



Mental health support for people with long term physical health conditions

August 2024

healthwatch
Bristol

Contents

Contents.....	1
Executive summary.....	2
Introduction.....	4
Methodology.....	6
Demographics.....	7
Results.....	9
- Impact	
- Healthcare experiences	
- Access to mental health support	
- Barriers to mental health support	
- Mental health support experiences	
- Physical and mental health service connection	
- Medication	
Project limitations.....	23
Provider responses.....	24
References.....	26
Appendices.....	27

Executive summary

The initial feedback collected by Healthwatch Bristol which led to the focus of this project suggested difficulties accessing mental health support. Through undergoing desk research and meeting with stakeholders, we decided to explore this topic further focusing specifically on people with long term physical health conditions (LTCs) and their experiences.

We collected feedback from 86 people living in Bristol during March 2024 to provide evidence-based recommendations around access and experience for local people. Our research explored how people feel their mental health is impacted by their LTC, interactions they've had with physical and mental health services, and barriers to mental health support they've encountered.

Most participants said that their physical health affects their mental health to some extent. Nearly half of the participants had some mental health support as a result. Participants spoke positively about support which allowed talking and self-expression, peer support groups, and holistic services which supported both physical and mental health. Around 80% of participants who did have mental health support found it helpful.

For those that didn't have any mental health support, this was largely due to a lack of knowledge about mental health services and how to access them. Other logistical barriers to accessing and benefiting from mental health support included GP access, the duration of support offered, and fluctuations in physical symptoms. Also, most participants thought that healthcare staff did not consider mental and physical health together and that this lack of integration between services impacted their care.

The following recommendations have been formulated for healthcare providers from the experiences participants shared with us:

Next steps

- Primary care to provide information about the individual's LTC, self-management advice and tools, and possible mental health impacts, at the time of LTC diagnosis.
- Healthcare providers to give information about mental health support for people with LTCs in easily accessible formats: digitally (online websites, apps) and hard copies (waiting room flyers, posters).
- Healthcare professionals to routinely enquire about mental health at LTC appointments.
- Healthcare providers to address known barriers to mental health support and offer appropriate solutions on a patient and service level.

- Mental health service providers to signpost individuals to other available forms of support, such as peer support, while they are on mental health waiting lists.
- Primary care to annually review the need for ongoing mental health support with patients.
- Identification and expansion of peer support networks and activity groups from commissioned voluntary sector sources for people with LTCs.
- Increase patient access to social prescribers.
- Mental health service providers to ensure that the support people are receiving is appropriate for the stage of their health journey.
- Training for mental health professionals around understanding the mental health impacts of LTCs and related stigma.
- Training for primary care around pathways for referrals between physical health services and mental health support.
- Expansion of integrated holistic health services where patients can receive support for both their physical and mental health needs related to LTCs.
- Primary care to regularly review individual's LTC medication, including pain relief and alternative coping methods for painful LTCs.

Introduction

Healthwatch Bristol's statutory duty and remit is to provide a voice for people who use health and social care services. We give people an opportunity to have a say about their local health and social care services and we report these experiences to influence service providers and improve outcomes. Healthwatch is committed to promoting equality and diversity and tackling social exclusion in all our activities. We aim to ensure equitable access to our initiatives and projects. We have a representative on the Health and Wellbeing Boards, Health Overview and Scrutiny Committees, and at the Integrated Care Partnership and Board. We feed issues back to local care providers and nationally via Healthwatch England and the Care Quality Commission.

Mental health relates to our 'emotional, psychological and social wellbeing' (1).

The NHS defines a **long term condition (LTC)** as 'a health problem that requires ongoing management over a period of years or decades and is one that cannot currently be cured but can be controlled with the use of medication and/or other therapies' (2).

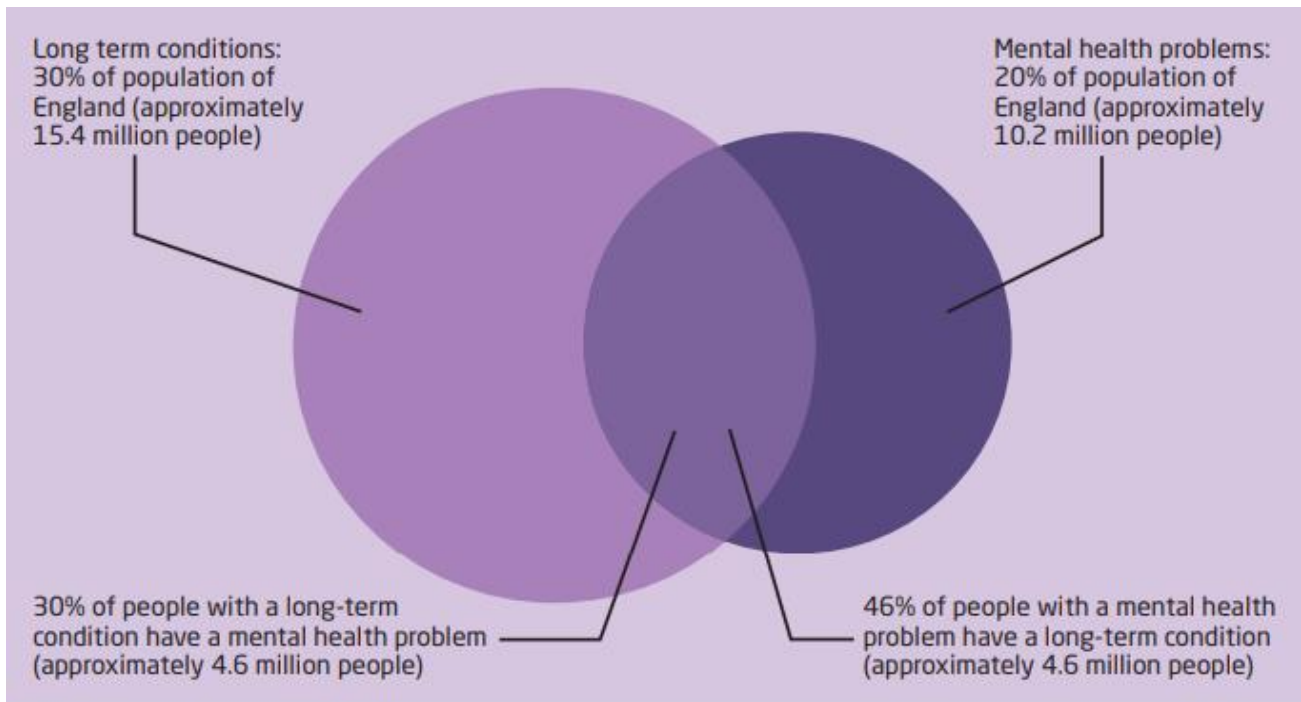
1 in 4 individuals encounter a mental health problem during their lifetime (3).

Over **15 million** people in England have a LTC (4).

Research consistently suggests that **people who have LTCs have a higher prevalence of experiencing common mental health disorders**, such as anxiety and depression, compared to people without LTCs (5).

Based on service-user feedback we received over 2022-23 our workplan determined a project focused on mental health. Through desk research and meeting with stakeholders, we decided to focus this project on individuals with LTCs.

The figure below is taken from a report by The Kings Fund and Centre for Mental Health, it demonstrates the prevalence of physical and mental ill health, and their crossover in the population of England (6).



In Bristol:

- More people are recording low life satisfaction compared to previous years: 19.8% of the Bristol population recorded low life satisfaction in 2022-23 (7).
- The number of people with depression is increasing, with 14.6% of people in Bristol reporting this in 2022-23 (8).
- Bristol residents have lower life satisfaction and higher depression prevalence compared to the average population of England.
- Mental health is a priority for Bristol, North Somerset and South Gloucestershire (BNSSG) Integrated Care Board.
- Our Future Health highlighted that access to quality care, including mental health services, was identified as a major barrier to the health, happiness, and wellbeing of individuals with LTCs (9).
- The Integrated Care System have noted that painful LTCs are some of the most impactful conditions across the life course of people within BNSSG and that 'there is significant overlap with mental health issues especially anxiety and depression' (10).

Methodology

1

We worked with the Independent Mental Health Network to arrange a focus group of individuals with lived experience of LTCs and mental health. This group consisted of three participants and occurred in February 2024. Semi-structured questions were used to guide the group; these questions were developed from experiences described in our past feedback and case study data.

2

After this meeting, a transcript was made, and the data was thematically analysed. The emergent themes were used to create survey questions.

3

The survey was designed using SmartSurvey and was open throughout March 2024. The survey was accessible online, and was available upon request in paper format, easy read, or other languages. An information poster was created for the survey, and this was advertised and shared in-person and on social media by community centres, voluntary, community and health organisations, patient participation groups, and in newsletters.

Our target participants were adults living in Bristol who have one or more LTCs and felt that this has affected their mental health.

In total, **86** people completed the survey.

4

Survey responses were thematically analysed; themes and quotes are in the results section. These findings were used to create recommendations for health services.



For example: diabetes, COPD, asthma, heart condition, arthritis, epilepsy, chronic pain, endometriosis, high blood pressure, IBS, and more.

Healthwatch Bristol would like to find out how this affects your mental health, and what could help you maintain wellbeing.



This is so that services in Bristol and NHS leaders know what is working well and what needs improving for local people.

Interested in participating? Scan the QR code to complete the survey or use this link:

www.smartsurvey.co.uk/s/HWBP24/



The survey will be open throughout March 2024.

Participants will have the option to be entered into a prize draw to win shopping vouchers.

If you would like the survey in another language, easy read, paper format or assistance completing it, please email contact@healthwatchbristol.co.uk or call 0117 2033594

Demographics

Figure 1: Age range of participants

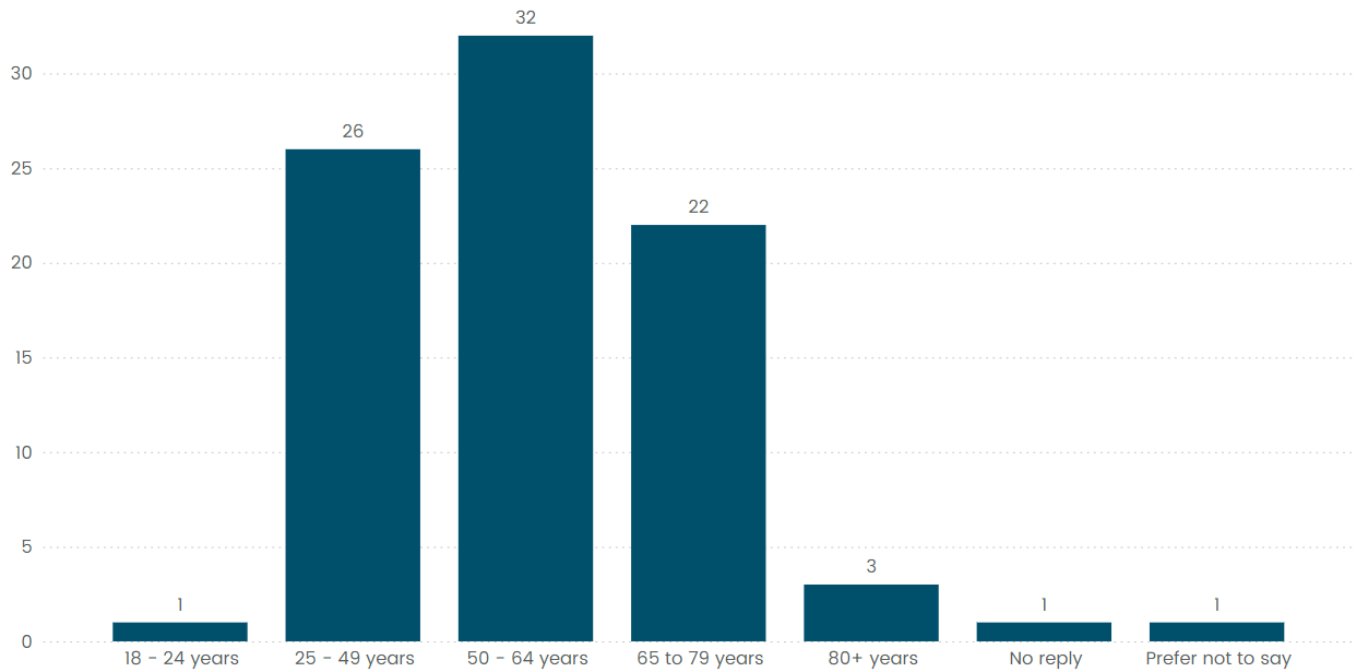


Figure 2: Gender of participants

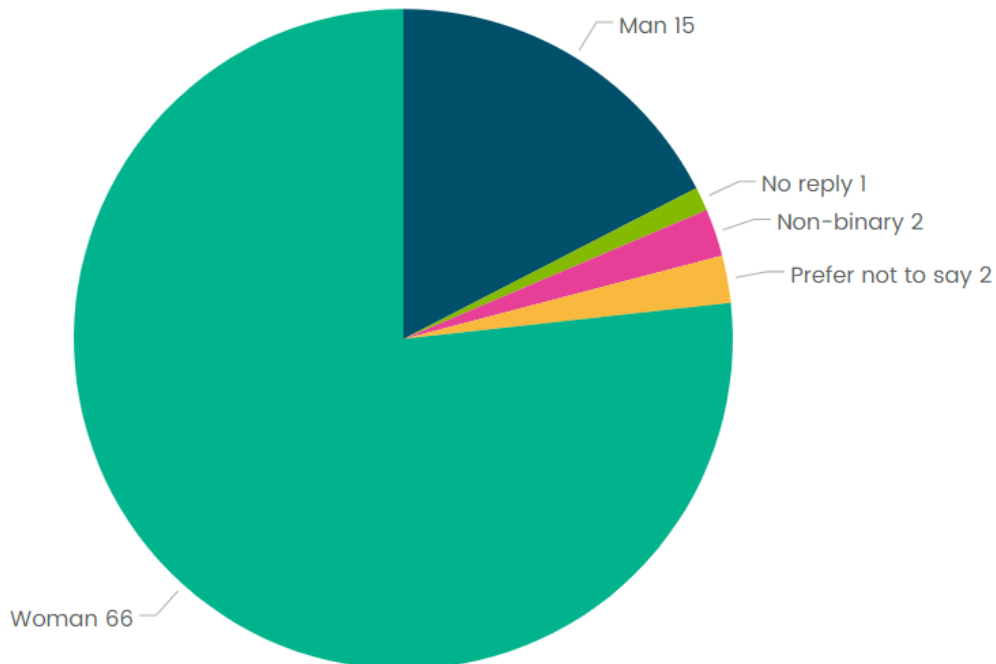


Figure 3: Ethnicity of participants

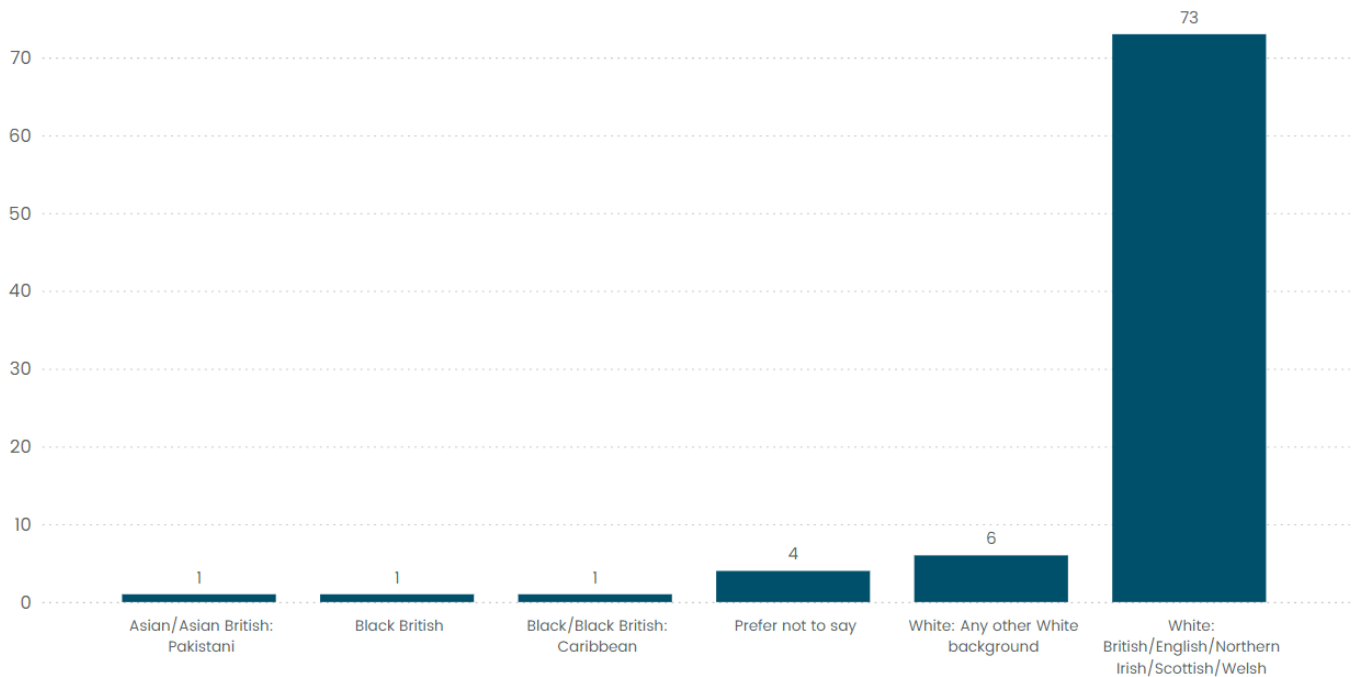


Figure 4: The most common LTCs that participants reported having



Arthritis was the most common LTC which participants reported having, followed by type 1 diabetes. Participants reported painful LTCs, including arthritis, fibromyalgia, and complex regional pain syndrome. A smaller proportion of participants reported LTCs related to digestion, which included IBS, ulcerative colitis, and coeliac disease.

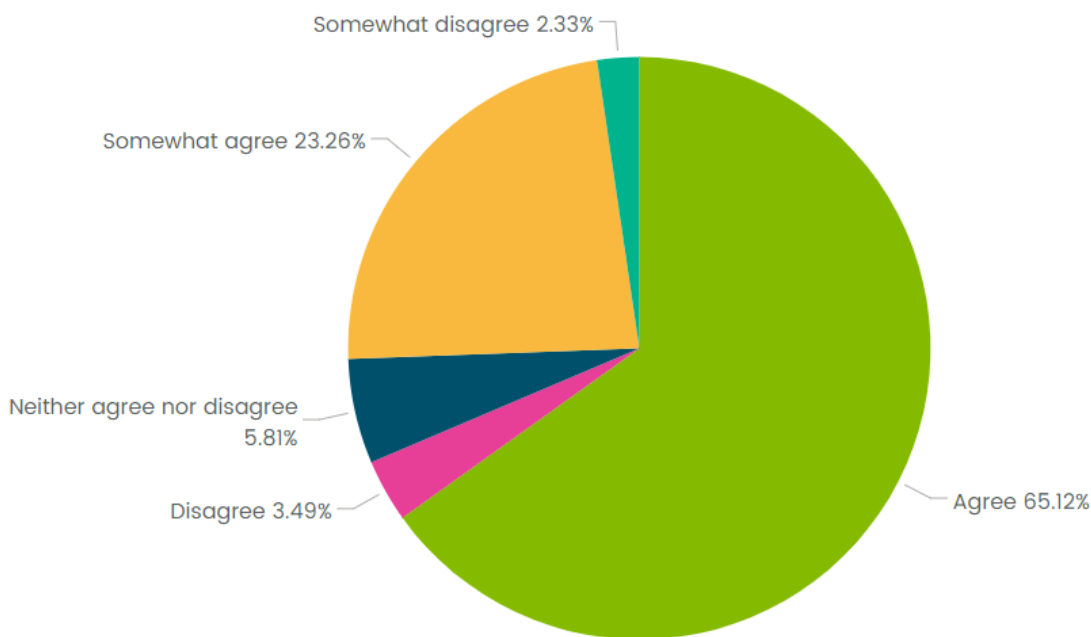
Just over half of participants reported having more than one LTC.

Results

Impact

Most participants said that their physical health affects their mental health to some extent.

Figure 5: Do you agree with the statement: My physical health affects my mental health?



Participants described how the physical effects of their LTCs, which included sleep loss, pain, and limited mobility, stopped them or made it harder to do the things they were used to doing, such as: working, hobbies, exercising, socialising, and caring for children, family members and their self.

One participant described how such changes to their life “felt like grief initially and has sometimes been very hard to come to terms with.”

Dealing with these life-altering changes negatively affected mental health. Individuals felt they lacked independence and self-confidence, which contributed to isolation and hopelessness. Here are some of their quotes:

“I was a fit and healthy person before Covid, I used to run and walk for miles with my dog, now I struggle everyday with fatigue and pain. My mental health has been greatly affected, most days my mind is in a fog, and I can’t make conversation, I’m unable to work and miss the interaction and just being useful. I suffer with depression now and struggle with that a lot. Everything feels hopeless.”

“[...] I had to leave my last job because they couldn’t accommodate

my symptoms, so have been unemployed for several years now. This has really knocked my confidence.”

“Managing type 1 diabetes, as well as having constant background pain, is wearying. I also sleep very poorly and am always fatigued. Consequently I do not have the energy to do all the things I want to do. I am always making plans to do activities which I then regret because I feel too tired to enjoy them. It makes me feel dispirited and anxious, and I have the sense that I am not living life to the full.”

“When having a bad day with my symptoms my mental health struggles massively.”

Alterations to lifestyle and abilities made some participants feel like a burden to others in their life.

“[...] being so reliant on my husband does put a strain on him and our relationship, which is then a source of anxiety and stress.”

Healthcare experiences

Participants felt anxious about their physical health which was worsened by not knowing the causes of their symptoms, and fluctuations in how they would feel day-to-day. Participants wanted to know more about their LTC and the reasons for their symptoms, so they could be supported to self-care where possible. A lack of accessible and practical support for their LTC contributed to their anxiety:

“[...] you're just left to get on with it. I think I have anxiety around not really knowing what the cause of symptoms are.”

“[...] there will be severe delays and long times before being able to access treatment or advice. Due to the nature of my conditions, it can be hard to tell who to speak with and this often ends up needing to be my GP who can speak to secondary care, but my GP practice is often inaccessible due to severe pressures and very limited appointments.”

“I don't feel I am getting any help from my surgery, it took 2 years for them to agree I had [a LTC]. I am not offered any support or pain relief [...] I would like support because I feel abandoned by my surgery.”

“It makes me feel depressed. If I could get help I would know how to deal with it.”

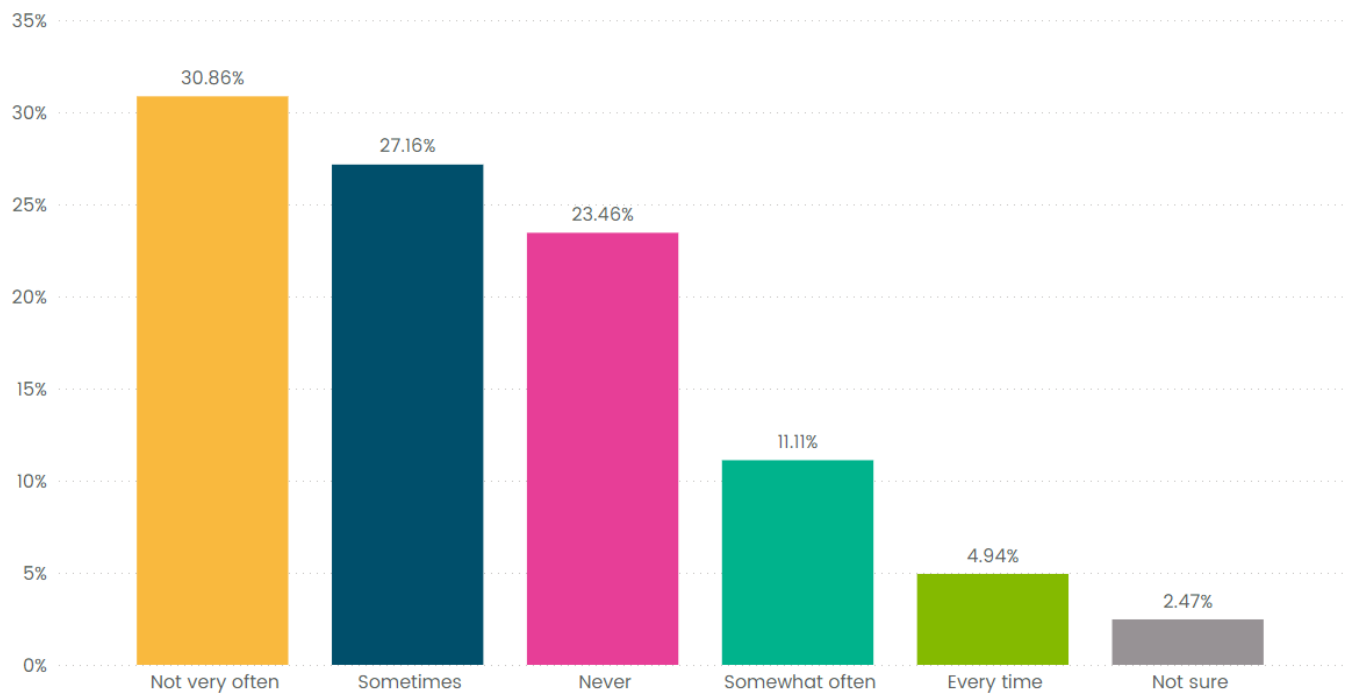
Participants found it upsetting when they felt dismissed or not listened to by healthcare staff about their LTC and physical health:

“It's like having a full-time job on top of everything else that happens in life. It can be difficult and sometimes overwhelming trying to get someone, including health professionals, to understand what's happening is a constant battle.”

“I find myself getting really anxious [...] sometimes you get made to

feel silly [...] I'm finding myself not explaining properly, my brain disappears when I'm in the doctors because of all that."

Figure 6: When seeing healthcare staff about your physical health condition how often have you been asked about your mental health?



Just over half of the participants had not been asked often about their mental health by a healthcare professional. Many said that being asked about this, such as during conversations about their physical health, would be helpful:

"It would be good if the professionals/docs/consultants I see at checkups were to ask me about mental health."

"[It would have helped] to be given an appointment to see a mental health advisor as soon as the condition was diagnosed as part of the treatment."

One individual suggested that "hospitals giving out info of what's available" would help them to know where to access mental health support when needed.

Next steps

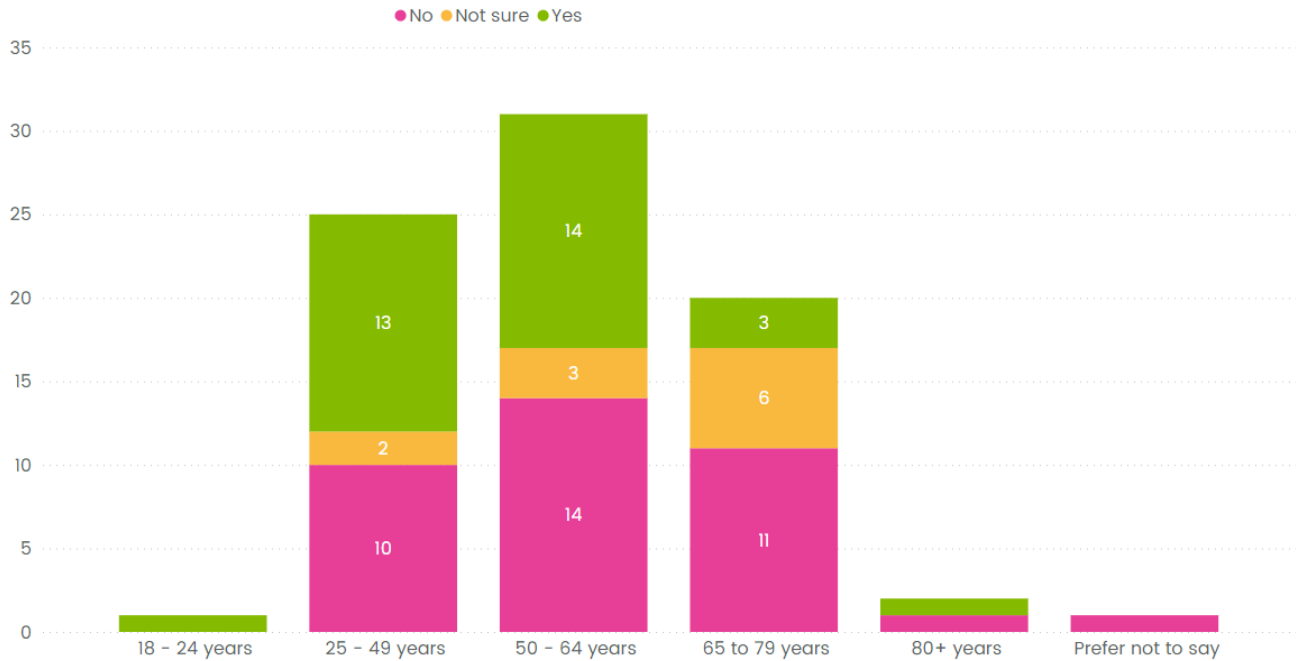
Recommendations specific to this section:

- Primary care to provide information about the individual's LTC, self-management advice and tools, and possible mental health impacts, at the time of LTC diagnosis.
- Healthcare providers to give information about mental health support for people with LTCs in easily accessible formats: digitally (online websites, apps) and hard copies (waiting room flyers, posters).
- Healthcare professionals to routinely enquire about mental health at LTC appointments.

Access to mental health support

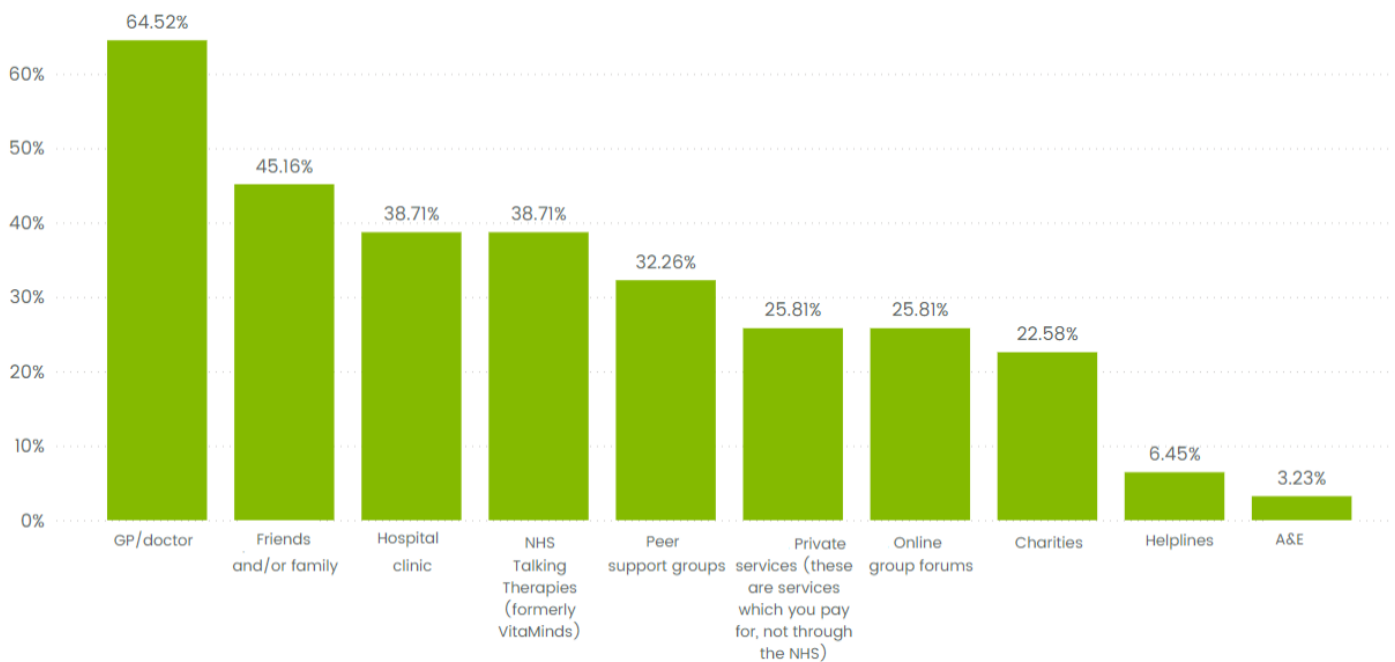
From our sample, 40% said they had received some mental health support.

Figure 7: 'Have you had any support for your mental health while living with your physical health condition?' split by age



Participants over the age of 65 were less likely to have had support for their mental health while living with a LTC compared to those aged under 65.

Figure 8: Where have you accessed mental health support?



Most participants who had received mental health support went to their GP first, and then friends or family.

More men than women had accessed mental health support from hospital clinics, charities, peer support groups, and online group forums (see the Appendix for result tables by gender).

Barriers to mental health support

GP access

As Figure 8 on page 12 indicates, most participants approached their GP first for mental health support. However, many respondents found it difficult to access this through their GP:

- They encountered difficulty booking an appointment due to limited availability.
- They were disappointed by only being able to talk about one issue.
- They felt like there wasn't enough time in an appointment to properly talk about their mental health.

"Never time to talk about [mental health] at GP appointment, given 'one appointment, one condition, 10 minute' rule."

"If GPs had more time it would be easier to talk to them about mental health challenges without feeling like you are holding them up. Being able to see the same GP would also help [...] they are under such pressure that it is not always possible."

Waiting lists

Participants encountered long waiting lists for mental health support and consequently weren't always able to access this support when it was most needed.

One participant felt that "mental health therapists should be offered within an acceptable amount of time, as it happens with physical therapy."

This made participants feel discouraged from seeking support and guilty using NHS services.

"I had to wait 15 months for the NHS Talking Therapies [...] I started medication about 9 months before the therapy started because I was struggling and I'm not sure I would have coped very well without it whilst waiting that long for help."

"Very long waiting lists [...] I only know of the NHS Talking Therapies that's free, so don't know where else to go for help."

"The wait for all services is the biggest hurdle and has needed me finding a way around."

“I feel [...] guilty for putting more work on them [the NHS].”

Duration of support

Participants felt that mental health support often did not last long enough, or fluctuated depending on funding, and it was then difficult for them to lose that support.

They also expressed uncertainty around whether they would be eligible for further support.

Individuals felt frustrated at restarting the process of seeking support, which often involved re-telling personal information.

“Everything is understandably time limited but can leave you feeling lost when the support you come to rely on is no longer in place.”

“I would have liked there to be more of it! [...] I have not requested a referral to this service again as I assumed it would no longer be available to me, or if it was, other people needed it more.”

“[...] you tend to get 1 or 2 sessions and that’s it. Which means you have to start right at the beginning again. I get frustrated at having to tell my story again and again.”

Cost

Participants spoke about the cost involved with accessing support, which involved transportation and paying for private support. Individual situations were exacerbated by not meeting certain criteria for benefits.

“Having spent lots of money already on my health, cost would be an issue.”

“Cost is a barrier, and because I’m ‘not sick enough’ my PIP has been declined.”

“To get help to target the main thing bringing me down at the moment [...] I think I’d need to pay for a private coach. So cost is a barrier and knowing where to go for help given my quite specific circumstances.”

Time available

Some participants cared for children or family members, which meant they didn’t have the time in their day for mental health support. Also, the time of day that support is offered was a barrier for participants who work.

“[...] with work and a young family, it’s always hard to find time available.”

“I work full-time [...] we are not allowed to go to medical appointments without making time up taking annual leave.”

“I found in-person support offered by a charity really helpful but did have to take time away from work to access this and travelled 30 mins each way, which possibly wouldn't have been sustainable longer term.”

Transport

Some participants spoke about transport issues and the time it takes to get around; this led some participants to prefer online support due to ease.

“I do not have my own transport [and] really struggle with public transport due to my mobility, but I'm happy to get a taxi if it's not too far and at a less busy time of day.”

“An hour at home can be easier than an hour face to face with travel each way.”

Fluctuating physical symptoms

Participants said that fluctuations in their physical health could stop them from going to mental health appointments and meetings. This made them feel unreliable. While they would still like in-person support, some reluctantly opted for online options.

“As I have fibromyalgia with long Covid I find it difficult to have the energy to do the simple things on some days, which makes me unreliable, however on my better days I can make appointments.”

“If therapy is offered face-to-face I would be happy to attend in principal but fatigue due to ME can make that harder. The rise in online therapy has been helpful for me from that point of view but there is something extra when you can meet face-to-face.”

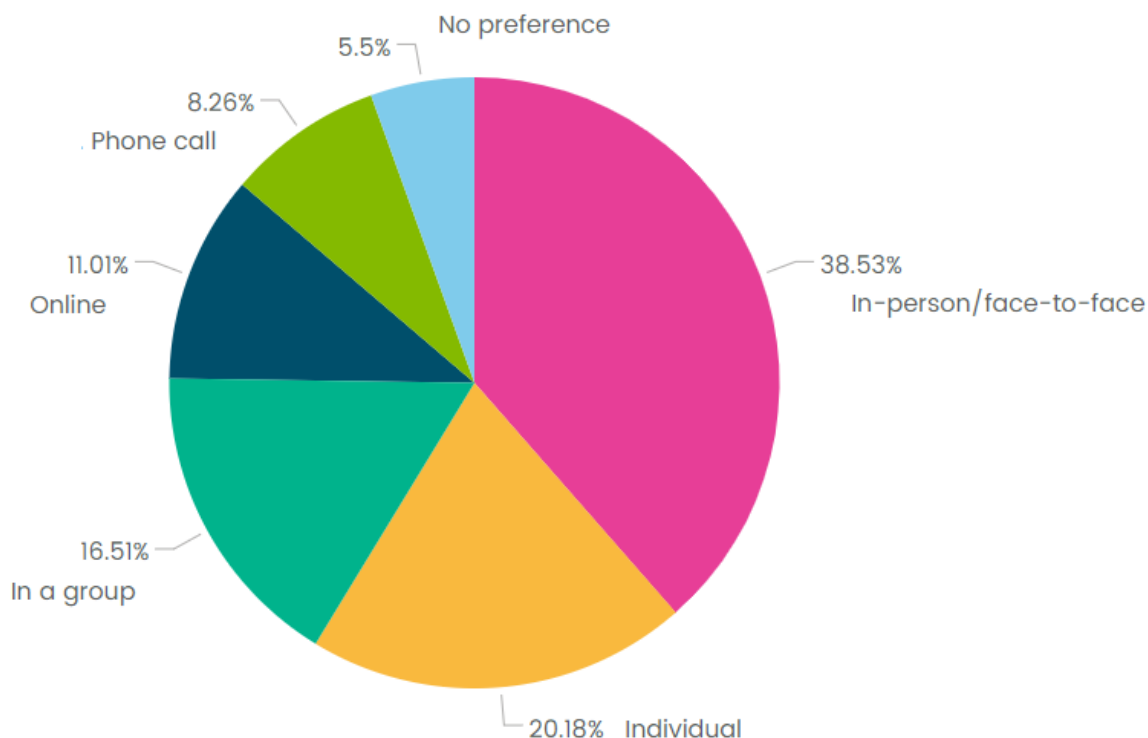
Stigma

Some people told us that being worried about what others would think had stopped them from accessing mental health support.

“I hide myself away, frightened of being hospitalised or just deemed mad!”

“Didn't want to admit my illness was affecting me.”

Figure 9: 'How would you prefer to have mental health support?'



Responses to this question varied by age. More participants aged between 18-49 years old said they would prefer to have mental health support online, by phone call or individually, compared to participants aged over 50. Participants over 50 showed a greater preference for support in a group compared to under 50s.

Next steps

Recommendations specific to this section:

- Healthcare providers to address known barriers to mental health support and offer appropriate solutions on a patient and service level.
- Mental health service providers to signpost individuals to other available forms of support, such as peer support, while they are on mental health waiting lists.
- Primary care to annually review the need for ongoing mental health support with patients.

Mental health support experiences

As Figure 8 on page 12 shows, participants accessed mental health support from a range of services across both health and voluntary sectors. We asked them what was good about these services.

Support that worked

Participants emphasised being able to talk about their experiences and feelings and being listened to by someone trustworthy. Participants found that this kind of support helped them come to terms with their LTC, rather than needing to find a solution. They also thought it was helpful to be presented with different perspectives on issues they were facing.

“I was offered counselling sometime after my diagnosis. It was helpful to talk about how I was feeling as it was very overwhelming.”

“Talking helps a lot.”

“It’s helped me feel less guilty about my lower energy levels and that I’m not working. It’s helped me learn some practical solutions to help me cope and live better with my condition.”

“My GP has been very patient and listened, as when I am stressed it is hard to explain things.”

Support which they could access immediately was highlighted by some participants as very positive and helpful, especially in moments when they were feeling overwhelmed.

“A consultant who I can access quickly through the secretary rather than waiting for the 2-day advice-line response has been a god send. Access to the social prescriber directly if needed help has [sped-up] support [...] the instant response from [National Rheumatoid Arthritis Society] has kept me sane.”

Participants highlighted how support needed to be appropriate for the stage they were at with their health, so it was valuable to be able to access different forms and types of support. A number of participants told us that Cognitive Behavioral Therapy (CBT) was not right for them at first, one participant said it was “too action focused too early on in my journey post diagnosis... I needed time to process without expectations or judgement before moving on to more practical therapies.”

Another participant told us that “private counselling was good as it helped me process things without any agenda of trying to “fix” things (as I found the case with CBT).”

Peer support

Many participants found peer support groups particularly helpful. They liked it when this focused on positive aspects and how to adapt and enjoy life. Peer

support was accessed through health services, charities, and participant’s own research.

“It always makes me feel better to talk about it. It is good to talk to others in the same situation and hear their experience.”

“Online group forums have been the only truly helpful thing that I've accessed, other patients going through the same thing have been sympathetic, supportive, and helpful in passing on healthy coping mechanisms.”

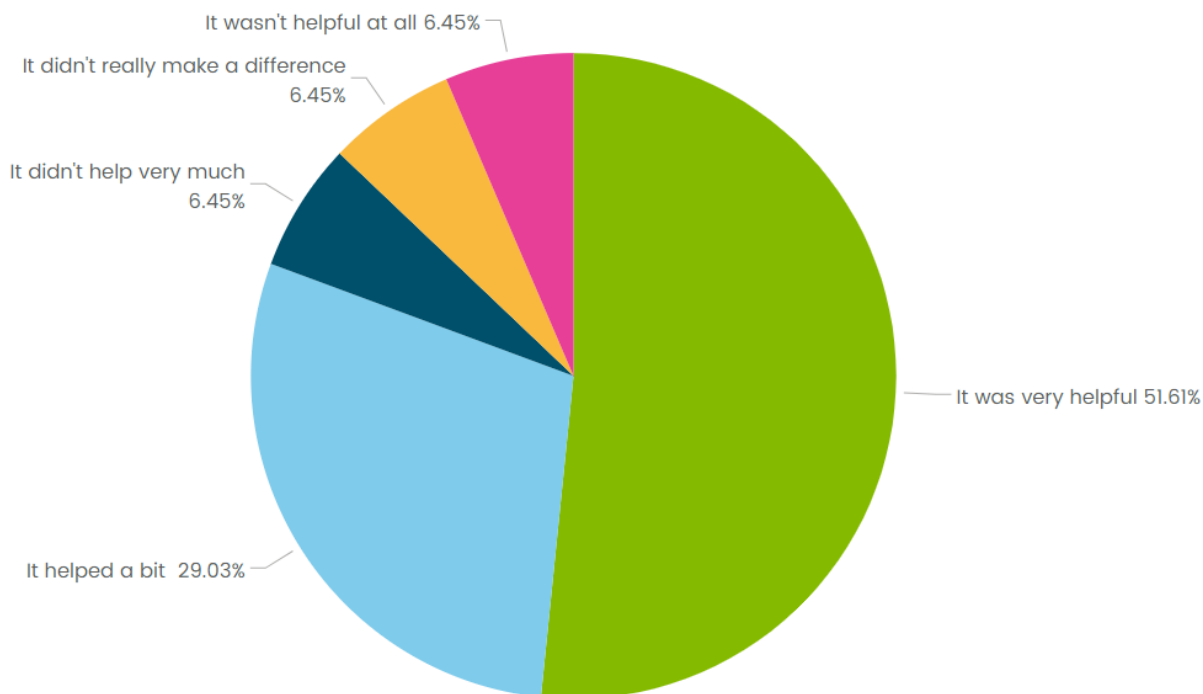
“Living with MS group course: the therapist was great, and it was good to connect with others going through similar experiences. The focus on values, being mindful and finding ways to enjoy life was positive.”

However, participants told us that peer support groups were not helpful when members made comparisons or shared horror stories about their health, which made participants fearful. They also thought it was important to be in a group with people at a similar stage of their health journey.

“Perhaps the group could have been put together with the severity/stage of condition in mind - it was alarming (and guilt-inducing) to see others with a much higher level of disability.”

“It doesn’t cheer you up feeling like it’s a comparison of who’s got it worse.”

Figure 10: Has this support made a difference to your mental health?



Around 80% of participants who did have mental health support found this support to be helpful to some extent.

Next steps

Recommendations specific to this section:

- Identification and expansion of peer support networks and activity groups from commissioned voluntary sector sources for people with LTCs.
- Increase patient access to social prescribers.
- Mental health service providers to ensure that the support people are receiving is appropriate for the stage of their health journey.

Physical and mental health service connection

Relationship between physical and mental health

Participants described how their physical health and mental health can act as a trigger for each other, forming a “negative feedback loop”.

“I find it's a negative feedback loop; the worse I am mentally the worse my arthritis is. Stress is a large trigger for my conditions.”

“I have found that if the ME is worse, it is harder to handle obsessive thoughts and try and stand up to the compulsions. Trying to deal with the OCD can be exhausting which makes the [ME] fatigue worse.”

Considering this, participants said it would have been helpful for potential mental health impacts to be acknowledged when they were diagnosed with a LTC.

“I think it would have been helpful to learn about the link between mental health and stress and rheumatoid arthritis at diagnosis. Instead I have learnt this over time during 10 years of diagnosis. Knowing about this earlier would have helped me with self-care.”

Holistic support

Some participants experienced support which they felt was holistic. This was characterised by services providing them with information and support for their LTC while also addressing their mental health needs.

“The support I've had is giving me insights into the condition along with really useful information about many aspects of the condition, how to try and look after both mental and physical well-being and how intertwined they are. Different ways of looking at things and different coping strategies are included which is really helpful, as I don't know where else I would have found that.”

“The ME/CFS in my area have been brilliant. They have looked after my physical health from an ME point of view and helped with the mental health challenges that have interacted with it.”

“I saw the health psychologist about my painful diabetic neuropathy. She helped me to look at it differently [...] and focus on adapting my life to the recurring pain rather than letting it dominate me. I found it extremely helpful, and it has meant that I stopped looking for a medical solution to the neuropathy (I had tried many types of pain reducing medications, but none had helped).”

Lack of understanding of LTCs by mental health services

Some participants felt that mental health services did not cater for people with LTCs, and they found it difficult when healthcare staff and mental health services they were working with did not understand their LTC.

“[NHS Talking Therapies], the charity, and peer support groups, were never tailored to sufferers of long-term health conditions, and especially not the cyclical nature of endometriosis, where symptoms can vary so widely across the month.”

“I haven't had help [...] because the toll [of a long] term condition has only just started to be recognised.”

“Everyone is lovely but getting people to understand that my low mood is due to the actual flare-up rather than the continuousness of the condition is really difficult. It has taken searching for very specific [doctors] and consultants.”

Participants found it difficult when their physical and mental health were not recognised, misunderstood, or connected in ways that they didn't agree with.

“[I'd like] more consideration given to my physical condition being the cause of my low mood.”

“[I] didn't feel they really understood my condition and how it affects me; felt they conflated it sometimes with depression- which it is nothing like.”

One participant felt healthcare staff had ignored their physical symptoms, which led to them suffering with physical ill-health for several years: “Everything can get blamed on your mental health [...] I was experiencing a lot of symptoms [...] it went on for something like 7 years before a locum picked it up because everything got put on my mental health.”

Too complicated

Some participants told us that they were made to feel too complicated for any one service, because of how their physical and mental health interact.

“Is there anything which exists that would take me as a person or is every service going to make me feel like I am too complicated because I don't have one issue? That's the thing with chronic health conditions is never just one easy thing.”

They felt like they were seen separately by mental and physical health services, and it was difficult to get a physical health service to refer them to a mental health one, and vice versa.

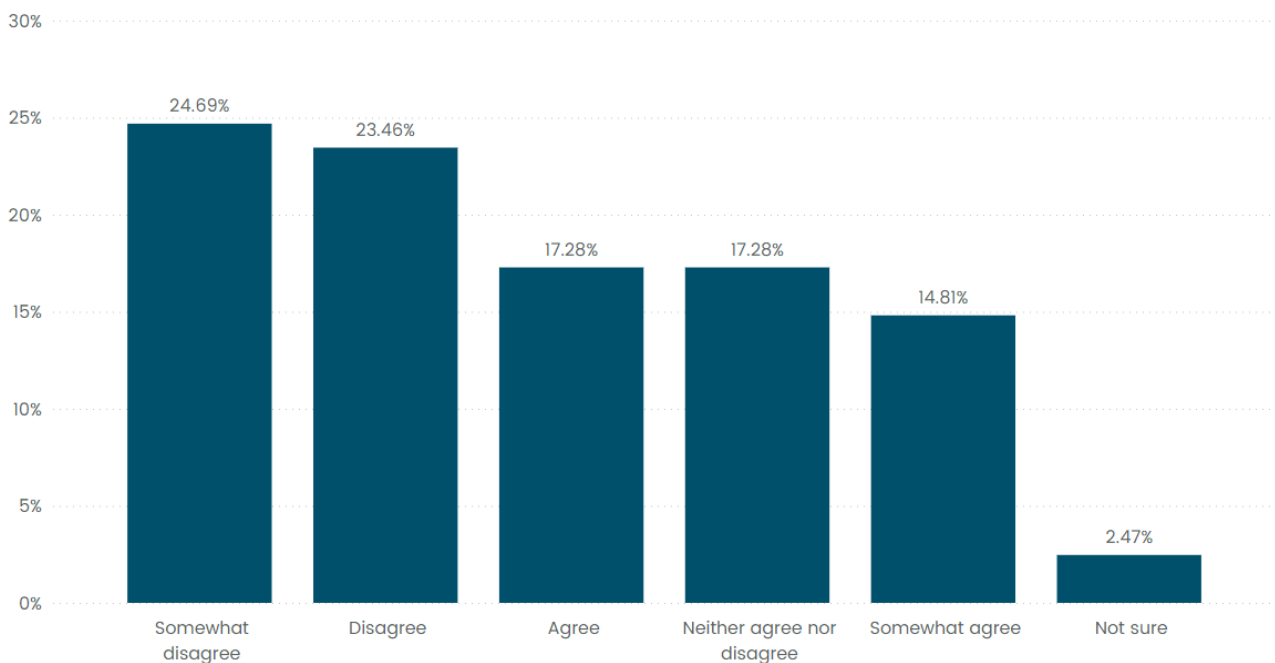
“I’ve never felt like the services talk to each other or acknowledge that they’ve got any impact on each other.”

“Nothing seems joined up.”

Some participants felt they had to be their “own best expert” when it came to mental and physical health service-navigation and treatment.

“[The] recurring thing with chronic health is that we have to know everything.”

Figure 11: Do you agree with this statement: Healthcare staff consider both my physical and mental health together?



Most participants thought that healthcare staff do not consider their mental and physical health together.

Next steps

Recommendations specific to this section:

- Training for mental health professionals around understanding the mental health impacts of LTCs and related stigma.
- Training for primary care around pathways for referrals between physical health services and mental health support.

- Expansion of integrated holistic health services where patients can receive support for both their physical and mental health needs related to LTCs.



Case study of an existing integrated holistic health service: Health Psychology Service North Bristol Trust (NBT)

The Health Psychology Service embeds mental health support within physical health services, alongside patient's medical care. They have been working within NBT for over 30 years, they currently have 74 staff, with 5 consultant grades. They are embedded within several services, including cancer, pain services, ME/CFS, and long covid. Individuals are usually referred to this service by doctors within secondary care, with some GP referrals too.

They use a wide range of psychological tools to help people adapt to changes in their health status and to make sense of distress. Their work impacts the behavioural, emotional and cognitive elements of health. They have found many evidenced-based benefits to using psychological therapy in acute healthcare settings: enhanced communication, reduced distress and disability, increased self-management, increased treatment compliance, decreased in-patient stays, and decreased readmission.

They believe that if you begin with this approach, many of the mental health issues that develop can be avoided: issues such as isolation, worry, uncertainty and basic mood management and adaptations strategies linked to changes in health status.

They have a strong lived experience ethos with all their services including service users as facilitators. The health psychology service at NBT has a national reputation and is one of the largest teams in the UK.

Medication

Participants reflected on how medication that they take for their LTC affected other areas of their life, such as their sleep and ability to think clearly, which in turn influenced their mental health.

"Not only does my physical health affect my mental health but so does all the drugs I take [...] Being constantly in pain and unable to do the things you want to do is frustrating, demoralising and depressing. [Medication] withdrawal causes a big black hole that feels like life isn't worth striving for."

"I was on all these drugs, and it was just so bad [...] I was going to lose my job [...] all my body had swollen up and I just felt awful."

"I'm unable to thrive in life, having to have additional medication alongside it."

Participants felt they needed more support around medication, particularly with withdrawal; they also highlighted their worries about becoming dependent.

“The support I have got has been great but had to be waited months for [...] the [withdrawal] is affecting my mood so badly I need help now not in 6 months.”

“Accepting that this is now my life for the foreseeable is really hard to come to terms with. I am severely depressed [...] and probably dependent on pain killers and antidepressants.”

“I try not ask for help, just get on with it and [rock the] pain away, Nurofen I live on usually 8 a day, but the internet says not good and not long-term use. I comfort eat for my sadness and in-between having full body itchy hives or boils in armpits or groin area I try sleep best can.”

Participants with painful LTCs said that they would like more support with pain relief and options other than over-the-counter medication. One participant told us how they had privately sought a medical cannabis prescription for chronic pain because of their difficulties obtaining a pain relief prescription.

“They never prescribed tramadol [...] I wouldn’t be able to fight hard enough for it [...] I am on medical cannabis which I have had to go private for [...] that’s it, there’s nothing I can do other than that.”

A different participant resorted to using illegal cannabis instead of prescription drugs due to the negative side-effects that the prescription drugs were having on their physical health. They expressed frustration that they “would be classed as a drug addict” despite using it in this context.

Next steps

Recommendations specific to this section:

- Primary care to regularly review individual’s LTC medication, including pain relief and alternative coping methods for painful LTCs.

Project limitations

We shared the survey with a wide range of organisations across the city, and organisations specifically working with people from non-white ethnicities to try and represent Bristol’s diverse population. Despite this, our participants are not demographically representative of the Bristol population; the findings of this study should be interpreted with this in mind, and future work focusing specifically on non-white ethnicities is paramount.

While we advertised that the study would be available in other languages and easy read, we didn’t receive any requests for this. With a longer time scale, we would have better utilised our community connections to reach individuals with these requirements.

Provider responses

Shane Devlin, Chief Executive, NHS Bristol, North Somerset & South Gloucestershire ICB

Dr Geeta Iyer, Salaried GP and Deputy Chief Medical Officer, NHS Bristol, North Somerset & South Gloucestershire ICB

This is an interesting report that shines a light on how, in trying to deliver good evidence-based practise, practitioners can miss what is important to the person. This is particularly important in general practice where most long-term condition consultations occur.

Balancing the limited time in general practice and pressure on appointments with the holistic approach needed is hard, but recognition for this approach is there with the funding for Additional Roles Reimbursement Scheme roles. Many practices and patients understand the need for continuity of care here and there is a need for further discussion about how that is best delivered that encourages personal autonomy and empowerment.

Steve Rea, South Gloucestershire Locality Director

An interesting read and really important points and recommendations included.

Dr Hazel O'Dowd, Consultant Clinical Psychologist, Clinical Lead for Pain Management Service, Chief Psychological Professions Officer for North Bristol Trust

I would like to thank the team for this excellent piece of work highlighting the need for embedded emotional support for those living with any health care challenge.

NHS England advocates integrated psychological and physical healthcare, viewing this as key to good service delivery. The financial cost to the NHS of not integrating care was calculated to be more than £11 billion in a report by The Kings Fund in 2016. The strategic direction is for the healthcare system to move towards a new standard of integrated and holistic care, alongside a need to move towards a more pro-active healthcare approach where health promotion and illness prevention are increasingly systemised as health enablers. This report adds the all-important service-users voice to this compelling strategy.

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Provider responses

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Psychologists who work in healthcare settings are already contributing the broader healthcare approach now mandated by government and requested by service-users. Incorporating evidence based psychological theory and practice into the care pathway, can support levels of psychological adjustment, symptom coping and condition management. This can improve health trajectory, health related quality of life and unplanned healthcare activity. And from this report, we can see this is what service users themselves are asking for. The ultimate system transformation ambition must be for all patients living with physical health conditions, especially long-term conditions, to have timely access to appropriate psychological support including input to their MDT medical care and rehabilitation whatever the disease or injury and wherever this is needed.

Whilst there are pockets of local provision, this report supports the further development of psychology services based in acute hospitals and I welcome it warmly.

Catrin Beynon, Chief Executive Officer, Independent Mental Health Network

We are delighted to see the publication of this important report by Healthwatch Bristol, which shines a much-needed light on the critical intersection between long-term physical health conditions and mental health. The findings underscore the complex challenges faced by individuals living with these conditions, particularly in accessing mental health support that is both timely and holistic.

At The Independent Mental Health Network, we have long recognized the vital need for integrated care that addresses both physical and mental health in a cohesive manner. We are incredibly thankful that this report brings these issues to the forefront, highlighting the voices and experiences of those directly affected.

We are also deeply grateful that our lived experience representatives had the opportunity to contribute to this work. Their insights, born from personal experience, are invaluable in shaping services that truly meet the needs of our community. We believe that by continuing to listen to and involve those with lived experience, we can work towards a healthcare system that is more compassionate, responsive, and inclusive.

We look forward to seeing the positive changes that will come from this report and remain committed to supporting efforts that improve the lives of those living with long-term conditions.

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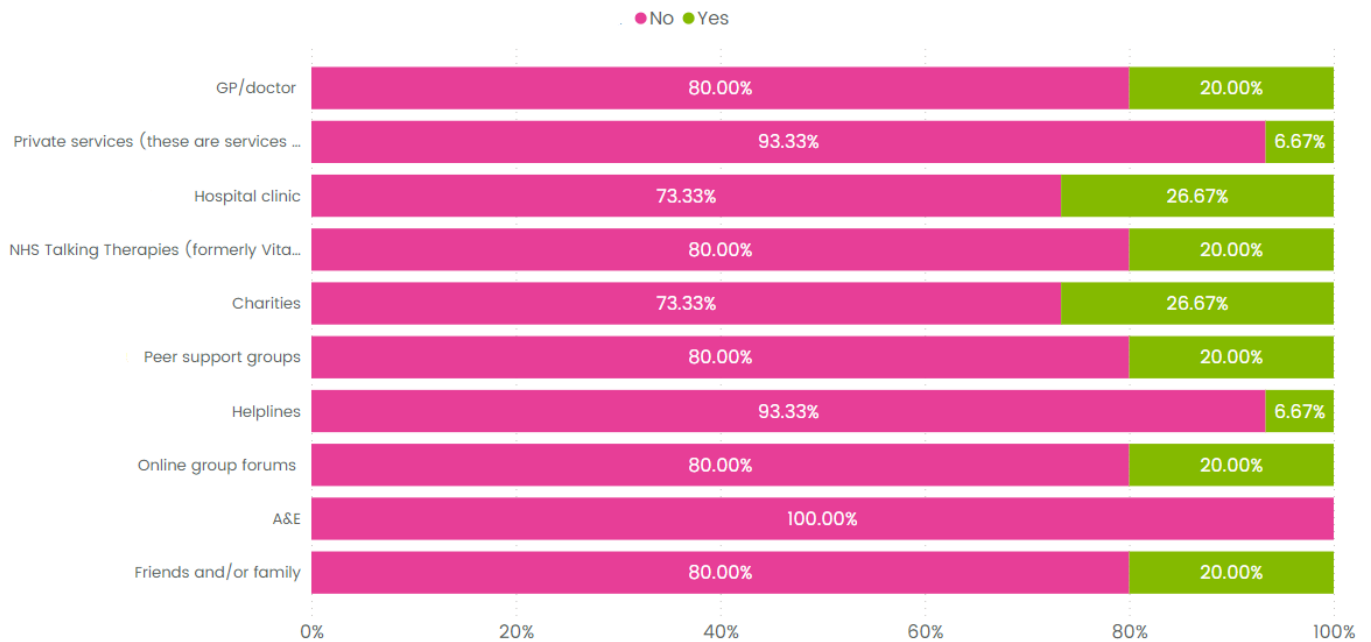
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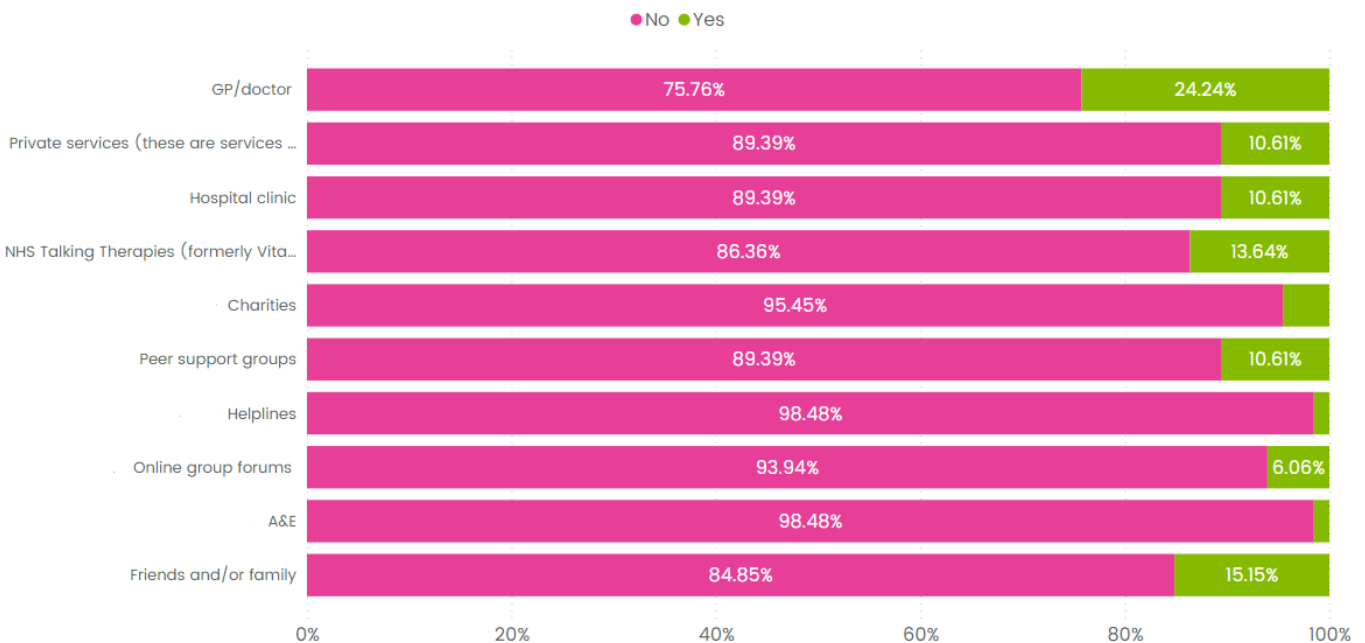
Appendices

Appendix 1:

Male participant responses to 'Where have you accessed mental health support?'



Female participant responses to 'Where have you accessed mental health support?'



Appendix 2: Equality Impact Assessment

Appendix 3: Theory of Change

Appendix 4: Survey

To view or download appendices 2-4, please visit:

<https://www.healthwatchbristol.co.uk/mental-health-support-people-long-term-physical-health-conditions-august-2024>

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