are not confident with digital access to make an appointment online could mean using some of a support worker's allotted time to support with this. This may mean the person then has less time with their support worker to do the other things that might keep them well, such as socialising, activities and food shopping.

It is also important to note that carers may experience challenges managing their own health because of the demands of being a carer. In the [State of Unpaid Caring in Leeds: Annual Survey, 2024/2025 findings \(Carers Leeds, 2024, p.4\)](#), 62% respondents said that caring had a negative impact on their physical health, and 76% reported a negative impact on their mental health.

“As a carer, it is more about wellbeing and having the help and support so I can look after 2 disabled family members” (respondent to public survey).

What helps?

- Involving family and/or carers in conversations and planning around self-management.

Several people told us that their family, friends and/ or carers are an important part of their self-management. Therefore, it's important to involve people's key support networks in discussions around managing their health.

“Communication is key between health professionals and family members; it needs to work like a team rather than just thinking the family can pick it all up. If we have to, at least communicate well and make it easy for us.”

- Access to groups and activities.

Many people throughout the survey and focus groups mentioned the importance of groups, activities and hobbies in the self-management of their health. These included arts, exercise and social groups, which help people to feel a sense of belonging and connection.

“Where we see patients, whatever it is for we discuss referrals to groups such as community plus to look the reduction of social isolation for the individual. We have had people join men's groups, educational classes online, craft groups and befrienders, etc. This meaning that people are often less concerned about the nurse not visiting as they have other social interactions planned.”

(professional)

- Access to peer support groups.

People and professionals across the surveys and focus groups spoke about the benefits of speaking to those with similar personal experiences to learn from each other and normalise these experiences. Several people felt that a supportive peer group gave them a voice and made them feel heard. One individual spoke to us in depth about the “life-changing” impact of attending a self-management course led by people with similar experiences of managing long-term conditions and disabilities.

They told us that being taught by someone who understood their experiences helped to deliver the right messages in a way that they could more easily understand.

"I have never been able to find support until I found the Leeds Autism AIM support hub. This is the first time I have found people who understand... For anybody who is excluded from society, their best chance of survival is to find a peer group where they can seek advice of others with lived experience and even find themselves in a position to help their peers and maintain some sense of dignity" (respondent to public survey).

- Asking carers about any challenges that their caring role may present to managing their own health and discussing any support that may be helpful.

In both the public and professionals' surveys, people spoke about the importance of carers' assessments as well as respite support and activities which enable carers to have a break from their caring responsibilities.

Risks of self-management approaches

Self-management without effective support

People and professionals told us about the potential risks of people being left to self-manage independently without having proper support and oversight of their conditions. These included:

- Changes in someone's health going unnoticed.
- Self-neglect.
- Taking medication incorrectly or missing doses.
- Important checks, tests or screenings being missed.
- Generic rather than personalised support could lead to health conditions worsening.

"Self-Neglect is always an area of concern, if after our work with an individual we can't say they are safe and reliable to be left alone then we would pass them back to the care of the Community Nursing Networks." (respondent to professional's survey).

These risks may be higher if:

- Someone is struggling to meet their basic needs and may be unable to prioritise their health.
- Someone has received limited or inaccessible information about how to manage their condition, what to look out for and when to seek support.
- Someone is digitally excluded or struggles to access information independently, e.g. due to language barriers or low literacy.
- Someone faces barriers to accessing their GP or other services.
- Someone is socially isolated and does not have support from family, friends or carers.

“[I worry about] no one checking on them, whether it’s right for them. Deterioration in condition and no one being aware, and them being isolated” (respondent to professional’s survey).

“We strongly believe that self-management is most successful when people are not left to manage alone. It’s about empowerment with support, not independence at the expense of safety” (respondent to professional’s survey).

Over-reliance on digital technology

People told us that various elements of self-management of health (e.g. access to information, booking appointments) relied too heavily on digital tools, which disadvantages people who face any level of digital exclusion. This was echoed by the findings of the recent report ‘Secondary Engagement Analysis for Bradford District and Craven Health and Care Partnership in Bradford’ by (Bradford District and Craven Health and QA Research. 2025).

For those who are unable to use digital technology, there is a risk of declining health if alternative methods are not provided. This risk also increases if someone does not have family, friends or other support networks who have the necessary digital knowledge and skills to support them.

“What begins as a digital barrier quickly escalates into a health and safety risk.” (professional from neighbourhood network for over 60s in Leeds).

Misinformation

In both the public and professional surveys, we heard that where 'supported self-management' is not in place, there is a risk of people turning to unreliable sources of information in order to understand and manage their health, such as search engines, social media or Artificial Intelligence (AI). If people self-manage their health based on misinformation, there are risks of worsening health conditions. This was something that was also highlighted in ['Keeping every door open: Ensuring access beyond digital in health and care'](#) (Healthwatch Leeds, 2025).

Good practice example one

Locala Self-Management Team

Overview of service

The Locala Self-Management Team has been running since June 2023 and covers the whole of the Kirklees area. It includes a registered District Nurse (Band 7), a Clinical Lead (Band 6) and four Self-Management facilitators. All staff have been extensively trained in both clinical and coaching skills to give people and their carers the skills, confidence and knowledge to do tasks that can support them with their own care.

This includes tasks such as:

- Using eye drops.
- Catheter care, such as changing a catheter bag or valve.
- Changing simple dressings for minor wounds.
- Using Compression Wrap Systems and hosiery – Leg wraps and stockings to manage swelling.
- Giving injections just under the skin (subcutaneous injections).
- Blood sugar checks and insulin injections – for people with diabetes.
- Applying medication patches.
- Looking after feeding tubes (that go into the stomach).

The service works from the basis that:

- Patients are experts in their own health and care.
- With the right coaching, training and support, many people will be able to develop the skills and confidence to perform tasks that will help them manage their own care.

It works in a holistic and person-centred way, starting from what matters to someone, and working with people to find solutions that will work for them.

They are conscious that they want the service to be about people and not be over-medicalised. They also take into account wider needs and support, and refer to other local services, such as [Community Plus](#), where appropriate. The team works in a trauma-informed way to try to understand how past experiences may affect the person they are teaching and adjust their approach accordingly to avoid triggers.

“They have really helped me. M is coming out today with someone about me getting out and about more... M has been great – not just with my patches but with other things too. Just a little thing like helping get something sorted on my iPad to claim a receipt back, I just couldn’t do it, but M managed it.”

Referrals come from the community nursing teams and services linked to them, such as continence, tissue viability and diabetic specialist nurses. The service has also recruited a nurse to start to do some work with patients in Huddersfield Royal Infirmary prior to discharge, so that they can build the skills and confidence to do tasks before they get home.

The team is funded by a budget from the community nursing team, with whom they work very closely. They feel it’s important that this self-management team is separate, instead of simply having an expert link nurse or lead practitioner who leads on self-management.

How the team works with people and carers

The team typically works with people and their carers for three months, visiting them regularly in their homes, for up to an hour per visit. This timeframe is flexible and can be longer or shorter depending on individual needs. Support is gradually phased out when the person, their carer and the team are confident that the person can manage independently. There is also phone support from the team if people need advice.

The team takes a flexible and holistic approach and doesn't see the endpoint as 'all or nothing'. Sometimes it may be only realistic for someone to achieve 'partial self-management' in that they may only be able to manage to do some aspects of a task, or that there are certain times they will be unable to do it due to other factors (for example, when someone is unwell and may need more support).

In these cases, they may come to an agreement on what and when the patient feels comfortable to self-manage and when they need support and oversight from the community nursing team, who are happy to undertake shared care.

People have an assigned Self-Management Facilitator who sees them consistently which means that trust and good rapport is built up with patients.

People are supported to build knowledge and skills of what to do in different scenarios, what to look out for, and who and when they need to ring for support or advice. All learning is backed up by providing written leaflets to the patient/carer. There is a focus on experiential learning, which means that over time they will inevitably face different scenarios and be able to, with support, 'try out' what they have learnt, and staff are able to provide feedback. This can build people's confidence so that they will eventually be able to cope on their own once support is phased out.

"C has been absolutely brilliant. She explains everything in a way that I can understand. I don't know what I would have done without her."

Benefits of Self-Management for people and carers

- Increased confidence in caring for themselves.
- Not having to wait around for the nursing team to call.
- Increased control, choice and flexibility around care.
- Having the knowledge to spot and tackle any issues quickly.
- People are able to work towards what matters to them.
- Reduced risk of infections

- Staff time spent with individuals to teach self-management skills can help to identify and tackle wider issues such as social isolation and make appropriate referrals for further support.

“It’s been great for me. I can do my catheter myself now. Someone just comes every 12 weeks now to change something, but the rest I do myself. I feel so much more confident. I didn’t always like to go out but now I can.”

- Benefits of Self-Management for staff and organisations.
- Reduced pressure on community nursing services, which helps them to focus on where they are needed most.
- Reduced ambulance call-outs and risk of hospitalisation when a patient builds the skills, confidence and knowledge to know when to act, and what to do.

“J has been amazing. She’s taught me how to change dressings and do it all properly. She’s really good, kind and caring. It’s nearly healed now too. It just wasn’t healing before.”

Barriers/challenges to self-management and how the service works to overcome them

- **Not understanding what self-management is.** Sometimes the service gets referrals, and people arrive not knowing why they are there or what self-management is. Usually, once the team has met with the person and explained what they do and how they can help, this usually helps to make people more comfortable and able to engage.
- **Lack of confidence/knowledge.** People and their carers often welcome the opportunity to learn, but can be quite fearful of getting things wrong or not being able to do something when they are on their own. The service addresses this by working at people’s own pace, using coaching techniques and providing positive feedback to reinforce people’s capabilities. They make sure that while someone learns, there is someone regularly overseeing their progress and that support is only tapered off once they feel confident that a person feels comfortable and confident to self-manage.

- **Lack of buy-in.** Sometimes, even when the service is explained along with the benefits and flexibility it can give to people, some people aren't willing to learn to do things themselves. This can be for a variety of reasons, including people thinking that this should be the nurses' job. It needs to be accepted that supported self-management is not for everyone, and without buy-in, it is very unlikely to succeed.
- **Memory issues and disabilities.** These can provide challenges to self-management, but the service has found ways to support with these, such as:
 - Sourcing aids to overcome physical barriers.
 - Using different modes of communication, such as boards with pictures and symbols, for people with learning disabilities.
 - Posters to aid memory.
 - Where possible, it will try to work with the person to think outside the box to put things in place to make things workable for them.
- **Loneliness/isolation.** For some people who are socially isolated or lonely, the regular visits from the self-management team provide interaction and company. In some cases, this leads to an over-reliance on the team. It is important to have clear boundaries from the start of the support and understand which other services the person may want to access to reduce future isolation.
- **Cultural approaches and language barriers.** There can be differing cultural attitudes towards self-management, and these need to be taken into consideration. Some cultures, for example, may have a strong preference for health professionals to carry out all care tasks or a stronger fear of getting something wrong. Staff need to have an understanding of cultural norms and cultural sensitivity built into the person-centred approach. The Locala Self-Management Team also supports inclusion of patients by recruiting staff members who represent the people they support and by working with interpreters. This is particularly helpful when staff can communicate with people in their chosen language.

Possible developments for the future

- Considering more use of technology as a temporary educational tool for patients, for example, Freestyle Libre, which can give continuous real-time blood sugar readings, giving patients instant feedback about the impact of what they're eating/doing on their blood sugar levels.
- Development of a progress star for patients and staff to measure their progress. It would include things like confidence to do tasks and wellbeing, and it aims to help the team ensure their care looks at 'the whole person'.
- Teaching self-management in care homes.
- Development of peer support mechanisms.

For more information contact Helen Arnold, Team Leader, Locala Self-Management Team helen.arnold@locala.org.uk

Good practice example two

An interview with Dr Frizelle

Overview

Dr Frizelle works as a psychologist in a long-term conditions team in Leeds. Within her role, she regularly sees the value of supported self-management approaches when these are used effectively.

We asked Dr Frizelle for their reflections on different aspects of supported self-management. Much of what she said echoed what people told us was important for supported self-management to be successful for them.

“We need to talk about SUPPORTED self-management.”

What is needed for self-management to work?

It is important to understand what is needed for someone to be able to implement or change behaviour related to managing their health.

In psychology, there are three key ingredients to health behaviour change, which refers to changing behaviours or lifestyle factors that may be having an impact on someone’s health, for example, smoking, diet, alcohol and drugs.

These are information, motivation and self-efficacy.

Information

There is so much information available to us already, but supported self-management is about so much more than this.

We can’t assume that information alone leads to changes in health behaviour.

There is an overreliance on professionals giving information, such as giving people a leaflet.

“People being told ‘you need to lose some weight’ isn’t helpful information alone.”

Motivation

Motivation can impact people's ability to change behaviours related to their health or implement advice they have been given.

It's important that we better understand what leads to low motivation, such as thinking about where someone managing their own health fits into priorities ('Maslow's Hierarchy of Needs'). For example, if they don't have enough food, safe housing, financial security and a degree of stability in their life, these may well become priorities over managing their own health.

Therefore, we need to approach low motivation with compassion and try to fully understand what may be contributing to this.

"Health behaviours are very hard to change; if they were easy, we would all be healthier."

Self-efficacy

Even with information and motivation, a person also needs to have belief and confidence in their own ability to work towards a goal.

Often, there is a strong focus on someone being 'unmotivated' and 'disengaging' without considering a person's level of self-belief and confidence that they can achieve a goal.

"It can be unhelpful to just think, 'We gave them information about gyms, and they didn't go'. Let's think about why they didn't go. Was it because of, for example, the cost, having to travel, or the motivation or confidence to do it?"

Why is it important to focus on the 'support' in 'supported self-management'?

I do believe strongly in the 'supported' element of self-management and that there is a risk that the move towards self-management could mean that some people will unintentionally not get the support they need.

I'm keen for staff to have greater training around how they can better support individuals to self-manage their health in a compassionate, non-judgemental and person-centred manner.

What tips would you give to professionals around self-management?

Focus on the quality of a conversation vs time:

- The quality of any conversation is the most important thing for supporting someone around their health behaviours.
- Often, professionals worry about not having enough time with someone to support them, but having shorter but more regular conversations with people can be as meaningful as longer sessions.
- There are lots of simple tools that health professionals can use, and you don't need to be a trained motivational interviewer.

Focus on positive messaging:

- Focus on what people have done well and have achieved through positive reinforcement.
- Give positive messaging when suggesting something that could work, for example, 'this is effective in x amount of people'. This helps someone's response to it.
- Fear tactics for behaviour change are not effective.
- Peer support spaces can be effective in helping someone to see and hear what works.

Be non-judgmental:

- Approach conversations with compassion – often people will fear judgement when sharing any updates around managing their health.
- Thank and praise people for sharing honestly about any difficulties they have in managing their own health.
- Focus on small steps and what someone has done, not what they haven't.

Dr Dorothy Frizelle

Head of Adult Psychology Services, St. James's University Hospital, Leeds Teaching Hospitals Trust.

For more information or to speak to Dr Frizelle, please email leedsth-tr.ClinicalAndHealthPsychology@nhs.net

Appendix 1: Survey demographics

Public Survey

In the public survey, we captured demographic information slightly differently to limit the number of questions and encourage people to share this information. One of our questions included a tick box of several factors which can impact on someone's health outcomes and access to or experiences of health and care services. For example, if someone is an unpaid carer, English is not their first language, or they have experience of things like homelessness, the prison system, or addiction.

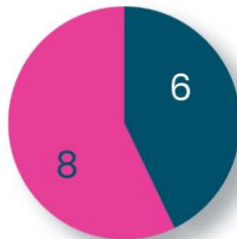
The figures below capture the demographics for both the online and in person survey responses. They do not include the demographics for the focus groups.

Unpaid carers

14 survey respondents were unpaid carers.

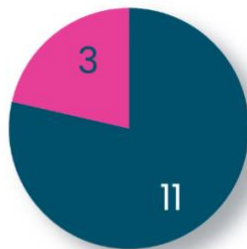
Health of unpaid carers

- Own disability or long term condition
- No disability or long term condition



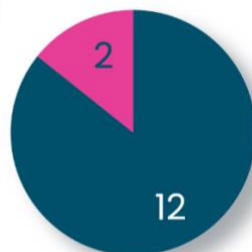
Gender of unpaid carers

- Female
- Male



Ethnicity of unpaid carers

- White background
- Asian or Asian British



Language

5 survey respondents told us that English was not their first language.

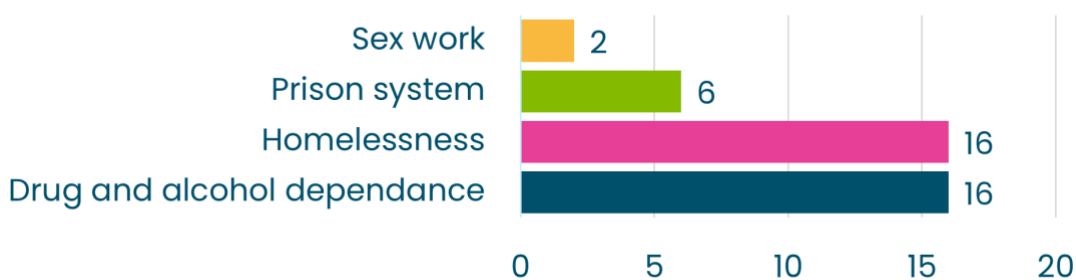
LGBTQIA+ identities

8 survey respondents identified as LGBTQIA+.

Inclusion health groups

21 survey respondents identified as someone from an '[inclusion health](#)' group and 11 respondents identified with more than one inclusion health group.

Respondents experiences of inclusion health groups



Financial hardship

22 survey respondents identified themselves as currently unemployed or on a low income.

Long-term conditions and disabilities

28 survey respondents said they did not consider themselves to be disabled.

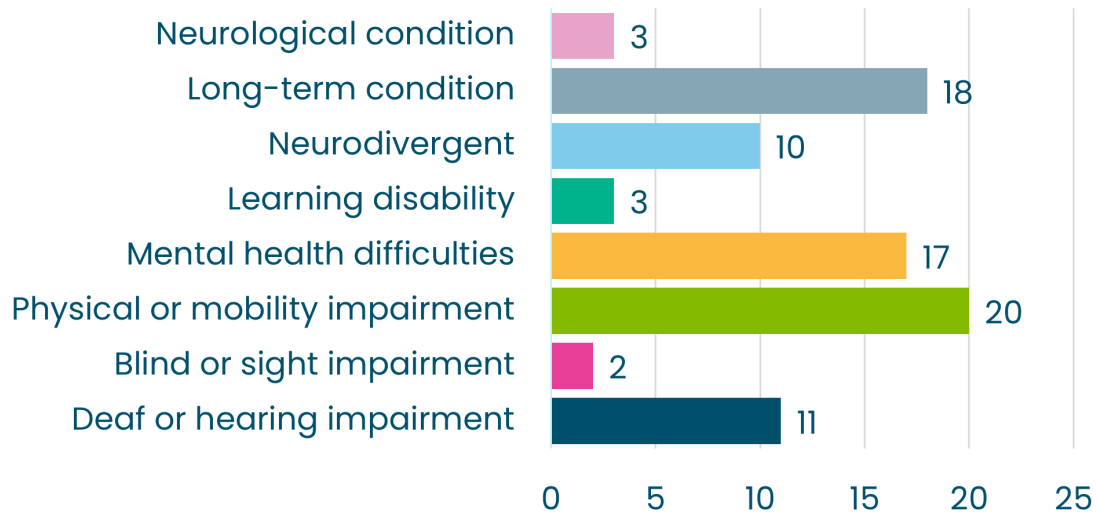
- 1 of these respondents still identified as having a long-term condition but not as disabled. Others still spoke about health conditions in their responses, including mental health and chronic fatigue syndrome (CFS), despite not identifying as disabled.
- 6 of these respondents were also unpaid carers who spoke in their answers about the long-term conditions and disabilities of those they provide care for.

14 people chose not to answer the disability question.

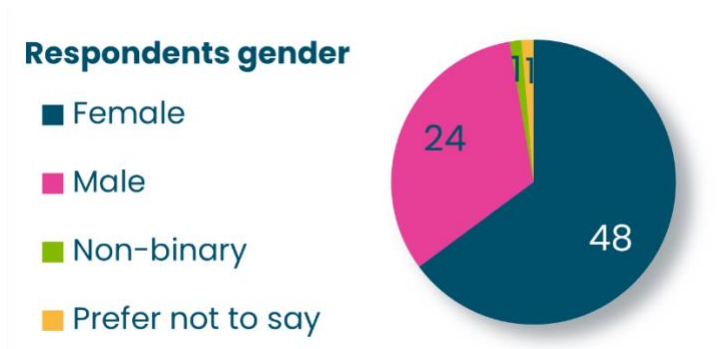
36 survey (46%) respondents shared that they have a disability or long-term condition.

- 22 of these survey respondents had more than one disability or long-term condition

Respondents long-term conditions and disabilities



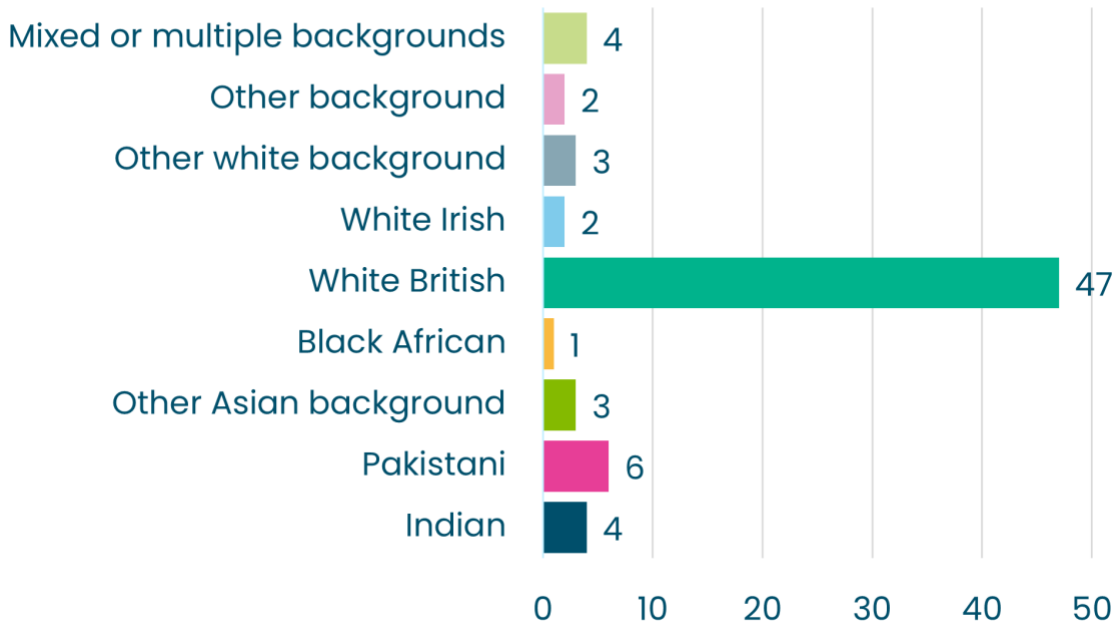
Gender



4 people chose not to answer the gender question. No survey respondents selected trans man or trans woman

Ethnicity

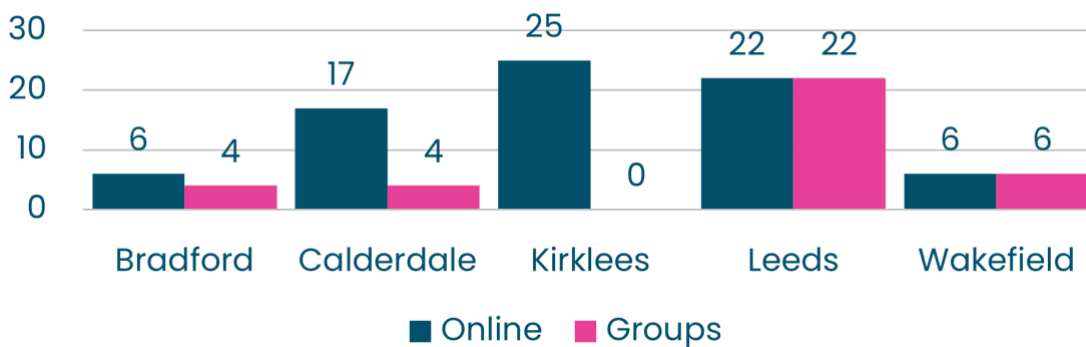
Respondents ethnicity



Respondents who said mixed or multiple ethnic backgrounds were (1) White and Black Caribbean, (2) White and Asian and (1) other). 11 people (14%) chose not to answer the ethnicity question

Location in West Yorkshire

Respondents location in West Yorkshire



In Bradford, we spoke to a further 4 people from the Healthy Living Group.

In Calderdale, we spoke to a further 4 people at the Inclusive Voices Group.

In Leeds, we spoke to a further 22 people at the Service User Network and the North Leeds PPG.

In Wakefield, we spoke to a further 6 people through the Prince of Wales Hospice group.

Limitations of the data

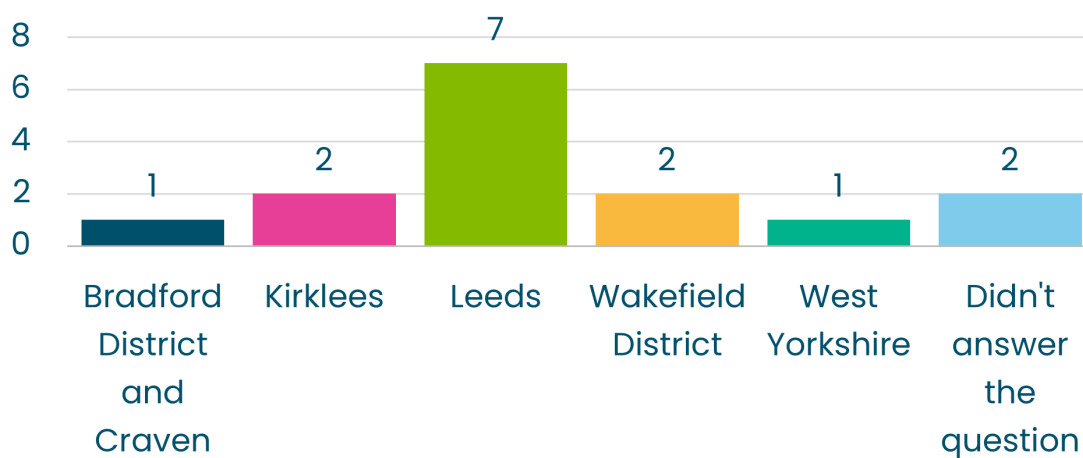
As the sample size of survey responses was small, it was more difficult to make conclusions about the views and experiences of specific demographics and to show intersectionality. The survey responses also lacked diversity in ethnicity and gender identity. We also did not collect data on age, religion and marital status.

Professionals' survey

15 people who responded to the professional's survey.

The areas they worked in are as follows:

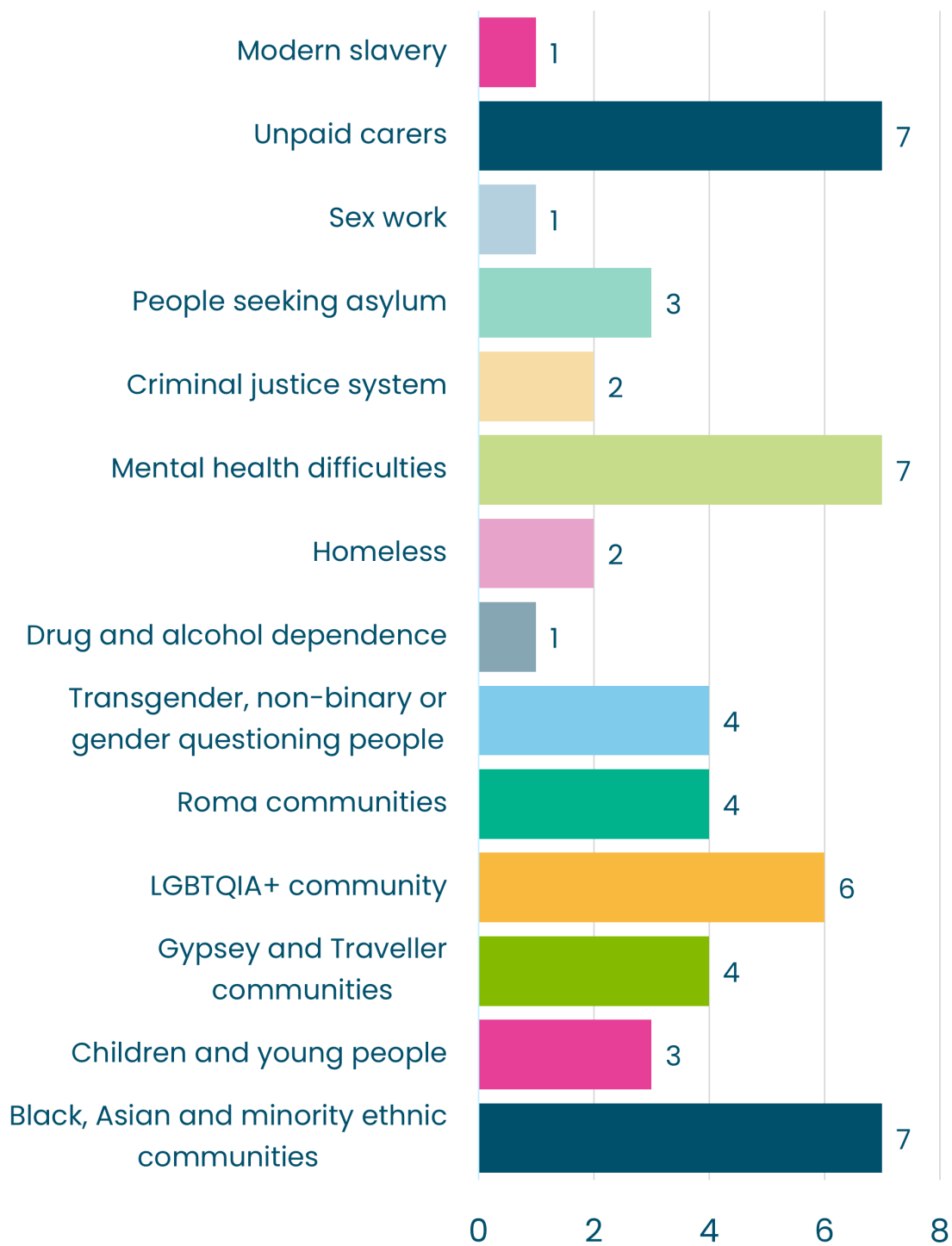
Professionals location in West Yorkshire



No respondents worked in Craven or Calderdale. 2 didn't answer this question.

The professionals worked with many different community groups and people with different experiences. Many of the professionals worked with multiple groups.

Communities and experiences that professionals work with



2 didn't answer this question.

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to quality**


We were awarded a committed to quality marquee from Healthwatch England. To obtain this we did an in depth audit which will be reviewed.

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