healthwatch Essex

*"Society will judge me if I do things for fun"*

# Women's experiences of living with multiple long-term conditions

March 2026

Lorna Orriss-Dib

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**Note**

In June 2025, as part of the Dash Review, the Government announced its intention to close the Healthwatch network. However, Healthwatch Essex is an independent charity, and the organisation is currently re-branding. We have developed a sustainable model that will protect the independence of patient voice into the future.

# Contents

# 1. Introduction

## 1.1. Multiple long-term conditions (MLTC)

This study explores women's experiences of living with multiple long-term conditions (MLTC). A long-term condition is defined as an illness for which there is currently no cure. Management is ongoing, using medications, therapies and monitoring (NHS Data Model & Dictionary, 2024). Conditions considered long-term include:

- Medically defined physical or mental health conditions, such as schizophrenia or osteoarthritis.
- Substance or alcohol misuse.
- Learning disability.
- Sensory impairments, such as hearing, taste or sight loss.
- Ongoing symptoms such as chronic pain.
- Infectious diseases with a duration of 6 months or more, such as tuberculosis or hepatitis.

MLTC (previously termed 'multimorbidity') refers to the presence of two or more long-term health conditions in a single individual (NIHR, 2021). Over 14 million adults in England are currently living with MLTC and this is predicted to increase by 37% by 2040 (The Health Foundation, 2023a).

The impact of living with MLTC varies according to an individual's access to resources, household income, support network, housing, education and access to transport. Residents in the most disadvantaged areas of the UK are more likely to be living with three or more long-term conditions that affect three different bodily systems (Pati et al., 2023). Existing studies have shown that increasing prevalence in MLTC leads to an increase in local authority spending on social care provision (Chukwusa et al., 2023). Currently, people with long-term conditions account for 70% of total health and care expenditure (Chukwusa et al., 2023).

## 1.2. Women and multiple long-term conditions

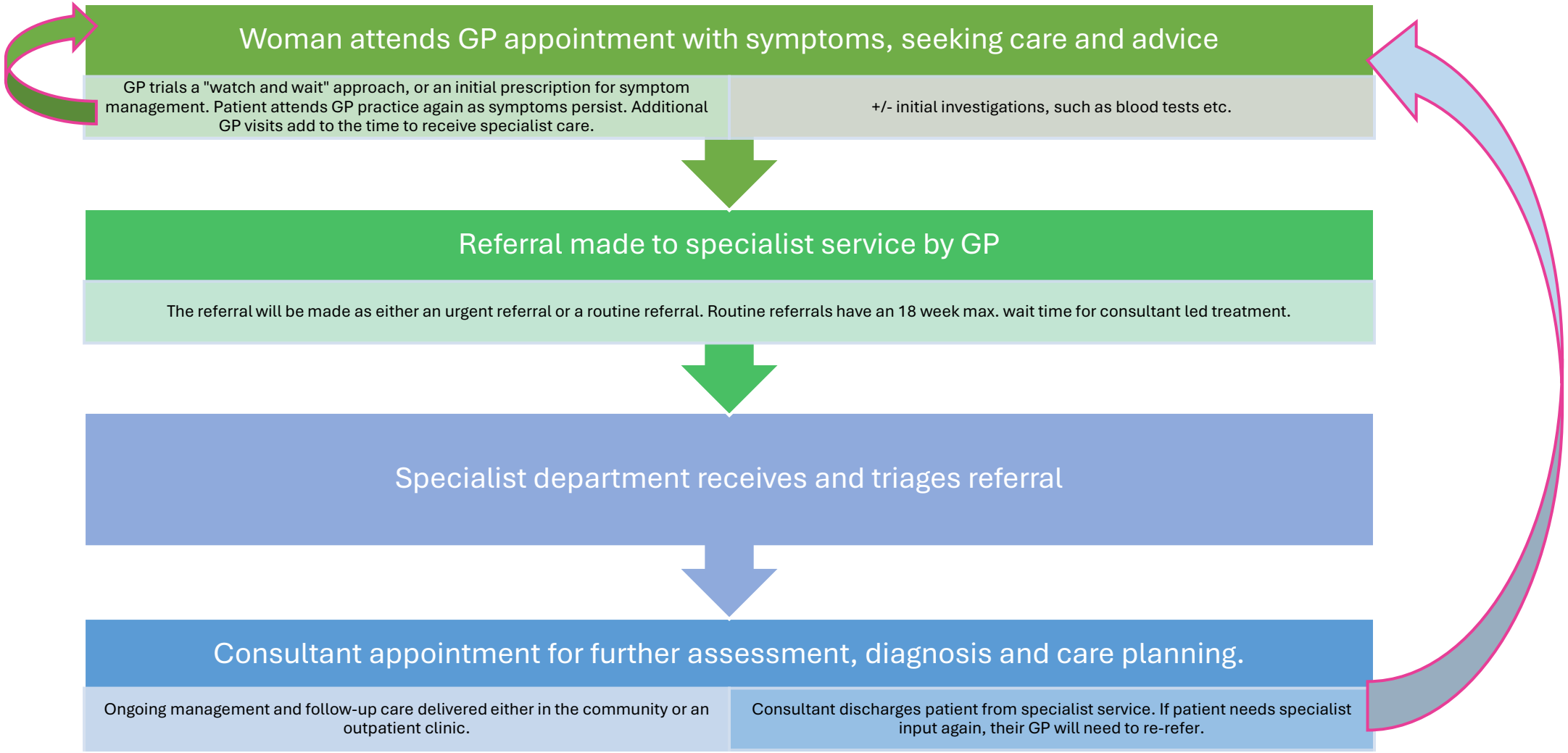
This study focuses on women's experiences of MLTC for a variety of reasons. First, MLTC are more prevalent among women compared to men, with women aged over 65 from areas of deprivation most at risk (Violan et al., 2014).

Second, women's experiences of MLTC are influenced by a range of social factors that prevent them from attaining the best possible health outcomes more broadly (WHO, 2023). Women, for example, provide more unpaid and informal care compared to men. Those providing unpaid social care for 20+ hours per week are, on average, 55 years of age and female (Joseph Rowntree Foundation, 2023). Providers of unpaid childcare are typically aged 38 and female. Those providing care have a greater chance of unmet health needs compared to those not providing care (Public Health England, 2021). Women, for example, are more likely to miss clinic appointments and higher rates of MLTC have been found among those with school-aged dependents (Alkomos et al., 2020; Seo, 2019).

Third, in 2022, the UK government published the Women's Health Strategy for England, with the aim of improving the health and wellbeing of women and girls across the life course. Providing high quality, reliable care across the life course can involve a multitude of specialties. Those with multiple conditions often access services across multiple specialties, as well as engaging with more generalist services such as the GP. There is limited qualitative data that explores the lived experiences of those with MLTC, and far fewer studies that focus on the health of women with MLTC using a life course approach. This research therefore provides valuable insights into how women's health and wellbeing can be improved across the life course. It also promotes an expansive view of women's health experiences that extends beyond their reproductive and maternal health. With the increase in MLTC and widening health inequalities, a broader definition of women's health needs to be implemented.

Finally, this report sheds light on the inefficiency of the current health system approach for women living with MLTC. Most health systems are organised around a single condition and singular specialist pathways of care (Anderson et al., 2022). For those with MLTC, navigating multiple specialists (e.g. scheduling appointments, chasing results, and managing medications) is hugely time-consuming and can lead to burnout (Tran et al., 2015;Kontoangelos et al., 2022). Negotiating singular specialities for MLTC symptoms is also inefficient. Currently, referrals are made to the clinical specialty that covers the bodily system most likely to be the source of the symptoms (e.g. gastroenterology for stomach pain). The diagram on page 8 highlights the repetitive process experienced by women with MLTC every time they are referred to a different specialty (after seeking care via the GP rather than in an emergency capacity). The current system does not

facilitate cross-sector working or the reality that one condition often affects another. This report identifies recommendations on overcoming these inefficiencies that are grounded in women's own lived experiences of MLTC.




**Note:** Repeat process for each long-term condition requiring specialist input.

# 2. Report overview

In the following chapters, we detail the recruitment strategy used to reach study participants, our approach to data collection, the demographics of the research participants, and a description of the data analysis process. We then share an in-depth examination of the study's findings and further discussion on how our study contributes to existing research, the key messages and recommendations from this research project, and opportunities for further exploration.

# 3. The study

## 3.1. Project aims

This project aimed to understand:

- How women negotiate care across multiple specialties.
- How women relate to, and negotiate their conditions alongside their other commitments
- To what extent individuals prioritise one condition over another.
- How early life course interactions with healthcare services impact upon (if at all) future service utilisation and engagement.
- The cumulative impact of positive or negative service experience across the life course?

## 3.2. Research methods

We explored these aims by inviting women to either:

- Complete a life history interview.
- Submitting a creative piece of their choosing reflecting their experiences of living with MLTC and completing a shorter interview.

Life history interviews capture people's lived experiences and situate these within broader social and political processes and provide insight into how the past informs decision making about the present (Atkinson & Walmsley, 1999). This approach supported our project's aim to understand the cumulative impact of service interactions on participants' lives. During our life history interviews, participants share their health experiences from birth to present day. This facilitated mapping of their diagnosis journeys and their changing relationships

and support networks. Interview transcripts were then analysed using the principles of Braun and Clarke's thematic analysis (Braun & Clarke, 2006).

Creative methods were offered to potential participants to support those who may not have felt comfortable initially sharing their experiences in an interview setting. Participants were free to suggest a creative outlet they felt most comfortable with and share a piece that reflected their experiences of MLTC. Most participants opted for a life history interview, citing fatigue or a lack of creative experience. One participant, however, shared a digital artwork. Another provided a series of online memes that resonated with their experiences. Both participants also completed a life history interview. Their creative expressions can be found in the Appendix on page 43.

### 3.3. Steering group

This project was guided by a project steering group consisting of four women with lived experience of MLTC. Group members were recruited via Healthwatch Essex's Ambassador programmes and recommendations. The steering group drew on their lived expertise to inform project documents and emerging themes during analysis. The group were pivotal in informing areas for exploration, project accessibility and how to use an intersectional lens during data analysis.

### 3.4. Recruitment

The project recruited women with two or more long-term conditions, who were over 18 years of age. The project was promoted across Healthwatch Essex social media pages. We also liaised with voluntary sector partners across Essex, including: community support groups; patient partner groups; parenting groups; and the Essex Faith Covenant.

Researcher flexibility was crucial to participant recruitment. Our lead researcher recognised that many participants with MLTC may experience debilitating fatigue. She also spent time to build trust through initial meetings and phone calls to ensure that participants felt comfortable sharing their experiences. Participants received the interview guide in advance if requested and interviews were offered either remotely or in-person. One participant's life history interview was conducted entirely via email due to selective mutism.

In total, nineteen participants took part. Eight had in-person interviews and the remaining participants completed their interviews remotely (one via email, three

over the phone and seven via Microsoft Teams). Interviews were conducted from August 2024 to May 2025 and lasted from 48 minutes to 2 hours and 25 minutes.

### 3.5. Analysis

We captured 33 hours of rich interview data. All interviews were transcribed verbatim, anonymised, read through several times and subjected to thematic analysis based on the research aims. Themes were created based on meaning. This could be moments of significance for the participants in their care journey or factors that impacted health outcomes. Generating themes based on meaning is good practice when undertaking thematic analysis (Braun & Clarke, 2006)

The transcripts were analysed by the lead researcher and then shared across the research team and eight volunteer Healthwatch Essex Research Ambassadors for triangulation purposes. Emerging themes were discussed with the project steering group and finalised with the research team.

### 3.6. Demographics

Participants' demographic details were collected via survey to provide an overview of the study sample and its representativeness of general population in Essex. This demographic data is outlined below.

- 69% of our participants considered themselves disabled. 31% did not consider themselves disabled.
- Most of our sample were unable to work due to a combination of health factors and employer inflexibility (53%). The remainder of our sample were either employed full time (10%), employed part time (17%), retired (10%), on sabbatical (5%) or self-employed (5%).
- Our participants were mostly of working age, with just over half (53%) of our sample aged between 45-55 years old. The remainder of the sample were either aged 18-25 (5%), 26-34 (10%), 35-44 (17%), 56-65 (5%), 65-80 (5%) or over 81 years old (5%).
- There was a mix of the highest level of education obtained by participants across the sample. Over a third had A-levels (37%), just over a quarter had undergraduate degrees (26%), some preferred not to say (11%), and the remainder had postgraduate degrees (5%), BTEC or vocational diplomas (5%) or were early school leavers (5%).

- Over half (68%) of our sample did not have a dependant who relied on them for care. Nearly a third were providing unpaid care for a dependant (32%).
- Most of the sample identified as heterosexual (90%), with the remainder identifying as bisexual (5%) or preferring not to say (5%).
- Participants were asked to self-describe their ethnicity. Three quarters (75%) described themselves as White British, with other participants describing themselves as British Pakistani (5%), English Jewish (5%), English Traveller (10%) and Mixed Heritage (5%).

### 3.7. Ethics

Ethical approval for this study was granted by Essex County Council in June 2024. High ethical standards were maintained throughout this study. All participants were assigned pseudonyms to ensure anonymity and participant details were not shared outside of the Healthwatch Essex research team.

# 4. Findings

In this chapter, we present the findings from this project. These are organised into the following key themes:

- Care navigation.
- Relational care.
- Maintenance or restoration of daily function.
- Advocacy and tackling ableism.
- Neurodivergence.

## 4.1. Care navigation

This theme highlights the significant amount of work and organisation involved in navigating care as a woman living with MLTC. Participants spoke of the administrative burden that this involved, including chasing referrals, and attending appointments, follow-ups and clinical tests. The number of tasks and potential clinical pathways they navigated multiplied with each long-term condition experienced:

> "It's knowing how to navigate the system, knowing what is available, who to ask for, how to make complaints, how to press for what you're wanting…"

This burden was reduced when participants could access their results and hospital letters online. Roseanna has a visual impairment. She described how the use of electronic systems – including accessible apps - at larger hospitals like Addenbrooke's Hospital in Cambridge made navigating care easier:

> "The fact that I don't even touch a piece of paper from the moment I walk in, to the moment I walk out. That's whether I'm an inpatient or going for an outpatient appointment, an X-ray or anything"

Other participants spoke of the need for care navigators who could administrate bookings, access accommodations, communication preferences and test results before consultations and scheduled procedures. This was particularly the case for participants who were neurodivergent, experienced fatigue, had communication difficulties or lived with five or more long-term conditions:

> "What would be really nice is to have someone [...] that is your primary person that can liaise with the other [specialties/departments] to make sure you get the right care [...] The amount of time and effort it takes me [...] and you're doing that when you don't have the energy of a normal person and you're dealing with like symptoms daily."

Paige, who lives with selective mutism, highlighted how a care navigator could support her by ensuring accommodations were put in place. At a previous GP surgery, she was told that she could not use paper to express herself or take notes down on her mobile phone during a consultation.

> "Stress effects my speech and can make it very difficult to find words to use and makes it more difficult to then get them out. If there was a better understanding of SM (selective mutism) this pressure would be removed to a degree because if they understood the condition and could work with paper then I would not have to fight my SM in a high stress environment".

As highlighted in the 'Analysis' chapter of this report, care navigators do exist in primary care. However, none of our participants were aware of or had accessed their support.

Participants found care especially difficult to navigate when seeking a diagnosis; a protracted and lengthy process, with referrals made only after multiple visits to the GP. Aubrey described her frustration at the lengthy wait to see a specialist as her symptoms were impacting upon her work and energy levels:

> "I mean, the system is completely broken. You don't actually physically see anyone. And if you do. The default is 'well, try this first'. I think, 'we know I've been experiencing these symptoms for friggin' ages. We need to get something done' [...] I probably would still not have even seen an endocrinologist if we hadn't have had our private medical".

In addition to diagnosis, discharge from specialist consultant-led care was also frustrating. Some participants had no say in being discharged. If their condition was then to flare, they had to be re-referred to the specialist by the GP. Often there were no direct referral pathways and no means of contacting the consultant specialist. Martine was referred to a gynaecologist for possible PCOS. However, she was then discharged without warning. This experience was mirrored by other participants:

> "He (Gynaecology consultant) said, 'we'll keep an eye on your symptoms for the next six months' […] So I thought, 'OK, I'll start tracking my symptoms' and then about two months in, I've got a letter saying they [gynaecology] discharged me. I haven't even finished tracking my symptoms. So, I've rung up the doctors again, [and] ended up speaking with a female GP."

Many of our participants further described having to accept referrals they deemed unnecessary as a stepping stone to the appropriate service. Paige, for example, felt obliged to attend a pain management session before she could see someone who could diagnose the underlying cause:

> "I had to go through a pain management session […] Then finally they referred me, and fibro[myalgia] diagnosed […] why should I have to listen to a three-hour lecture to access healthcare? I was in pain but had to walk a long way to get to a lecture and sit for three hours".

Effective and respectful communication was often a facilitator in navigating care pathways and contributed to trust in professionals and trust in the wider healthcare system. This is discussed in further detail in the next section, Relational care.

### 4.2. Relational care

Participants valued professionals who built a relationship with them based on collaboration, trust and mutual respect. They highlighted communication breakdown, the delivery of diagnoses, building trust and an overt focus on patients' weight as factors that influenced the relational care they received.

Participants who reported negative healthcare experiences often attributed this to a communication breakdown with their healthcare professional. For some, these communication breakdowns were recent. Other participants were still feeling the effects of previous harms from a hospital admission or an accumulation of dismissive interactions. Participants described how they were required to fit systems of care rather than the other way round, as summarised by Fran:

> "Pretty much my whole life is that when my body breaks, it doesn't break in a way that they [healthcare professionals] expect. It doesn't have textbook symptoms […] Basically, the NHS works with like, boxes, and if you don't fit into a box then it's very hard to get treatment or be believed or get help".

The women we interviewed shared that they were not listened to or believed by professionals, which affected their trust. They felt that professionals did not consider them to be accurate witnesses to their own lived experiences. Erin repeatedly sought help for symptoms of weight loss and abdominal pain. Despite clearly telling the GP that she did not have an eating disorder, they attributed her weight loss to anorexia and bulimia. Eventually she was correctly diagnosed with Colitis:

> "Cause I was a young female, um, one of the conclusions was I was either anorexic or bulimic. Right? But I think looking back, […] if they truly believed that was the reason for my thinness, why no treatment?"

Other participants described not being trusted to administer their own medication when admitted to hospital. As recalled by Roseanna:

> "I need my insulin 20 minutes before I eat. And you've now got my dinner there. I can't eat my dinner until I've had my injection. '[Ward nurse]: Ohh well, we have to go and get it. Be round with you in a little while'. An hour later it might turn up."

Women's self-management skills were often overlooked in clinical settings despite being expected to carry out these activities in their everyday lives.

Several of the women we spoke to described that their weight was frequently brought up in consultations as a cause or treatment for symptoms. Bushra spoke of her frustrations when professionals incorrectly attributed her symptoms to weight gain:

> "He wrote in the report, 'I don't believe she has fibromyalgia, I believe because she's not active and she's put on weight, it could be that', and I actually cried when I read that letter, I thought, 'God forbid you have to go through what I go through. Then you'd understand what it feels like, how it affects your day-to-day life'".

Participants reported better interactions with healthcare professionals when they were respected and treated as individuals. Naomi described how a clinician advised her to lose weight during their initial consultation, but consequently adopted a more tailored approach when she challenged the relevance of BMI:

> "I just thought I've lost all respect for you as a doctor because you've talked about my BMI. And I said, 'because BMI is nonsense, isn't it'? And he went,

> ‘oh, yeah […] I can, I'll look into [referring to] a doctor who won't tell you to lose weight […]And I was like, I thought, ‘Bloody hell, you know? This has never happened to me before’.”

Participants also built positive trusting and therapeutic relationships with healthcare professionals who delivered their diagnoses in a supportive and informative manner. Adele was diagnosed with heart failure. However, she was not fearful in terms of the diagnosis as the doctor was reassuring when explaining what would happen next:

> “She was very reassuring. The doctor that sent me to the hospital first explained it to me. And she explained it to me very well. And so then, there's no fear.”

Conversely, Shannon felt that she and others with similar neurological conditions were despondent when their diagnoses were delayed. Shannon started to experience uncontrollable shaking in her late twenties. It took approximately six years to receive a diagnosis. Prior to this, practitioners suggested that her symptoms were ‘psychosomatic’:

> “I would shake, spasm muscles and tear them. Now, that is, in my book, is no fun. ‘If I'm doing that to myself’, and I described it as such to two male neurologists who suggested that this was psychosomatic and he went ‘oh’. And I said ‘so, refer me. If I'm self-harming, you should be referring me’”.

Naomi also described how one doctor initially diagnosed her with fibromyalgia before rejecting it. This left Naomi feeling invalidated and disregarded.

> “When you have a condition that goes undiagnosed for years and years, and someone finally gives you a diagnosis, it's, it's like the validation you've been looking for. […] And then six months later […] he clearly didn't remember me, and he was saying ‘it says here you've got fibromyalgia. Who diagnosed that? I don't think you've got that’, and I went ‘well, you did. You diagnosed that’. And it was just this moment where I was just like, ‘Oh my God. That's been so quickly taken away from me’”.

This study aimed to capture the views of diverse communities and their interactions with healthcare institutions and practitioners. Members of the English Traveller community shared their experiences of relational care. Lisa described

how Addenbrooke's Hospital in Cambridge provided effective care for her and her family:

> "Most of my family, yeah, we do go to Cambridge […] We know we're gonna get treated right […] Addenbrooke's did, they just explained everything so that I fully understood it. […] They said like, 'once we explain this to you, if you feel you don't understand what we're saying, please ask us so we can fully explain, you know, we'll explain it deeper for you'. But everything was so clear and plain."

Trust was a significant cornerstone for all the women we spoke to in terms of communication and ongoing engagement with healthcare professionals.

### 4.3. Maintenance or restoration of daily function

This theme captures how participants wanted their own priorities included in management plans for their MLTC. These priorities included what they wanted to achieve in their daily lives, and how to maintain or restore specific levels of function. These priorities often conflicted with the clinical markers favoured by healthcare professionals, such as blood test results and BMI. In exploring these priorities, this theme also indicates the diverse ways in which women sought to maintain daily function across the course of their lives.

Shannon managed her neurological condition and MLTC by conserving energy and prioritising tasks. She had limited her engagement with the NHS because they did not value this approach:

> "I manage my symptoms very well. And how I manage it is by not doing. And that is incredibly hard for an NHS which is all 'just do more and you will get more'."

Participants with fatigue highlighted how healthcare professionals and the Department for Work and Pensions (DWP) failed to recognise 'doing less' as a form of self-management. Some were denied social welfare benefits because they could complete some daily activities independently, even though they were sacrificing a significant number of other activities to do so:

> "I feel I am being penalised by DWP for maintaining a lifestyle that minimises symptoms as much as possible so that I am not in constant pain, with high fatigue levels, brain fog, IBS etc".

Maintenance of daily function included fulfilling caring responsibilities. In our sample, 32% of the women we spoke to were responsible for providing care for dependents. Of these, a third were caring for their children or grandchildren. Caring for and supporting family members was imperative for members of the English Traveller community. The community was close-knit and the women we spoke to supported both their immediate and extended family, as Lisa explained:

> "You have respect for children, elderly, the dead. You just have respect for all of them [...] You know, I can stop doing what I'm doing. It's not important. They're important. I will do that because you know, they need it and you need help. So, we're always there to help."

Parents and grandparents in our sample often wanted to keep well so that they could prioritise care for their children and grandchildren. Bushra shared her experiences as a parent and carer living with MLTC and how she was learning to prioritise herself:

> "My eldest one, he's autistic, so I'm a carer for him [...] it does get difficult when you're in charge of somebody else as well. [..] Now I have to take each day as it comes. Because I can't predict how I will feel when I get up".

Riley is a single parent who is autistic. Her child is also autistic and lives with other health conditions. Healthcare services did not acknowledge her caring role when she went into hospital. She had to delay elective procedures because she could not find appropriate care for her children.

> "I think hospitals also have to understand that it isn't just that person. They, there's always things going on in their lives. [...] they have to understand that I'm not being difficult if I can't make something"

Participants described frustrations with not knowing where they were on NHS waiting lists. Without approximate timeframes, they could not put support in place for their children.

Most of our participants wanted professionals to build information about their social support network and desired level of daily function into their self-management programmes. This would make them more realistic to engage with. Some participants felt that occupational therapists (OT) were already good at doing this:

> "They don't care about your diagnosis. They just care about your function. They just care about your activity. What can you do, etcetera and how can we facilitate you to do the things you're really needing to do?"

Participants also welcomed a focus on prevention rather than cure, including signposting to voluntary organisations. Mandy described how practitioners often focused on her medical history rather than her current self-management of COPD through community sessions like Singing for Lung Health:

> "It's just still a bit stuck in the past and not taking on the new therapies […] You know, being able to recommend to their patients that there are groups […] It'd be great if they're more proactive about what you can do an not just looking at how things have gotten to this"

Our participants spoke of the need to be consistently listened to by health and care professionals. Shannon felt that practitioners should work with individuals to optimally manage their conditions based on their individual experiences and capabilities:

> "It's incredibly important to listen to the patient and go, 'OK, let's try X' and them say, 'oh, don't think so. I've tried it before'. […] If you are having sensible co-created interventions, tracking the responses, listening and believing your patients and their carers, you will create care."

Participants did not want to be passive recipients of services. They wanted their skills and priorities acknowledged and incorporated into their care.

### 4.4. Advocacy and tackling ableism

Several participants experienced some form of ableism or discrimination due to their MLTC. Ableism refers to the biases and practices that discriminate against people with disabilities or impairments. Our participants described the inaccessibility and ableism of services and support, verbal abuse they received from the public, and the impact of MLTC on their friendships. This theme highlights how support for women with MLTC also needs to tackle the ableism that they can experience.

Participants described how the built environment only accommodated the able-bodied. Shannon shared her frustration with GP accessibility, as they did not have a hoist on their premises. Dental surgeries were also inaccessible, and she had to wait to see a specialist dentist:

> "I've never known a GP to have a hoist. And I really do think that should be a minimum standard […] I can't go to a High Street dentist because most of those are in places that are above the shops, or upstairs or are inaccessible […] also, I need sedation to be worked on, and that has to be done under NHS care. I can only attend specialist dentistry. That means I've lost teeth."

Several participants shared how support services and benefits were often inaccessible and confusing to access. They highlighted the costs that came with living with MLTC, including paying for equipment and prescriptions, higher utility bills, and reduced dietary options. Bushra applied for Personal Independence Payments (PIP) – which can help with extra living costs and day-to-day support if you have a long-term condition or disability. However, her application was denied by the DWP several times before seeking advice from the Citizen's Advice Bureau and it went to tribunal:

> "They [DWP] wrote to the tribunal saying the case should be dismissed. But I still pushed for it. I thought, 'no, I am in genuine need over here. I'm not making things up. I am a genuine person'. I put the claim in for PIP 2021 and I didn't get the hearing till 2023 […] They awarded me basic…but it was a very long-winded process. And they don't make it easy for you".

Our participants found it stressful and exhausting to constantly advocate for themselves. Lauren shared memes that reflected the constant flux of having to prove to the DWP she needed support whilst also appearing 'normal' to others.

As well as negotiating ableism in services, participants had to navigate abuse and discrimination from the public. Several participants spoke of having evidence of their disability ready if people questioned their use of disabled parking spaces, as Mandy explained:

> 'I've been accosted by people in supermarkets like, 'why have I parked in a disabled place? They're really ill, they can't get a blue badge. How did I get a blue badge'? And I've literally lifted up my top and shown like, my battery [for the spinal cord stimulator]… And then they get the hump that that they're not right [laughs]".

Participants felt that public responses to their MLTC depended on whether or not they were visible (e.g. use of a wheelchair or hearing aid). Those with visible

conditions found that people might acknowledge they required accommodations. If their conditions were not visible, people often questioned or ignored their needs. This was the case for Abbey, who felt that people forgot that young people could have MLTC too:

> "This is what I found at work. I say to them 'yeah, because I look OK, you can't see it on me, but doesn't mean that I don't still get pains and I'm still getting really bad fatigue'. So, people kind of take advantage of that, because you look normal. Treat you by how you look, rather than [what] you've got".

Many of the women we spoke to felt that the ableist assumptions they encountered were perpetuated by the media:

> "I know that because of mainstream media, the general population seem to think those on benefits are just lazy scroungers and that people with disabilities are a drain on resources".

Our participants wanted to live fulfilling lives. Naomi described, however, how her social network reduced because some friends were unwilling to accommodate her needs:

> "I think a common thing you find as a disabled person is being told you're too much. That's a big thing. So you're too, you're too much to deal with, like you're too, you bring the mood down, you know, with all your problems or you, You're too much to accommodate for."

This sentiment was shared by Abbey, who described how loneliness affected her mental health:

> "It was really lonely […] a lot of my friends kind of regarded me as too boring because I couldn't go out and walk and I thought, "t doesn't take a lot to come over and have a coffee or a drink or anything'."

Our participants highlighted how ableism manifests both in society and their daily lives. Ableism was reflected in the lack of accessible services, the additional costs of living with MLTC and in the lack of autonomy and choice afforded to those with disabilities.

### 4.5. Neurodivergence

Just over a quarter of our participant sample (26%) had Autism and/or ADHD. Neurodivergence appeared to add an additional layer of complexity in terms of self-management of MLTC for the women in our sample. Lauren, for example, has ADHD and myalgic encephalomyelitis (ME), which is also referred to as chronic fatigue syndrome (CFS). She often felt as though these conditions conflicted with one another:

> "My body is saying 'no can't do that. I am too tired. There is not enough energy in my system to be able to do that'. But the brain doesn't register that fact. So, the brain still goes 'I can do all the things that I used to be able to do, and I'm just lazy if I don't do it'."

All neurodivergent participants felt that services were designed for neurotypical people. Fiona described the challenges she faced as a neurodivergent individual with MLTC and sensory processing disorder (SPD). She struggled in hospital environments but was not eligible for support provided by Learning Disability & Autism Nurse specialists.

> "Surely, if it's a learning disability team and autism, surely ADHD should come onto their remit? And then they [could] support those people that struggle like me"

Our neurodivergent participants described how access accommodations and communication requests were seen as 'optional' by service providers and were often not implemented. Riley, who is autistic and has ADHD, also found that some professionals failed to accommodate adjustments - including quieter spaces and tailored, well-paced communication - to support her when attending hospital:

> "I think people need to be taught about how autism and ADHD can affect people [...] that's never facilitated with grace. It's such an inconvenience. And that's bad"

Even when participants advocated for their right to accessible care, the relevant accommodations were not guaranteed. Fiona struggled with telephone consultations and could not process information over the phone. However, this was the only option offered by the endocrinology team.

> "In the end I just gave up and just went, 'Yeah, whatever. Just do whatever. I can't access this'. So anyway, I went to PALS because I was told, 'Well, that's just how we're doing it'."

When access accommodations were granted, this was due to the efforts of individual professionals, rather than a system-level adjustment. Participants felt that staff knew about autism, dyslexia and ADHD but did not consider how these conditions affected their ability to self-manage their MLTC. Executive dysfunction, for example, affected their ability to organise appointments or apply generic health information to daily life. Fiona was referred to and completed the same weight management programme four times. She did not find it beneficial but was not offered an alternative:

> "I've done More Life (weight management programme) 4 times and never lost a pound […] It's to do with your executive dysfunction, your ability to plan and organise. Yet nobody will sit down and write a full [meal] plan. Nobody will help me to, well, like, put strategies in place to be able to go out and buy food".

Lauren also expressed frustration about the limited support she had received for her mental health and ADHD. She also has aphantasia - an inability to mentally visualise things, which meant that approaches like cognitive behavioural therapy (CBT) were inaccessible:

> "There appears to be lots options for physical therapy if you have an injury, but only CBT for mental [health conditions]…I can't imagine the future or what I want things to be, so parts of therapy don't work".

Participants spoke of the benefits they experienced when their accommodations were met. Fiona, who also described the value of quieter spaces in GP surgeries, benefitted when her GP came to get her from the waiting area for her appointment. This meant Fiona could use her headphones whilst waiting:

> "For the first time, I felt like someone's actually recognised [that] there were some extra needs there".

Riley felt that her hospital care greatly improved when a ward nurse referred her to their autism support team:

> "She referred me to the autism support team at the hospital, who were amazing. So, they came and sat with me and talked to me. I just sobbed on

> this woman. I absolutely sobbed on this woman [from the Autism support team] and I said to her, 'I'm really sorry [...] but I didn't realise how bad the experience was gonna be' [...] But she went and spoke to a number of people. She spoke to the ward sister. Attitudes changed dramatically on that day"

The forward planning and collaboration between Riley and the hospital's autism support team meant that her care was more suited to her needs, less stressful and facilitated a smoother recovery. The autism nurse acted as an advocate for Riley during the initial emergency admission and the subsequent planned admission. Increased training and knowledge of neurodivergence among non-specialist staff would ensure that individuals receive care that is more tailored to their needs and increase the likelihood of access accommodations being provided. This would contribute to ensuring services are accessible for those who are neurodivergent.

# 5. Discussion

This study has helped us to gain a deep insight into the lives of women living with MLTC. In the following discussion, we will explore how the central themes that emerged during analysis of participants' accounts both support and expand existing research on the topic of MLTC.

## 5.1. Care navigation

Our participants described the work involved in accessing and navigating care. The intensity of this work has been recognised in other studies. Some researchers have defined the work of accessing healthcare and the associated tasks as 'treatment burden' (May et al., 2014; Tran et al., 2015). The interplay of demands placed on the individual, and their capacity to meet these demands are also described in Shippee et al's (2012) Cumulative Complexity Model. Each additional health condition and prescribed medication add to the complexity in managing care (Shippee et al., 2012).

Our participants highlighted that information was not transferred seamlessly across services. This lack of cross-sector communication has also been identified by the Health Services Safety Investigations Body (HSSIB, 2025). Their report found that those who were unable to navigate the healthcare system were more likely to experience delays, longer hospital stays, missed appointments and deterioration in their MLTC (HSSIB, 2025). This affected patients' mental and physical health. They described feeling 'burnt out', 'frustrated' and 'exhausted' - phrases also frequently used by our participants.

Some of the women we spoke to felt that there should be a dedicated professional to assist with navigating care. However, none of our participants had heard of existing care navigation professionals. Since 2019, primary care networks (PCNs) can apply for funds from the Additional Roles Reimbursement Scheme (ARRS). ARRS can cover the salaries of an expanded range of multidisciplinary staff, including Care Coordinators (NHS England, 2026). Care coordinators can support people with MLTC to manage their conditions, prepare for appointments, and connect to other professionals including social prescribers and community services (NHS England, 2026).

As of September 2025, there were 6963 full-time equivalent care coordinators across England, though numbers in Essex are not known (Gault, 2025). There are

still barriers that impact the recruitment of care co-ordinators through ARRS, which could indicate why our participants had not encountered them (Jones et al., 2024). Existing GP surgeries may not have the space for care coordinators to have a designated room. They are often employed on a fixed-term basis, and recruitment and supervision costs are not covered by the scheme (Jones et al., 2024). This particularly affects areas of high deprivation and demands, where PCNs may not have adequate budget for these upfront costs. Typically, a care coordinator's caseload comprises of those experiencing frailty, predominantly those residing in care homes (Budde et al., 2022). However, our findings suggest that care co-ordinators would also benefit working age women living with five or more long-term conditions. Their support could help to reduce burnout among those living with chronic conditions (Kontoangelos et al., 2022).

Our participants spoke of the need for enhanced collaboration, communication and timeliness when it came to diagnosis and follow-up support. Several of the women we spoke to struggled to be referred to additional support or were subsequently discharged from specialists without their knowledge. Those with PCOS, ME/CFS and fibromyalgia appeared most affected by this issue. A 2023 survey by the British Association for Clinicians in ME/CFS (BACME, 2023) found that the vast majority of those living with CFS had no access to local specialist services. Current specialist services are only reaching 15,500 of the 400,000 individuals living with ME/CFS (BACME, 2023). Services for PCOS are often fragmented and it can take up to 4 years to receive a diagnosis. Even after receiving a diagnosis, over a third of women are not provided with further support or resources (All-Party Parliamentary Group on Polycystic Ovary Syndrome, 2025). The women in our sample had not received further support after being diagnosed or were only referred to gynaecology for a short period of time before being discharged without their knowledge.

The women in our sample also struggled to navigate their care due to a general lack of investment and resources across services. They described difficulties in getting primary care appointments, understaffing in hospitals, and increased waiting lists. The number of appointments in primary care settings in England are at their highest levels whilst the number of permanently employed GPs across the sector has decreased since 2015 (The Health Foundation, 2023b). This increases the workload on the remaining GPs working in the system. Earlier discharge from either specialist management or hospital admission has resulted in an increase in

tasks referred from secondary to primary care.  A cross-sectional analysis of hospital discharge summaries revealed that a third of tasks that GPs were asked to action were inappropriate (Mughal & Maharjan, 2022). Inappropriate tasks are defined as ones that were initiated by hospital teams and should continue to be managed by them but instead were assigned to GPs.

This theme has highlighted the complexities of navigating care. The health system is made more complex due to fragmentation, singular-disease focus, poor communication and inappropriate referral of clinical tasks across the various settings. This subsequently affects the views and trust people have in the health system, which leads us to the next theme: Relational care.

## 5.2. Relational care

The women interviewed for this study needed their relationships with health and care practitioners to be based on collaboration, being listened to and mutual respect. They wanted professionals to ask them about their experiences, what they had tried previously and what was important to them. Interpersonal trust in healthcare professionals and institutional trust in the NHS was important for our participants. Active listening, honesty, giving detailed explanations and providing holistic, collaborative care are behaviours that increase patient trust in professionals (Greene & Ramos, 2021). A meta-analysis found that patients reported an increase in quality of life, reduced symptoms and higher satisfaction with management of their conditions when they trusted professionals (Birkhäuer et al., 2017).

Trust is multidimensional and shaped by previous experience. Our study found that women who had experienced repeated breakdowns in communication or several episodes of poor care, were more likely to disengage from services. Some participants stated they prefer to “stay well clear” or “avoid” healthcare services because of previous negative experiences. Long-term avoidance of care can lead to deteriorations in MLTC (Chronic Illness Inclusion, 2021). For those who had been harmed as a direct result of healthcare, their trust in health care systems and professionals was irrevocably damaged. In one study, a third of participants who had experienced harm caused by healthcare, reported that they would not seek further hospital care (Ottosen et al., 2021). Individuals who experience harm feel further traumatised when hospitals defensively handle complaints, fail to apologise and show no regard for the individual’s ongoing health and wellbeing (Ottosen et al., 2021). Similar findings were found in our study.

Several participants also felt that their symptoms were dismissed due to professionals' biases and assumptions about their gender, weight and medical history. A UK Government survey on women's health found that 84% of respondents had not been listened to by healthcare professionals, with symptoms and side effects dismissed or disregarded as 'part of being a woman'. Women's treatment preferences were dismissed and respondents had to make multiple visits to services to be taken seriously (Department of Health and Social Care, 2022). One qualitative study has found that doctors formed judgements on how reliable a patient was when giving their account, early on during consultation (Pelaccia et al., 2016). Our findings suggest that women detect when this is happening. Some sought alternative providers, whilst others disengaged with individual practitioners or services.

Previous studies have revealed that people living with overweight and obesity experience discrimination and weight stigma from healthcare professionals (Phelan et al., 2015). Healthcare professionals spend less appointment time during with individuals who are obese and increasingly use terms such as 'non-compliant', 'undisciplined' or 'lazy' (Brown et al., 2022). These experiences of weight stigma mean that women living with overweight or obesity are less likely to access screening programmes and more likely to disengage from healthcare (Phelan et al., 2015). Our findings also reflect existing studies into chronic pain. Researchers have found that women who experience pain dismissal by clinicians are more likely to adopt strategies such as self-advocating, rotating between or requesting another doctor, and turning to complementary medicine (V. L. Brown et al., 2023).

Our participants highlighted how doctors were likely to contest conditions with no visible physiological changes such as ME/CFS, functional neurological disorder (FND) and fibromyalgia. Professionals can be unsure how to manage these individuals so pass them on to another specialty or service (Barnett et al., 2022). The individual is then bounced around various specialties and loses confidence in the healthcare system, leading to worsening of symptoms and delayed treatment (Barnett et al., 2022). Participants with ME/CFS, fibromyalgia and FND were often told their symptoms were 'psychosomatic' or 'due to stress'. Research shows this is a common experience (Barnett et al., 2022; Horton et al., 2010). A minority of professionals in a 2022 survey questioned whether fibromyalgia even existed (Wilson et al., 2022). Increased training for professionals and funding for specialist

services is needed to improve outcomes for women living with these conditions. GPs in a systematic review have called for better MLTC management guidance, renumeration and policies that support the development of trusted, long-term patient partnerships, suggesting that there is an appetite for this training (Damarell et al., 2020).

Women we spoke to from the English Traveller community favoured respectful care over local care, travelling to a larger hospital where they were listened to and staff explained things in a way that they understood. Cultural competence has been found to improve patient satisfaction among those from minoritised communities (Tang et al., 2019). However, its inconsistent application across local services can affect access to timely preventative care. Romani (Gypsy), Roma, Irish and Scottish Traveller communities experience disproportionate poorer health outcomes. They are more likely to develop MLTC at a younger age and their life expectancy is 12 years less compared to the general population (The Traveller Movement, 2026). Services currently fail to account for premature onset of age-related conditions and tailor care to this population (Friends Families & Travellers, 2022).

The women in this study described a paradox where they self-managed complex conditions and care plans every day, but consistently had their knowledge, credibility and experience questioned by professionals. They called for relational care that was rooted in collaboration, trust, cultural competence and respect; that acknowledged that they were the experts in their own MLTC. A collaborative, respectful relationship sets the foundation for MLTC management that reflects the priorities and aims of the individual.

### 5.3. Maintenance or restoration of daily function

Our participants shared how they sought to maintain or restore daily function whilst self-managing their MLTCs. Most of our participants prioritised strategies that minimised their fatigue, which had the greatest impact on daily life. This had increased importance for the women who were caring for or providing support to another person. Participants who had child dependents (of any age) were more likely to prioritise their own health so that they could continue to care for their children or grandchildren. However, circumstances beyond their control could make this difficult, resulting in missed appointments and delayed procedures.

Unpaid carers are at increased risk of social isolation, depression, musculoskeletal conditions, heart disease and insomnia (Public Health England, 2021). This has led to calls to define caring as a social determinant of health (Burchardt, 2025; Public Health England, 2021). A scoping review found that gender, intensity of care work, older age of care recipient and socioeconomic status increased poorer outcomes for carers (Stowell et al., 2024). Carers with chronic conditions were found to report a decline in their physical health over time, whilst carers who had no chronic conditions reported their physical health remained stable (Tommis et al., 2009). Healthcare professionals supporting women with MLTC should enquire about their caring responsibilities. Community services for carers also need to be flexible and inclusive to ensure accessibility for carers living with MLTC.

The women we spoke to emphasised a need for health care practitioners to work with them to maintain or restore daily function on their own terms through tailored goal setting, continuity of care, and longer appointments. A systematic review in 2020 found that GPs wanted to understand individuals' goals and social circumstances and support their continuity of care. However, they struggled to achieve this due to time pressures and limited resources. GPs were concerned about how treating one condition may exacerbate another condition. However, they had limited guidance on responding to this concern. GPs also reported difficulties in contacting specialists for advice. They suggested longer appointment times for those with MLTC but were unsure of how funding models would accommodate this in primary care (Damarell et al., 2020).

GP surgeries are paid a lump sum per registered patient. This is a fixed payment regardless of how much care the patient requires and is known as 'capitation payment' (Peckham & Gousia, 2014). This can lead to GP practices attempting to cost contain if they have a significant number of complex patients on their register. Clinicians must also accommodate system or population-health priorities, and this can occasionally create tension when they misalign with the priorities of the patient (Schuttner et al., 2022, 2025). The sustainability and supply of primary care staff also directly affects the quality of care women with MLTC receive. Women with MLTC living in areas of deprivation are less likely to receive continuity of care due to a higher turnover of GPs in deprived areas and chronic under-recruitment (Jerjes, 2025)

Many of our participants limited their activity levels to avoid fatigue, pain and breathlessness. This resulted in slightly better daily function. However, these measures were often seen to be at odds with the views of medical professionals; the health system focused on 'doing' and increasing physical activity, regardless of any negative impacts. Community-based interventions that are professionally led, patient-centred and focused on addressing functional difficulties yield significant improvements in daily life (Gitlin et al., 2006). This was highlighted in the praise our participants afforded to both OTs and voluntary sector initiatives. Those who attend interventions aimed at addressing functional difficulties, are more likely to confidently fulfil activities of daily living, such as bathing and dressing (Gitlin et al., 2006). The community-based group Singing for Lung Health, for example, aims to improve individuals' functional abilities and prevent hospitalisation (Asthma and Lung UK, 2023).

Our participants offered valuable insights on what good health in everyday life should look like. In a study that conducted focus groups across eight European countries, participants defined good health as being able to conduct their daily activities, contribute to society, live a life free from stigma, and maintain positive mental wellbeing (Leijten et al., 2018). Participants across all focus groups placed greater emphasis on care processes (e.g. continuity and collaboration), as opposed to measures of health. This strongly reflects findings from our research and should encourage policymakers and professionals to focus on these areas.

## 5.4. Advocacy and tackling ableism

The women we interviewed described navigating environments that were not designed with them in mind. The challenges of living with MLTC were magnified in a world built for the able-bodied. This occurred on many levels: inaccessibility of buildings, public attitudes, media discourse and reduced social security.

Participants detailed how the accessibility of services and screening programmes was mixed. GPs, high street dentists and opticians, for example, were restrictive to wheelchair users. Whilst breast screening satellite clinics were wheelchair accessible, cervical screening could prove challenging as many GP surgeries do not have a hoist. This means that some women who use a wheelchair are unable to transfer onto the examination table. A survey by Healthwatch North Lincolnshire found that none of the GP surgeries in the area had hoists on their premises (Healthwatch, 2025). Women with a physical disability are 33% less likely to attend cervical screening and are more likely to be diagnosed with cervical cancer at a

more advanced stage, increasing the mortality rate for this population (Choi et al., 2021). Similarly, most high street dentists in the UK do not have hoists. NHS Community Dental Services (CDS) are more likely to have hoists, wheelchair recliners and adapted dental chairs (Scope, 2025). However, they have extensive waiting lists.

GP practices have a duty to make reasonable adjustments according to the Equality Act 2010. However, a survey by the British Medical Association found that there are widespread critical infrastructure issues across primary care (BMA, 2025). 83% of GP respondents felt that their premises were not suitable for future needs. Funding is available to improve estates and facilities, but only 28% of practices that had applied for grants from the NHS Property Services were successful (BMA, 2025). NHS estates and infrastructure need to be upgraded to ensure it can meet current and future needs.

Many of our participants spoke of the hidden costs of living with MLTC, including increased utility bills, higher insurance premiums, restricted and expensive food choices, reduced social life, costs of specialist equipment, transport and prescription charges. Their experiences are reflected in research findings elsewhere (Banks et al., 2025; Karpouzou, 2024; Scope, 2024). Several participants discussed their difficulties accessing Personal Independence Payments (PIP). A large part of the PIP assessment is based on how the individual presents on that day. This is highly problematic for those who have fluctuating health conditions or feel compelled to mask their symptoms, resulting in individuals not receiving the financial support they are entitled to (Galloway et al., 2018). Claimants are led to believe that their experiential knowledge combined with supporting evidence from their doctor is sufficient, credible testimony. However, research has found that the evidence of outsourced 'independent' assessors is given the most weight in the DWP's final decision (Porter et al., 2023).

In 2025, the UK government further narrowed the eligibility criteria for PIP (Citizens Advice, 2025). For many women living with MLTC, being in receipt of PIP is a gateway to other benefits and support measures including the health element of Universal Credit, higher rate local housing allowance and council tax assistance (Citizens Advice, 2025). Carers UK report that over half of those who receive Carer's Allowance have their eligibility tied to their PIP (Carers UK, 2025). For some women with MLTC, losing out on PIP will affect their Carer's Allowance entitlement. This risks plunging entire households into financial struggle. Welfare reforms and

assessments for the DWP were a source of great stress for several of our participants. This stress led to flares of some health conditions and deteriorating mental health. One participant described the additional stress of going to tribunal to appeal the DWP's decision. 7 in 10 applicants win their appeals on the same evidence that the DWP already has on record (Disability Rights UK, 2025).

Many of our participants who were in receipt of benefits spoke of the negative media portrayal and public perception of those with MLTC who claim support (E.g. PIP or UC). Cultivation theory suggests that the more time people spend consuming media, the more their way of viewing the world resembles it (Morgan & Shanahan, 2010). A study by the Glasgow Media Group found that print media coverage that referred to individuals with mental health conditions or conditions that were not visible to others (e.g. chronic pain), were often framed as 'undeserving' of benefits (Briant et al., 2011). Pejorative language was more frequently used in these articles, compared to articles that referred to those with physical conditions.

The majority of women we interviewed spoke of how poorly understood MLTC is- particularly among able-bodied members of the public. Several had experienced hostility, intimidation and verbal abuse from strangers whilst in public places. Studies elsewhere have reported similar findings. Young people with invisible conditions in other studies have reported incidents of intimidation and verbal abuse from strangers or staff in public spaces (Smith & Daly, 2019).

Our participants encountered ableism in the workplace, in public spaces, when applying for benefits and when confronted with a built environment that was inaccessible to them. Routine screening, dentistry and eye care needs to be accessible to all, whilst benefit assessments should provide equal weighting to the expert input of the individual with MLTC and their doctor/specialist.

### 5.5. Neurodivergence

Eight participants (42%) in our sample were either diagnosed or self-reported as being neurodivergent. They spoke more frequently about disengagement, difficulty organising appointments and how interacting with the health system often left them feeling confused. This population group has a high level of unmet need. There are common co-occurring conditions experienced by some women with autism. These can include ADHD, obsessive compulsive disorder (OCD), Ehlers-Danlos syndrome, Prada Willi, ME/CFS, Irlen's syndrome and Tourette's

syndrome (Jadav & Bal, 2022; Rose, 2019). Over a third of neurodivergent individuals are diagnosed with depression (Kelly et al., 2024). Neurodivergent women are at increased risk of premature death when compared to neurodivergent men and their neurotypical peers (Kelly et al., 2024).

Neurodivergence, such as autism, involves processing sensory input differently to that considered 'neurotypical' (Rose, 2019). Environments like GP appointments, which involve bright lights, noises, smells, and rapid-fire questions, can pose a challenge for neurodivergent sensory processing. Participants reported that this sensory overload could be reduced through longer appointments, lower lighting, limited noise and clearer communication. These reflections mirrored findings elsewhere regarding recognising and responding to the health needs of neurodivergent women and girls (Kelly et al., 2024).

MLTC management is complex for the neurotypical and neurodivergent alike. However, neurodivergent women experience difficulties contextualising generic health information. It may not have the level of depth or detail those with autism and/or ADHD require. A neuroinclusive approach to care delivery is one of acceptance - that neurodivergence is part of the natural range of human development (Doherty et al., 2023). One framework for ensuring settings are autism friendly, is the SPACE framework (Doherty et al., 2023). The framework can be useful for identifying areas in the environment for sensory management. The SPACE acronym represents five core areas: Sensory needs, Predictability, Acceptance, Communication and Empathy.

Our participants felt that healthcare professionals' knowledge of neurodivergence was poor. A survey of 798 staff across health, social care and teaching educational settings, found that most had received minimal training (Dillenburger et al., 2016). Respondents who had received training said it was a one-off workshop or lecture lasting 1-2 hours. Professionals want training that is co-designed and co-produced by neurodivergent individuals, delivered in-person and provides 'real-life' scenarios or case studies relevant to their place of work (Dillenburger et al., 2016). There is an incorrect assumption that those who are autistic lack empathy (Fletcher-Watson & Bird, 2020). Due to these biased and incorrect assumptions, they are less likely to receive empathetic care from professionals. However, a study in Australia found that training led by those with lived experience led to attendees reflecting on their own previously held biases

(Bernard et al., 2025). Attendees also reported feeling more confident caring for neurodivergent individuals after the training (Bernard et al., 2025).

Whilst increased training and practical measures to reduce sensory overwhelm are good starting points, clinicians need to further their knowledge of the most common conditions that co-occur with neurodivergence.

Any lifestyle and self-management advice (or programme) needs to address their holistic needs and allow for any challenges with executive function. 1:1 sessions may work better for neurodivergent women. Some of our participants discussed difficulties they encountered with 'one-size-fits-all' programmes or patient workshops. These included weight management courses and diabetes management programmes. Detailed patient histories were rarely passed on to external services delivering programmes, so holistic care was difficult to achieve. Programmes were delivered with the neurotypical in mind, usually in group settings. One participant described how it set back her eating disorder recovery. ADHD has been found to correlate with depression, bulimia and binge eating (Makin et al., 2025) .

Going forward, researchers must work in more neuroinclusive ways to ensure representation of neurodivergent women in data. Data informs developments in evidence-based care and service improvement. However, previous studies have typically operated in fixed, inflexible ways that have denied neurodivergent women the chance to participate (Kelly et al., 2024). Previous studies may exclude those with neurodivergence in their eligibility criteria, insist on in-person interviews conducted in one sitting or may use technical, specialist language in recruitment materials. An article co-authored by those with lived experience, describes the important role funding bodies can play in encouraging inclusive studies (Fletcher-Watson et al., 2021). Funders can make the inclusion of community consultants or steering groups a requirement of receiving grants.

# 6. Conclusion

This research has explored the challenges and complexities of women's experiences living with MLTC, as told in their own words. Using flexible and inclusive qualitative interviewing methods, this study has captured the in-depth experiences of 19 women living with MLTC in Essex. Drawing on the invaluable insights of our project steering group, this study has identified 5 themes that reflect our participants' experiences of MLTC. In doing so, it has highlighted how women manage their conditions day-to-day, the barriers they face when accessing services, examples of best practice when supporting women with MLTC, and the real impact of systemic under-resourcing and infrastructure issues on the lives of people with MLTC who use the NHS. This approach moves away from the single condition focus of health and care services, specialties and settings; championing the need for health and care systems to recognise the steps they can take to ensure that women living with diverse MLTC receive the support that they need on their own terms.

This section draws on our participants' reflections to highlight key recommendations for how women with MLTC can be best supported. It subsequently discusses the limitations of this study, along with opportunities for future research in the field of MLTC.

## 6.1. Recommendations

These recommendations were finalised following consultation with our project steering group. Its members emphasised that the recommendations for this project should not further promote self-advocacy or initiatives that insists on individual-level measures. Both our participants' experiences and the wider literature suggest that those living with MLTC already are asserting themselves, self-advocating and learning about their conditions. These recommendations therefore focus on how health and care services can be increasingly receptive to women who self-advocate, viewing their own expertise as on par with that of professionals, and support their staff to deliver holistic care. They are categorised based on the emerging themes and suggestions put forward by our participants.

**Accessibility:**

- **Access accommodations are not optional.** Implementing and ensuring continued accessibility will benefit everyone.

- **Accessibility begins before the patient has even entered the room.** Ensure the individual is aware of what to expect during elective procedures or diagnostic tests and adhere to communication preferences and accessibility needs when reaching out.
- **GP practices need to have hoists for those with reduced mobility.** The inclusion of hoists in all GP practices would ensure the accessibility of invaluable screening programmes. This would improve, for example, rates of early detection of cervical cancer for disabled women with MLTC.
- **Ensure the option of longer appointment times at outpatient clinics and GP appointments.** This especially benefits women with MLTC, complex needs and neurodivergence.

**Preventative care:**

- **Preventative care applies equally to those with MLTC, and those yet to develop chronic conditions.** It should focus on supporting women to maintain their daily function as well as preventing the onset of other diseases and conditions.
- **Refer/signpost women to community services that promote this approach to prevention**. Singing for Lung Health is a valuable example of one such initiative.

**Relational care:**

- **Value women's expertise by ensuring collaboration in every consultation.** Ask women what they have tried before, what has worked, and what has not. Enquire what if and what they have understood during the consultation and if anything requires clarification. Use clear language and terms that they are comfortable with.
- **Co-create self-management plans.** Include the provision of rescue packs for those with COPD, rapid access appointments to physiotherapy where appropriate, contact numbers for clinics and involve carers in self-management.
- **Relational breakdown requires a relational solution.** This is particularly important for women who have disengaged from the healthcare system.: Provide a named doctor to ensure continuity of care and rebuild trust. Invite carers and/or a family member to attend with the individual, if they wish.

**Training:**

- **Provide high-quality, co-produced training on neurodivergence for all health and social care professionals.** Training should specifically cover how neurodivergence presents in women, and how environments can be adapted to avoid sensory overwhelm.
- **Deliver cultural competence training for those caring for women from ethnic Roma (Gypsy), Romani and Irish Travellers.** Learn best practice from settings trusted by these communities.

## 6.2. Limitations

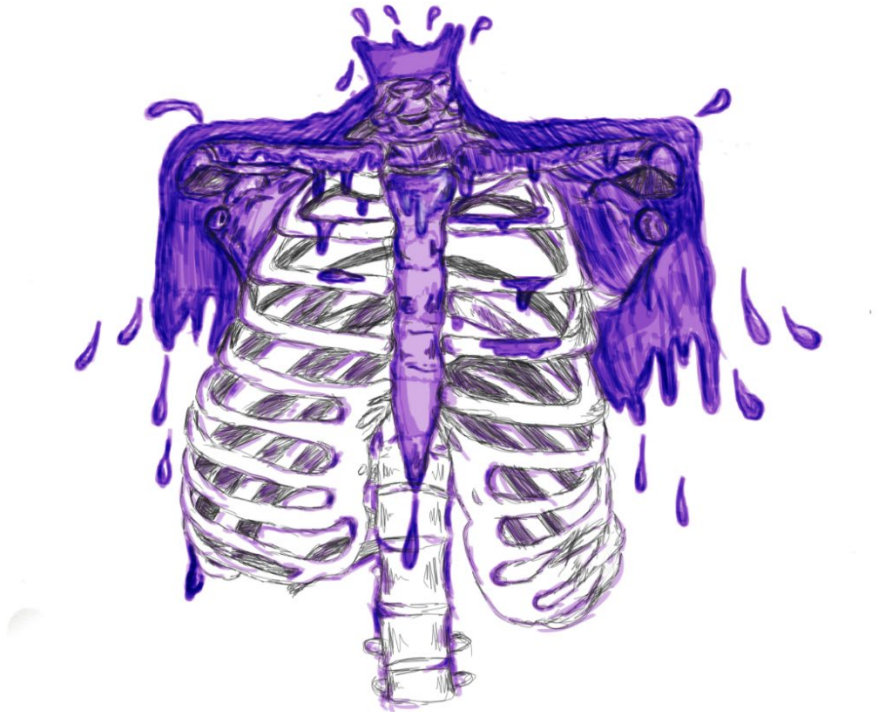
Unfortunately, Black British/Afro Caribbean women were not represented in our study sample, despite our engagement with organisations that serve these communities. Future research could engage peer researchers or fund a community consultant to interview members who attend organisations that support Black British women with MLTC. This study did have representation of women who live with visible and non-visible conditions. We also heard from neurotypical and neurodivergent women. Most of our sample were women of working age, which reflects the steady rise of MLTC among this age group in the last decade. This study was informed by a project steering group, whose members had lived experience of visible and non-visible conditions.

## 6.3. Future research

There are several urgent areas for further study relating to women and MLTC. Further research is needed, for example, into the needs of neurodivergent women living with MLTC. This is essential to understand the accessibility needs and barriers to care that this population face. Data is needed to inform service improvement and ensure the delivery of service that meets the needs of the neurodivergent and neurotypical. It is also imperative to understand the views and experiences of those working in primary care. GPs are at the forefront of supporting those living with MLTC in the community but often are under significant pressure and funding constraints. A study that explores the perspectives of primary care staff would further our understanding of MLTC management. Those working in this sector can offer insight on the factors influencing care delivery and the resources needed to ensure holistic, respectful healthcare for those living with MLTC.

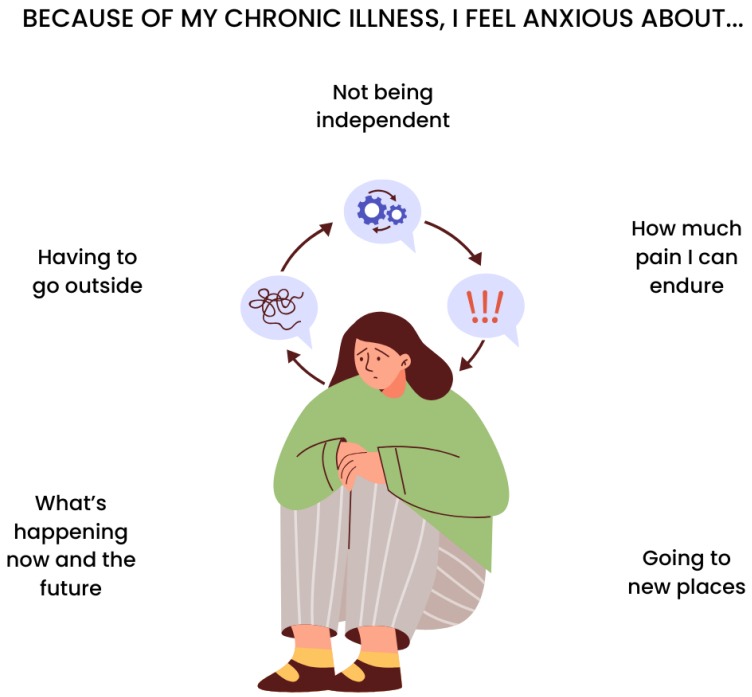
# 7. Appendix – Creative Methods

As part of this project, all potential participants were offered the option of sharing their experiences during interview or they could share their experiences via their preferred creative method and complete a shorter interview. 2 participants opted to engage with this method. Martine completed a shorter 1:1 semi-structured interview and then submitted a digital drawing of her reflections on living with MLTC. You can find Martine's drawing below along with her reflections on how it reflects her experiences:

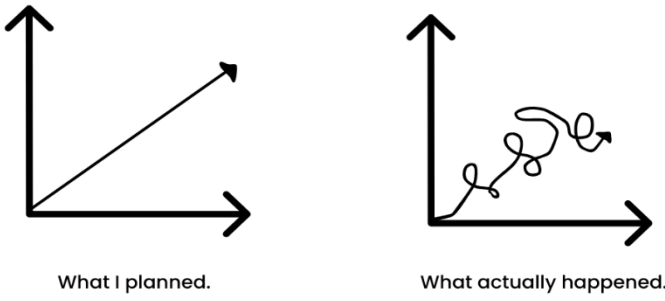


"I want to share this piece to give viewers an alternate perspective on the human body, treatment options and medications. As more than often, doctors will prescribe tablets to wane away side effects and symptoms of a long-term condition as a short-term relief as opposed to a more sustainable, possibly holistic, approach which doesn't affect other parts of the body and reduces the risk of side effects".

Lauren shared a selection of memes that resonated with her and reflected her lived experience of MLTC. Two of these memes have been re-created below, with captions supplied by Lauren explaining why she chose the meme:




"Anxiety is an energy drain. Losing my independence is a large problem for me. I am now reliant on my partner for a roof over my head. There is always background worry about this."




"This one speaks to the ADHD part of me. I can't do a straight-line task or indeed chat, there are always tangents and detours, side quests if you like. This means than any task I attempt invariably takes longer and more energy than planned or indeed should. This causes extra anxiety in the planning."

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