Neurological Health

Research Project Findings Report

April 2025

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Please note that all quotes included in this report are presented verbatim unless otherwise indicated. Only filler words such as 'um' and 'you know' have been omitted for clarity and brevity.

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Executive Summary

- Our third project of 2024 focused on neurological health and conditions.

- In total **375** service users shared their views. Service users shared their views on the following (*please note that this is not an exhaustive list; it highlights the conditions respondents most frequently shared their views on*):
    - Fibromyalgia - 38%
    - Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) - 13%
    - Multiple sclerosis (MS) - 11%
    - Migraines - 5%
    - Epilepsy - 4%
    - Functional Neurological Disorder (FND) - 4%

- According to the data collected, experiences did not appear to differ based on characteristics such as age or the type of neurological condition.

Key headlines include:

Diagnosis

- 58% (205) were diagnosed correctly first time. Diagnosis times varied between less than one month and over 18 months. For 46% (153), getting a diagnosis took more than 18 months.

- Many patients reported feeling unheard and dismissed by healthcare providers. A lack of knowledge and empathy around certain conditions, like fibromyalgia and ME/CFS, led to delayed diagnoses which impacted patients' lives, social connections, and employment. Frustrated with the lack of support, some sought private diagnoses.

- Even after being diagnosed, many were left to manage serious, life-altering conditions on their own.

Waiting Times

- 29% (108) were waiting for additional tests, treatments or diagnosis.

- Regardless of the condition or what they were waiting for, respondents shared they had often been waiting for months, with little communication or support offered in the meantime.

Executive Summary

Treatment and Management

- 71% (263) took medication for their neurological condition and 71% (88) of these individuals had faced challenges getting medications that worked for them.

- Common challenges included side effects of medications, finding medications and dosages that helped manage symptoms, shortages and needing specialists’ input to change dosages.

- 47% (173) had been offered or received treatment other than medication. Signposting to support and referrals to other services appeared to be inconsistent. Also, service users appeared to be unaware of what support is available and what could be beneficial.

What works well?

- Those who accessed specialist care, including MS nurses and consultants, praised its quality. However, not everyone is able to access specalist care.

- Repeat prescriptions.

What could be improved?

- Listen to patients and show understanding.

- Increase healthcare professionals' knowledge of neurological conditions including recognising fibromyalgia, FND and CFS/ME as real conditions.

- Provide clear information for patients on diagnosis, prognosis, and management.

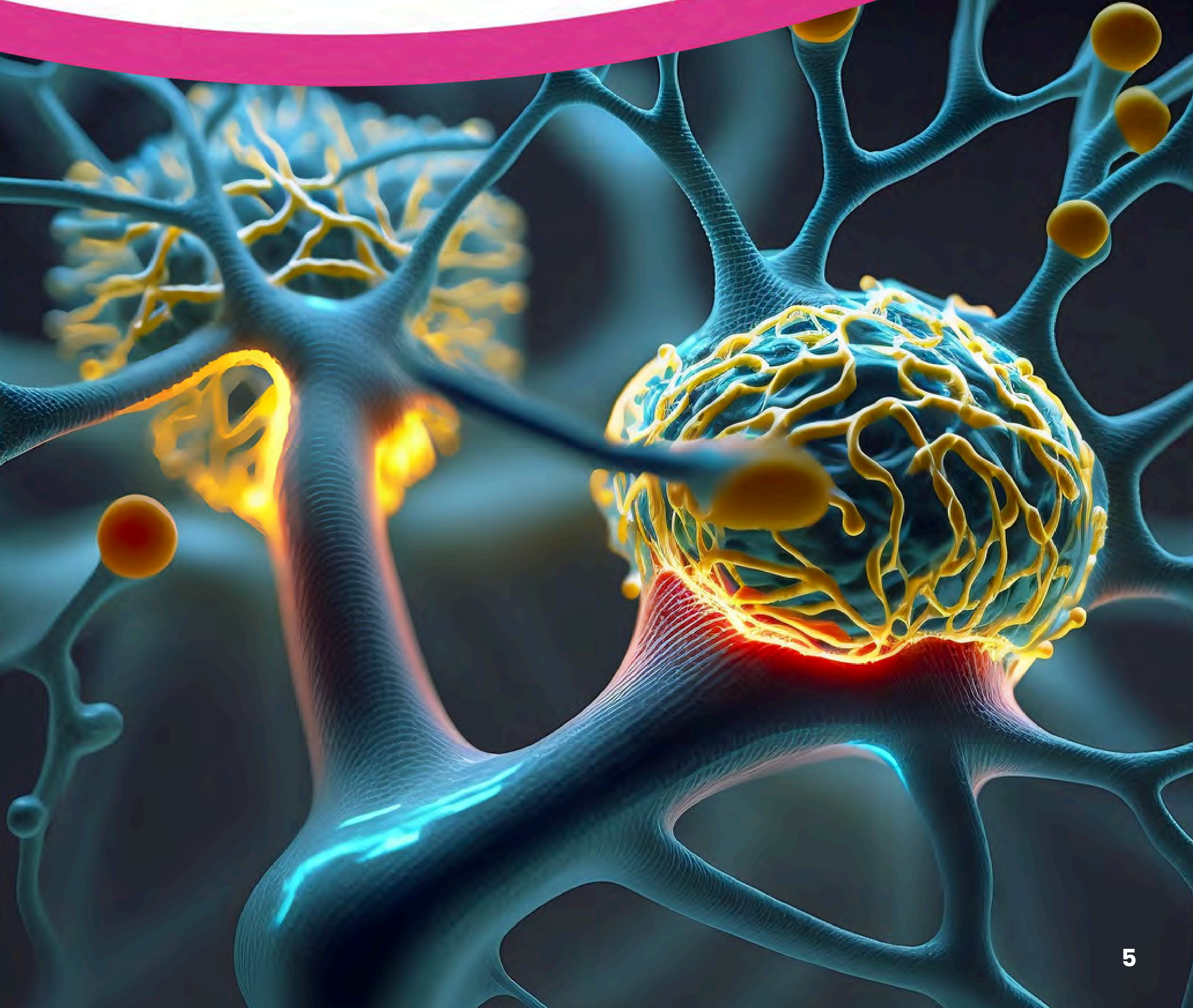
- Establish local specialist neurological centres, hubs, or clinics.

- Improve access to pain clinics and better pain management strategies.

Executive Summary

What could be improved?

- Offer holistic support, recognising that individuals are affected in different ways.
- Develop local support groups, including options outside standard working hours.
- Ensure joined-up care with coordinated services.
- Reduce waiting times for specialist support and offer interim support while patients wait.



Background

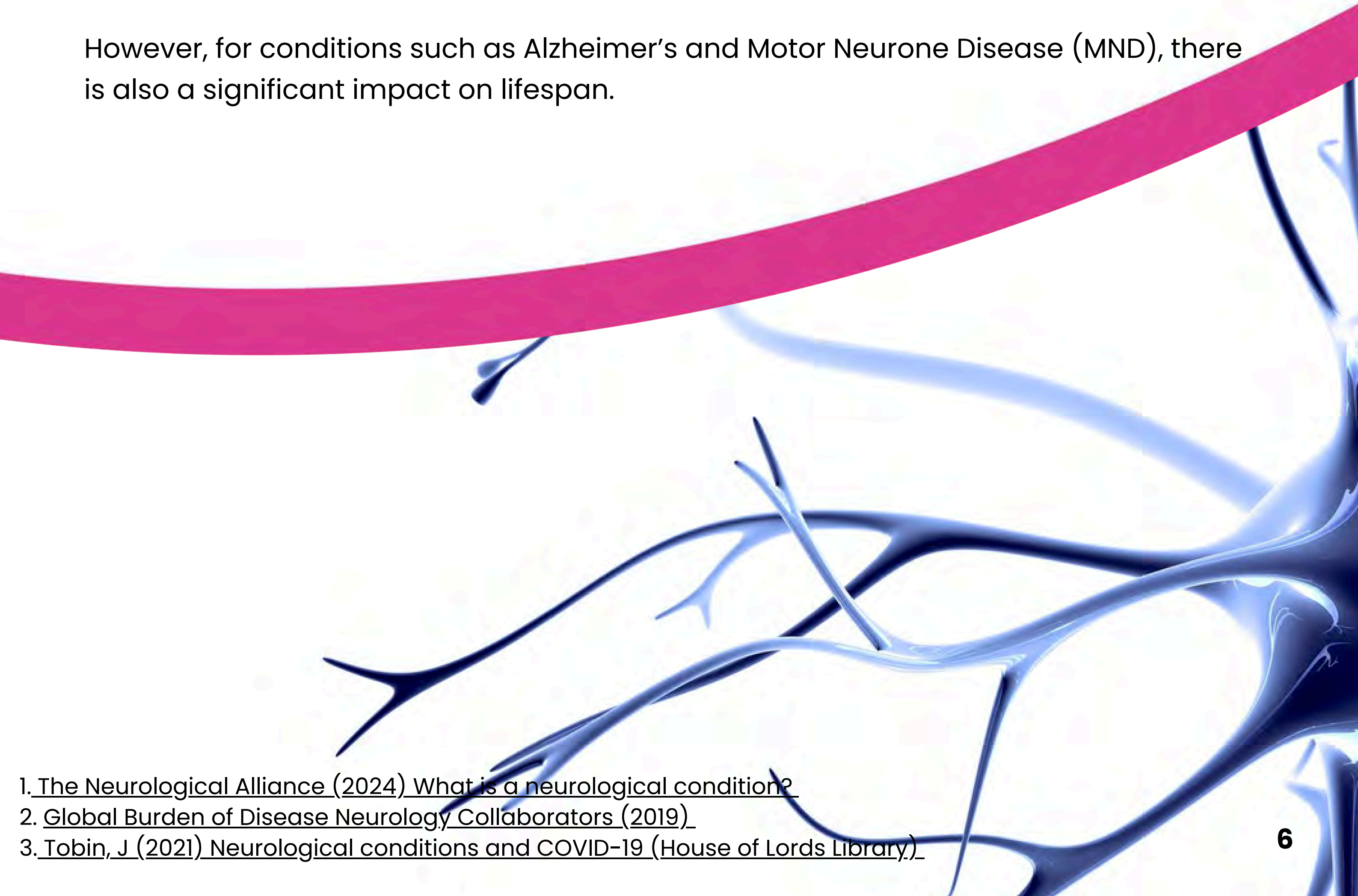
Our third project of 2024, focused on neurological health and conditions.

“A neurological condition is any condition that affects the brain, spinal cord and/or nerves. Because these systems control your mind and body, neurological conditions can affect the way you think and feel and interact with the world. Neurological conditions can affect anyone at any age.” - The Neurological Alliance[1]

Neurological conditions include multiple sclerosis (MS), stroke, migraine, traumatic brain injury and epilepsy. For this research project, we included conditions with neurological components such as chronic pain, fibromyalgia and functional neurological disorder (FND).

The Global Burden of Disease report shows that those with neurological conditions are more likely to live with significant disability over many years, rather than a reduced lifespan. This prolonged disability affects their ability to work, carry out daily tasks and maintain independence.[2] Therefore, while some neurological conditions might not immediately shorten life expectancy, they greatly impact the quality of life over time. This is supported by NHS England who say “people with neurological conditions have the lowest-related quality of life of any long-term condition”.[3]

However, for conditions such as Alzheimer’s and Motor Neurone Disease (MND), there is also a significant impact on lifespan.



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1. The Neurological Alliance (2024) What is a neurological condition?
2. Global Burden of Disease Neurology Collaborators (2019)
3. Tobin, J (2021) Neurological conditions and COVID-19 (House of Lords Library)

Background

The local picture

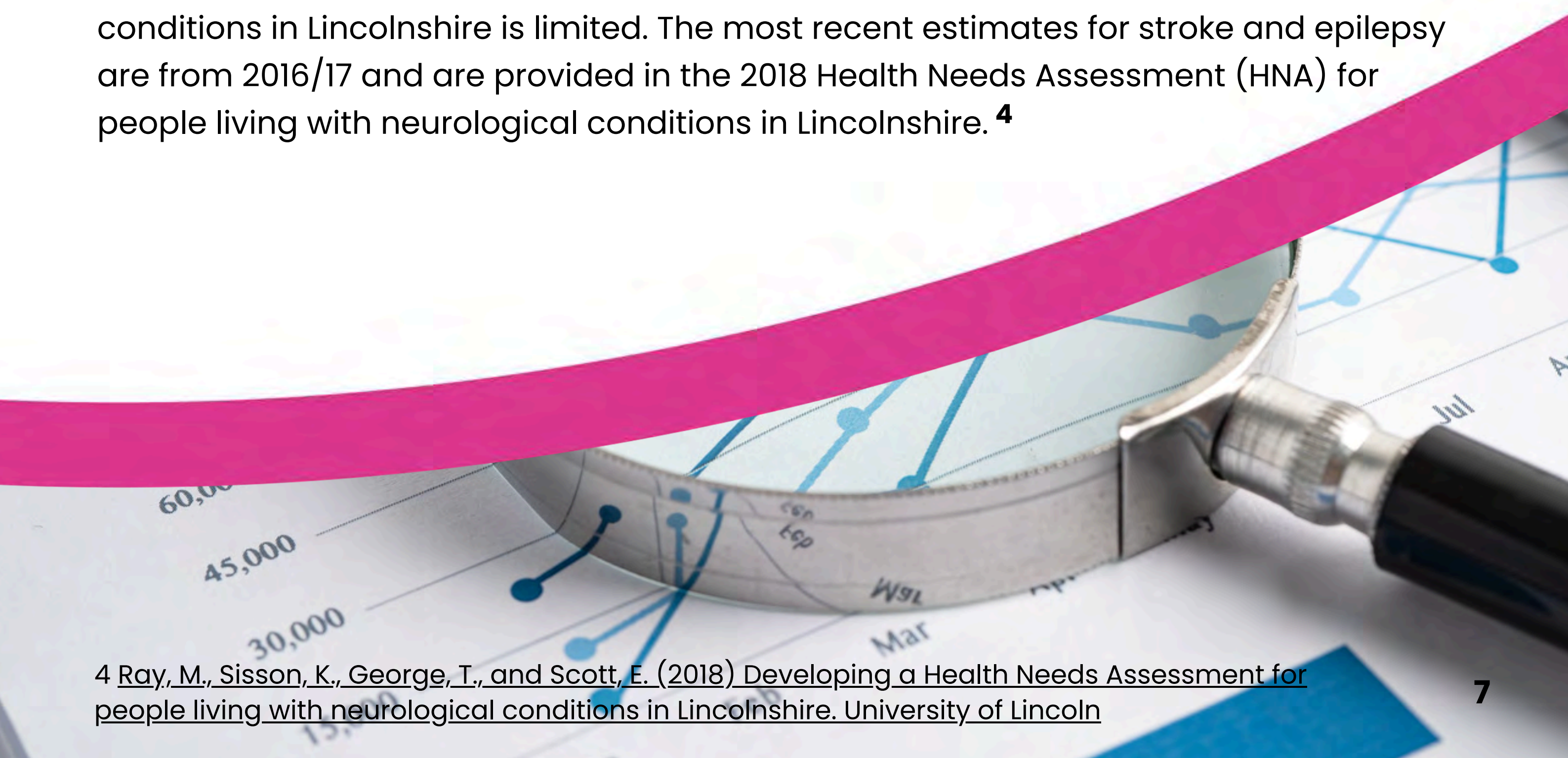
Neurological conditions are a key priority in the Lincolnshire Joint Strategic Needs Assessment (JSNA). Headache disorders are one of the top causes of years lived with disability for children and young people and those aged 20-64 in Lincolnshire.

“Of the Lincolnshire residents claiming Personal Independent Plan (PIP) payments for neurological conditions, the majority were due to MS, cerebrovascular disease and epilepsy. A larger proportion of claimants are eligible for enhanced rates of PIP or Disability Living Allowance, compared to other conditions which demonstrated the impact neurological conditions have on daily life.” - Lincolnshire Health Intelligence Hub

The number of day care admissions for neurological conditions in Lincolnshire has risen. However, it's unclear whether this is due to an increase in demand or the expansion of available services. The availability of specialist neurology support in the region has fluctuated significantly, which is likely to have played a role.

A low prevalence of some neurological conditions means that medical care for Lincolnshire residents is often managed by specialist centres in Sheffield and Nottingham. Community support services, such as those provided by Headway Lincolnshire and other voluntary groups, play an important role in helping those affected by neurological conditions, offering rehabilitation, guidance, and support.

With the exception of stroke and epilepsy, data on the prevalence of neurological conditions in Lincolnshire is limited. The most recent estimates for stroke and epilepsy are from 2016/17 and are provided in the 2018 Health Needs Assessment (HNA) for people living with neurological conditions in Lincolnshire.[4]



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[4] Ray, M., Sisson, K., George, T., and Scott, E. (2018) Developing a Health Needs Assessment for people living with neurological conditions in Lincolnshire. University of Lincoln

Background

A Health Needs Assessment (HNA) for people living with neurological conditions in Lincolnshire - Ray et al., (2018) [5]

The Healthy Ageing Research Group (HARG), at the School of Health and Social Care at the University of Lincoln, were asked in 2017 by Lincolnshire County Council (LCC) to carry out a health needs assessment (HNA) for people living with neurological conditions in Lincolnshire. A HNA involves reviewing the current resources available to meet the needs of a population e.g. those with neurological conditions.

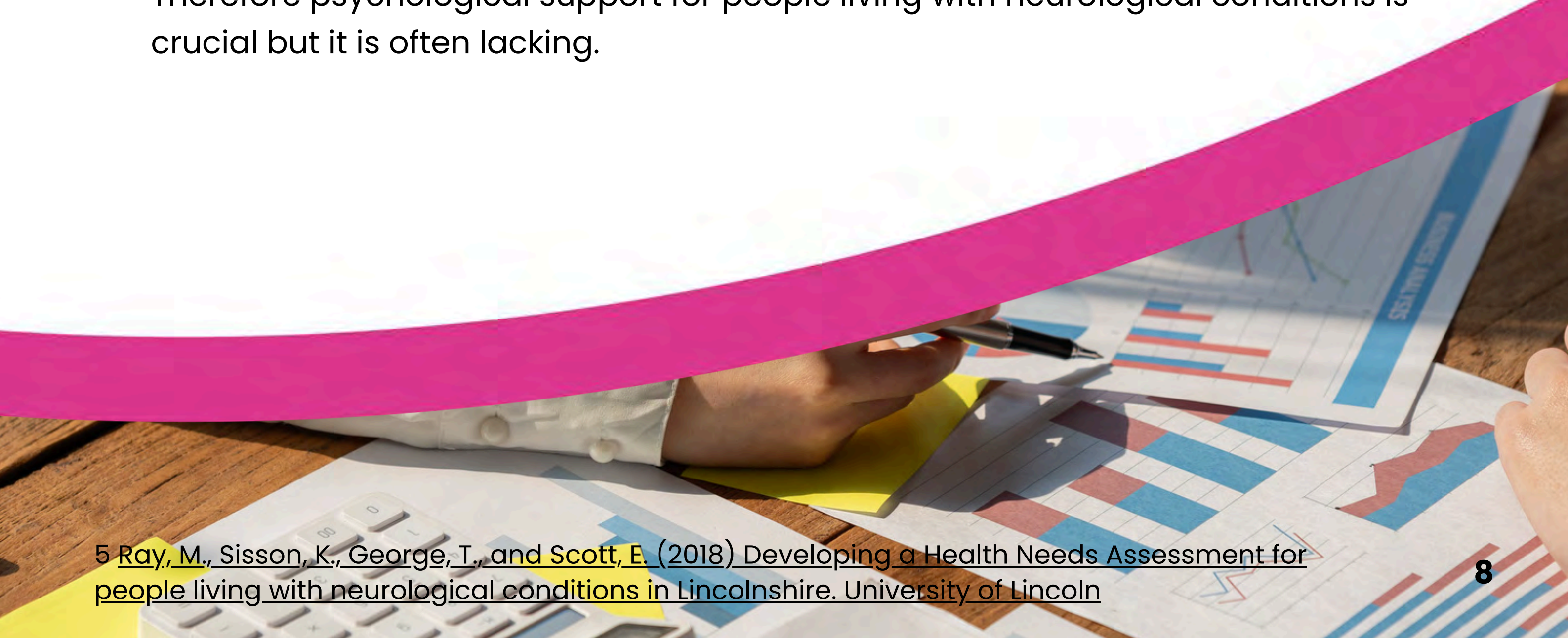
The HNA focused on adults, those transitioning into adult services and conditions including stroke, epilepsy, Parkinson's disease and multiple sclerosis.

The below is a summary of the findings from the work by Ray et al. (2018). The findings of their work can be read in full by **clicking here.**

There were three phases of the HNA:

Phase one: a national review of the services for adults with neurological conditions
Key findings included:

- Patients with neurological conditions reported poor experiences with diagnosis and delays and difficulties in accessing treatment.
- There was variation in the services available nationally.
- Healthcare professionals sometimes lacked knowledge on neurological conditions.
- Neurological conditions can impact mental health and wellbeing significantly. Therefore psychological support for people living with neurological conditions is crucial but it is often lacking.



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[5] Ray, M., Sisson, K., George, T., and Scott, E. (2018) Developing a Health Needs Assessment for people living with neurological conditions in Lincolnshire. University of Lincoln

Background

Phase two: analysis of local and national data to estimate the prevalence of neurological conditions in Lincolnshire and the services used
The data analysed was from between 2005 - 2017 when clinical commissioning groups (CCGs) were still in place and there was no centrally collected data. However, the data from 2016/2017 remains the most up to date.

The data showed that:

- More people were affected by strokes in Lincolnshire (2.15%) compared to the national average (1.7%).
- This might have been due to the varying rates of smoking, obesity, physical inactivity and high blood pressure. These are known risk factors for stroke and strokes are more common in deprived areas.
- Two areas in Lincolnshire had higher than national rates of epilepsy. Again research suggests that epilepsy is more common in deprived areas.
- People in the east of Lincolnshire accessed health services the most for neurological conditions - correlated to east being more a deprived area.
- In 2012/13 in United Lincolnshire Hospitals Trust (ULHT) there were around 35,000 outpatient appointments for neurological conditions. Appointments were most commonly for pain management.
- 47% of appointments for Lincolnshire patients took place outside of the area they lived in and more than 12% took place out of county.

Background

Phase three: a survey of service users, carers, voluntary sector organisations and healthcare professionals

84 people shared their views. Key findings included:

- All agreed that the current services available did not meet demand.
- Service users highlighted a perceived lack of knowledge of neurological conditions amongst healthcare professionals.
- A lack of information about services available.
- Poor communication and coordination between services, especially for those receiving care out of county.
- Voluntary organisations reiterated the problems of:
    - Service users having to travel out of county to access care. Making long, frequent and expensive journeys could cause delays in diagnosis and treatment and worsen symptoms.
    - Poor coordination of services.
    - The need for better training for healthcare professionals in diagnosing and treating/managing neurological conditions.
- Healthcare professionals supported the above issues and expressed frustration in providing services in a rural area with high demand and limited resources.

Background

Recommendations

The findings informed a series of recommendations, which included:

- Those with neurological conditions need to be looked at holistically. Healthcare professionals need training to ensure they can recognise these needs and signpost to appropriate services.
- There needs to be a balance between developing national treatment centres and the potential difficulties for patients in rural areas accessing services.
- There should be a review of the coordination of services inside and outside of the county to ensure continuity of care and that service users do not 'fall through the gaps' between services.
- Widespread, easy-to-access practical advice and emotional support is needed. Care Navigators should be informed about the services available so that they can actively signpost patients and carers to support.

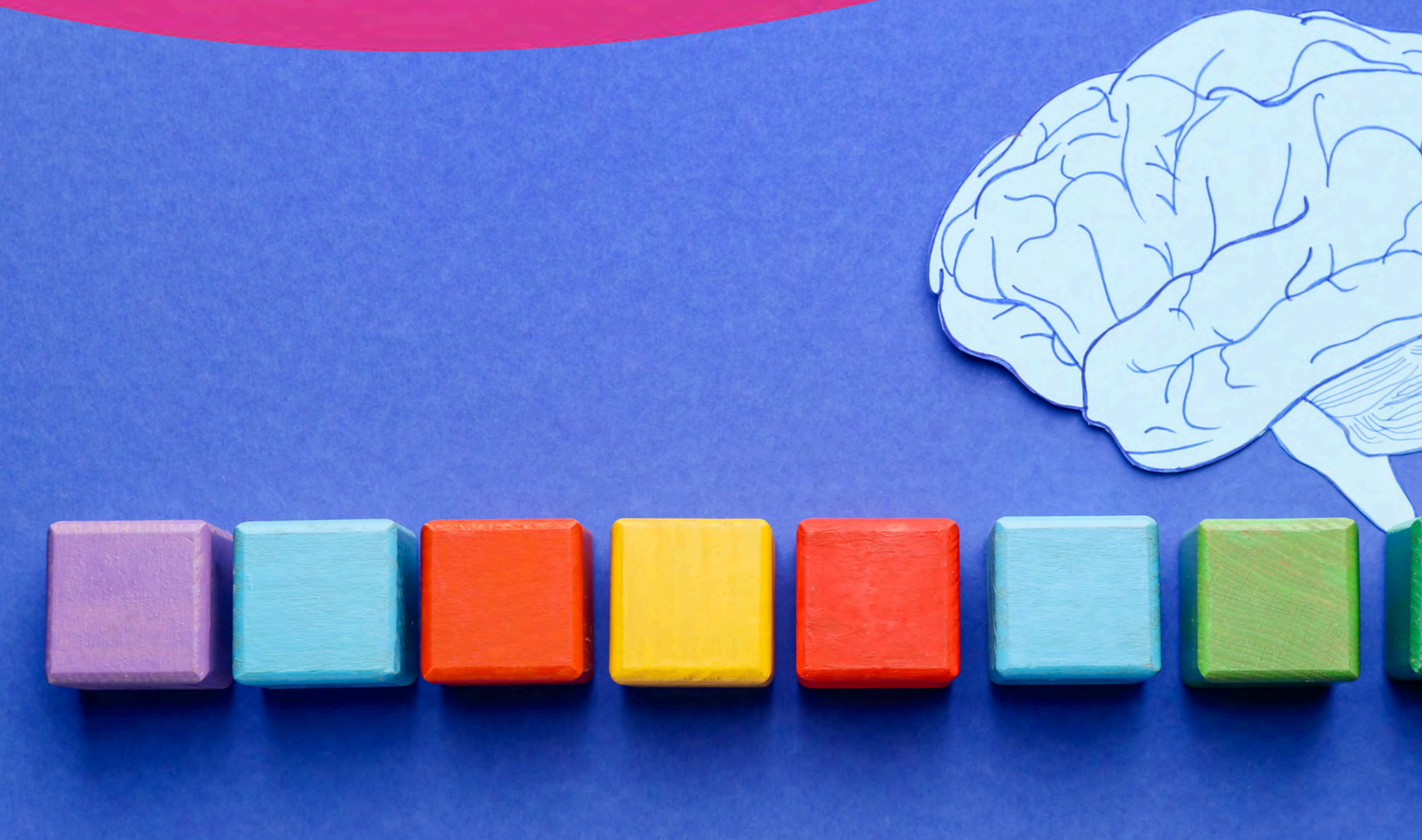
Click here to read more about the HNA.

Background

Before the introduction of the Integrated Care System (ICS), NHS Lincolnshire asked Healthwatch Lincolnshire in 2022 to conduct a survey to explore people's views about health and care services. Within this work we were especially keen to hear from people who had fibromyalgia, epilepsy, MS and myalgic encephalomyelitis (ME).

Overall, the feedback provided about services and support for these conditions in Lincolnshire was poor and echoed many of the issues raised in the HNA. Concerns included access to services, quality of care and not being taken seriously (especially by those with fibromyalgia and ME). For many with these conditions, this survey was the first time they had been asked for their thoughts on services.

Therefore, we wanted to invite everyone with neurological conditions or those with conditions involving neurological components in Lincolnshire to share their views and have their voices heard. We also wanted to assess whether experiences have since improved.



Engagement (Methodology)

We launched two surveys, one for service users and one for professionals. Individuals were also given the opportunity to share their experience over the phone, email or in any format that is easiest for them. The team including our amazing volunteers also distributed paper copies of the survey to those who preferred to engage this way* and to local support and community groups.

**The survey could be sent back to us using our Freepost address.*

Engagement (Methodology)

The surveys covered the following:

- Diagnosis
- Waiting times
- Treatment and management
- What works well?
- What could be improved?

Acknowledgments

We would like to thank:

- Everyone who took the time to share their views.
- Your experiences are invaluable.
- The HWLincs staff team including our amazing volunteers, local support groups for their support.

Disclaimer

We recognise and acknowledge that the experiences shared may not be fully representative of:

- All service users who have accessed health and care for their neurological health and
- All professionals diagnosing and supporting those with neurological conditions in Lincolnshire.

We do however believe that all individual experiences are important and should where/when possible be reflected on. A strength of this data is that common themes persisted throughout responses from service users and professionals.

- According to the data collected, experiences did not appear to differ based on e.g. whether the individual was a carer or neurodiverse.
- Regardless of the neurological condition, generally the majority of respondents rated their care poorly.

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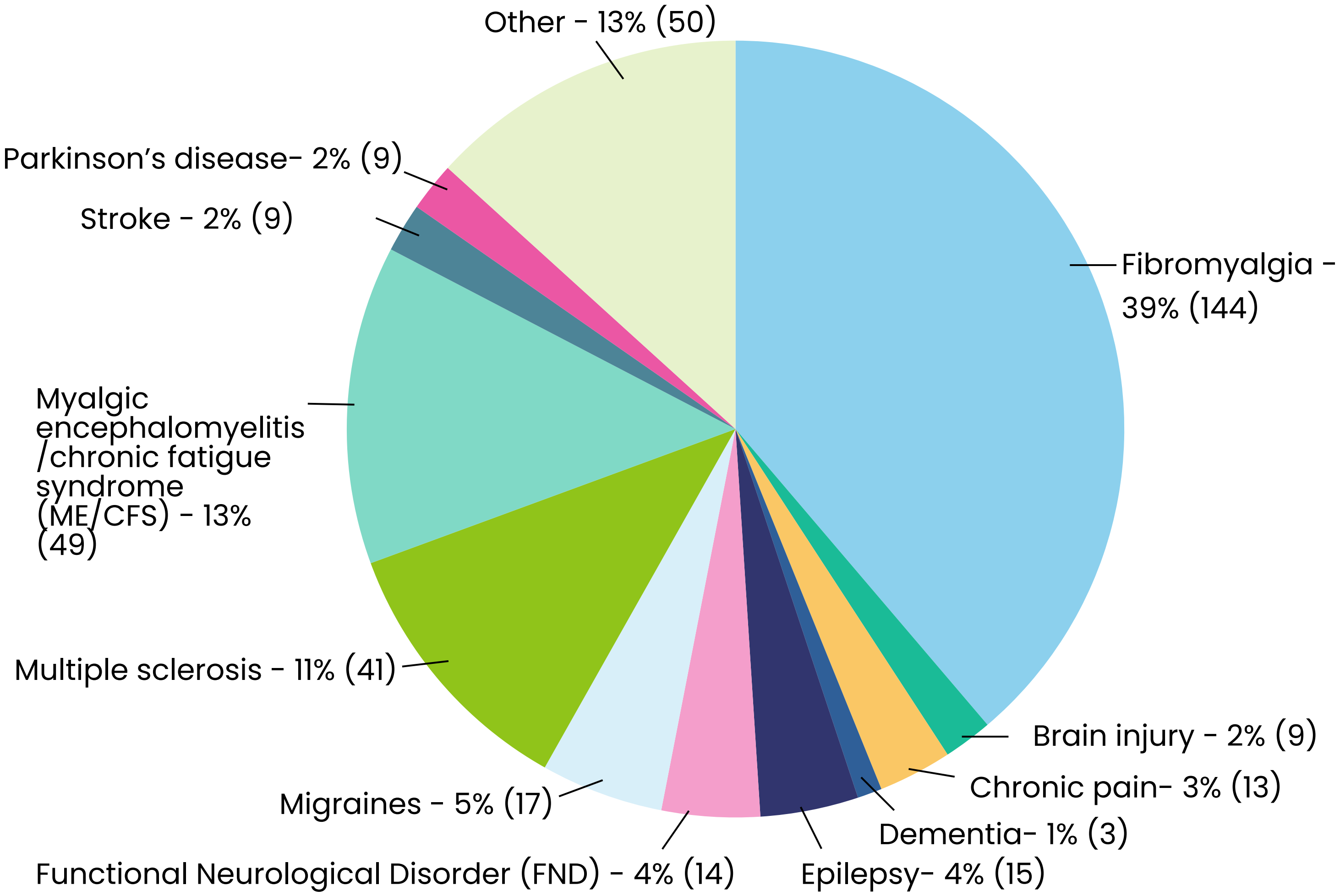
Findings - Who shared their views?

375

people shared their views*



- **3% (11) were veterans**
- **13% (50) worked in health and/or social care**
- **1% (2) worked in the farming/agricultural industry**
- **12% (43) were carers**
- **7% (27) belonged to the LGBTQ+ community**
- **13% (49) considered themselves neurodiverse**

**Only one professional shared their view. A full breakdown of who shared their views can be seen in the demographics section of this report.*

Overall

Overall, 375 people shared their views on accessing health and care services in Lincolnshire for various neurological conditions. This section provides a brief overview of the findings. The findings for individual conditions are discussed separately and in greater detail in the following sections. Overall:

- 58% (205) were diagnosed correctly first time.

- Diagnosis times varied between less than one month and more than 18 months. For 46% (153), it took more than 18 months to get a diagnosis.

Common themes in experiences of being diagnosed included:

  - Patients not being listened to.

  - Symptoms being dismissed, normalised or being put down to being overweight or depressed.

  - A lack of understanding of conditions both in terms of knowledge and empathy. In some cases such as for fibromyalgia and ME/CFS, healthcare professionals did not believe the conditions existed.

  - Patients would present to their GP practice multiple times over months and years.

  - Not getting a timely diagnosis had a significant impact on life and social circles, and resulted in some giving up their job.

  - As a result of these issues, some sought a private diagnosis.

  - In some cases there was little relief after a diagnosis as they were left to manage their condition on their own and cope with a life-changing condition.

Waiting times

- 29% (108) were waiting for additional tests, treatments or diagnosis. Respondents shared that they had often been waiting for months, with little communication or support offered little support in the meantime.

Overall

Medication

- 71% (263) took medication for their condition.

- 71% (188) of those who took medication for their neurological condition had faced challenges getting medications that worked for them. These challenges most commonly included:
  - Side effects of medications.

  - Finding medications and dosages that helped manage symptoms.

  - Shortages, especially for epilepsy medication - replacements appeared to be less effective at controlling symptoms.

  - Medications and dosages often could not be changed without seeing a specialist but there were long waits to see them.

Treatment other than medication

- 47% (173) had been offered and/or received treatment other than medication.

  - Signposting to support and referrals to other services appeared to be inconsistent.

  - Service users also appeared to be unaware of what support is available and what could be beneficial.

Urgent and emergency care

- 17% (61) had needed to access emergency or urgent care for their neurological condition in the past 12 months.

Respondents received care from a variety of practitioners/services

  - 75% (247) NHS GP and practice team
  - 33% (108) NHS hospital services (both in and outpatient care)
  - 32% (104) NHS community health services
  - 27% (90) NHS pain management
  - 22% (73) Private healthcare
  - 20% (67) NHS pharmacist
  - 17% (55) NHS mental health services
  - 13% (44) Social care

Overall

Respondents were asked to think about the care they receive for their condition and rate a range of areas. Overall, the majority rated the following as:

Overall	Very good	Good	Poor	Very poor	N/A or Prefer not to say	Overall
Being able to access care for your condition when you need to	4% (13)	21% (71)	30% (101)	43% (144)	3% (9)	POOR 73% (245)
Listening to you	7% (23)	24% (80)	33% (111)	35% (117)	1% (4)	POOR 68% (228)
Explaining tests and treatment	5% (16)	31% (104)	28% (95)	28% (93)	8% (26)	POOR 56% (188)
Involving you in decisions about your care	7% (24)	30% (100)	26% (85)	30% (101)	7% (25)	POOR 56% (186)
Offering you different forms of treatment not just medication	3% (10)	12% (39)	31% (104)	45% (151)	10% (33)	POOR 76% (255)
Treating you with care and concern	9% (30)	29% (97)	29% (97)	30% (101)	3% (11)	POOR 59% (198)
Addressing your needs or making plans to do so	5% (17)	20% (66)	33% (111)	37% (125)	5% (17)	POOR 70% (236)

Overall

Overall	Very good	Good	Poor	Very poor	N/A or Prefer not to say	Overall
Communicating with you clearly about your care	5% (18)	24% (80)	32% (107)	34% (113)	5% (17)	**POOR** **66%** **(220)**
Providing you with information about your condition, treatment and care	5% (16)	19% (63)	34% (113)	39% (132)	4% (12)	**POOR** **73%** **(245)**
Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)	2% (7)	14% (48)	29% (97)	41% (139)	14% (46)	**POOR** **70%** **(236)**

Overall

What currently works well about how neurological conditions are managed in Lincolnshire?

- The following areas were highlighted as currently working well:
    - While generally those who accessed specialist care, including MS nurses and consultants, praised its quality, this was not the case for everyone
    - Repeat prescriptions

What improvements or changes would respondents like to see in the care and management of neurological conditions in Lincolnshire?

- Overall, when asked how care and management for neurological conditions could be improved in Lincolnshire the following were highlighted:
    - Listen to patients and show understanding.
    - Increase healthcare professionals' knowledge of neurological conditions including recognising fibromyalgia, FND and CFS/ME as real conditions.
    - Provide clear information for patients on diagnosis, prognosis, and management.
    - Establish local specialist neurological centres, hubs, or clinics.
    - Improve access to pain clinics and better pain management strategies.
    - Offer holistic support, recognising that individuals are affected in different ways.
    - Develop local support groups, including options outside standard working hours.
    - Ensure joined-up care with coordinated services.
    - Reduce waiting times for specialist support and offer interim support while patients wait.

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Fibromyalgia

143 (39%) **people shared their experiences of fibromyalgia**

Diagnosis

- 57% (82) were diagnosed correctly first time.

- 39% (56) were initially diagnosed with something else and the remaining 4% (5) were trying to get a diagnosis.

- Diagnosis times varied considerably, but for 58% (80) it took more than 18 months to get a diagnosis. Regardless of whether or not an individual was diagnosed correctly the first time or initially with something else it took the majority over 18 months to get a diagnosis.

- When respondents discussed their experiences of being diagnosed, there were many commonalities in their journeys, including:
  - Patients not being listened to.
  - Symptoms being dismissed or downplayed.
  - Lack of understanding of the condition both in terms of knowledge and empathy. In some cases healthcare professionals did not believe the condition exists. In other instances symptoms were put down to depression and/or being overweight.
  - Patients would present to their GP practice multiple times over months and years. In the meantime their health deteriorated which resulted in some having to give up their jobs, being left in extreme pain and fatigue.
  - For some there was little relief in a diagnosis as they were left without support.
  - As a result of these issues, some opted to seek help privately.

Fibromyalgia

Diagnosis

“I was borderline suicidal”

“I first started experiencing problems when I was 16, I was diagnosed with Ehlers-Danlos Syndrome but the pain almost became too much. I was told I had 'Mechanical Back Pain'. After years of having to tell the professionals something wasn't right my mum ended up coming with me. After years of physio, scans and x-rays I was finally diagnosed with fibromyalgia. I felt like I was being fobbed off. I had to drop out of school and finished my GCSEs and A-Levels at home due to not being able to climb the stairs to my classrooms. I was borderline suicidal.”

“Twenty years of suffering”

“I was continually prescribed Naproxen for nearly 20 years. I was often told ‘we all get tired at some time in our lives’, ‘change your job’, ‘rest more’ (not an option with a young family and a shift working husband). GPs were very unsympathetic. It took a hysterectomy and a massive fibro flare to be referred to a rheumatologist. He diagnosed me on the day I saw him, gave me an NHS leaflet, told me I may end up in a wheelchair as there was no cure and discharged me. That was after 20 years of suffering in 2005.”

“Had to give up working”

“It took over three years to get diagnosed. First doctor told me to stop being so silly and that doctors do over a 100 hours a week work, when I said that every time I do an extra shift a month at work, I get ill with something Like the flu. Took another doctor before I was sent to a consultant, who told me that other than painkillers nothing could be done and to go home and just live as best I can. That was 16 years ago. Since then I have had to give up working and give up living hardly ever leaving my home where I live alone.”

“Made me feel like a timewaster”

“I had been seeing the doctor with pains in multiple areas progressively getting worse. Blood tests came back ok so i got forgotten about. This happened a few times each time i was made to feel like a timewaster and a bother. Eventually two years later I was referred to a neurologist who then said it is fibromyalgia.”

Fibromyalgia

Diagnosis

“Depressed and suicidal”
“I have been suffering symptoms for over 30 years. This last flare up has been going on for two and a half years. I was first diagnosed with undifferentiated connective tissue disease. Spent two years on a medication that made me depressed and suicidal.”

No advice, no explaination”
“I had routine rheumatology appointment, I told the consultant I was in pain all over and it was not like rheumy flare. He didn’t examine me, left the room came back with a leaflet on fibromyalgia and said you’ve got this. Then was it, I was stunned, no advice, no explanation as to what to do, nothing. I was in shock. Still not had any medical advice on fibro and it’s been at least five years since then. When I mention it to GPs… they don’t believe I’ve got it, I tell them about the pain which is on top of my rheumy pain and don’t get any painkillers (I’ve been on cocodamol for years it does very little). I am very careful with thanking pain killers, I rarely take them unless I’m in absolute agony.”

“I couldn’t walk”
“I had to take the paperwork in to explain how fibromyalgia can be diagnosed and explain how this matched my symptoms. I was prescribed numerous drugs in the run up to this which made me very poorly and I couldn't walk for a while having to use a walking stick and having to give up my job.”

“Dismissed by GPs multiple times”
“Pain, fatigue, brain fog, sleep disturbance etc. I was dismissed by GP multiple times. Had to ask for referral to rheumatologist. Being dismissed and gaslit while experiencing chronic pain and other debilitating conditions takes it’s toll on your mental health, and work and social life.”

“AskmyGP helped considerably”
“Due to covid the askmyGP system helped me considerably. I was able to fully list all my medical issues and so the doctor was better able to connect the conditions to help diagnose. This was easier for me than a quick appointment when there is never enough time and you have to make different appointments for different issues. Not helpful when you are struggling with a multitude of issues.”

“GPs fobbed me off”
“Had to go private and have many tests as GP’s just fobbed me off.”

Fibromyalgia

Waiting times

- 21% (30) were waiting for additional diagnosis, tests or treatment.

- This included pain management, MRI scans and specialist neurology appointments. Regardless of what the respondent was waiting for, limited support on how to manage symptoms whilst waiting and poor communication were highlighted as issues.

“Don’t know if I’m still on the waiting list“
“No support, don't know if I'm still on the waiting list. I have been trying to manage my health myself without any support.”

“Having to pay for private counselling”
“I'm waiting to speak to a pain medication specialist. I've have not been given any support while I wait. I did try to get help through my local steps to change but was offered six thirty-minute telephone counselling calls. I did the first two and found that they didn't help at all. I am now having to pay for private counselling because I'm struggling with how much the pain has changed my life.”

“Still waiting”
“I was put on a waiting list for a referral to the fibromyalgia clinic when I was diagnosed by my GP (pre-first Covid lockdown) and when I chased up the year later got told no clinic existed anymore and I was to try medication: antidepressants again. W hen I went back to them this year and said it's not working I got referred for talk therapy- that was Feb and I am still waiting for an appointment for the online CBT course.”

“Unable to travel”
“Help from local Boston dietician to loose weight to help with mobility. Given an appointment at Royal Derby Hospital but unable to travel these distances. Why cannot i access grade 3 dietician locally in Boston Lincs?”

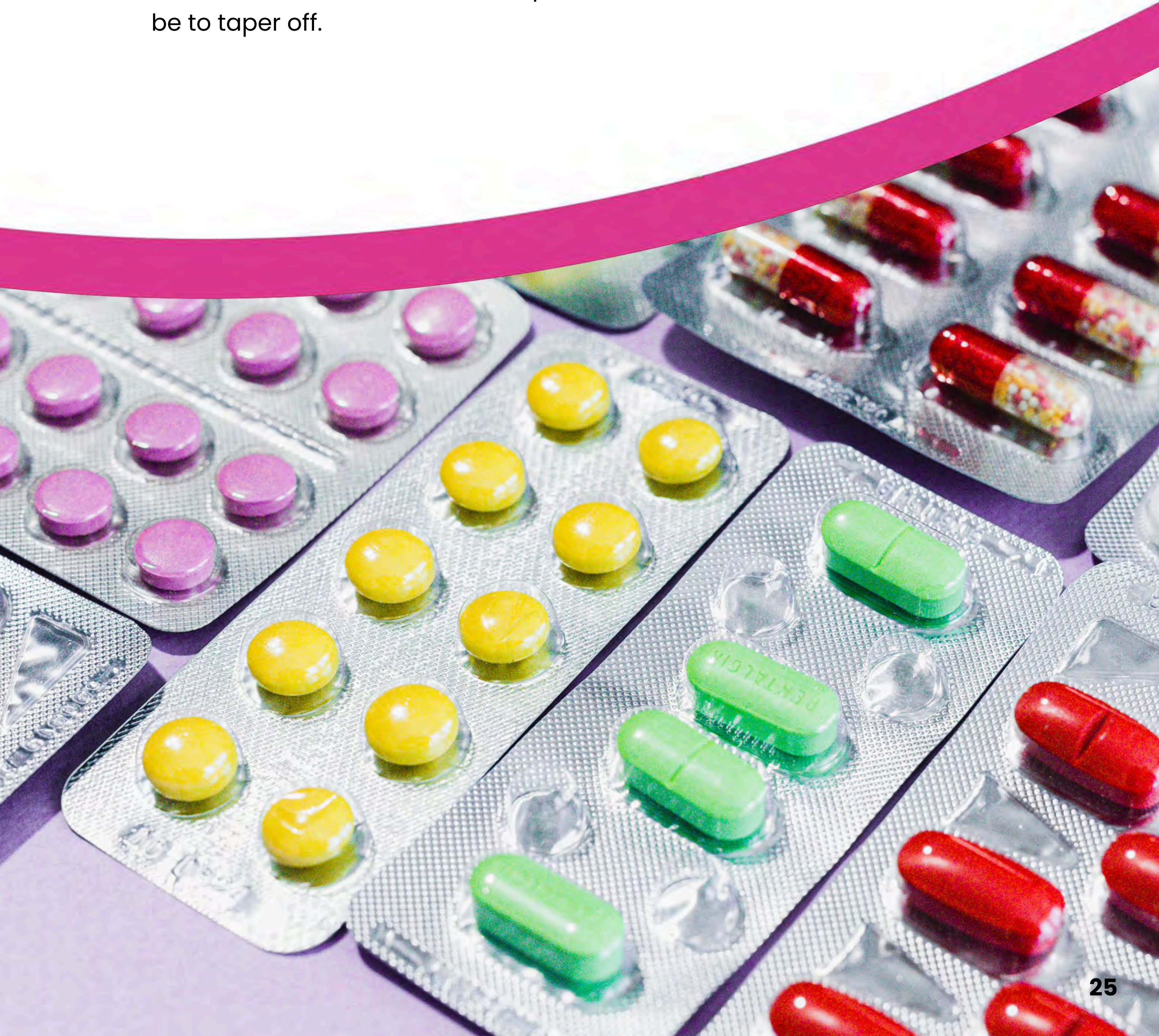
“No support”
“Another surgery. A year wait. No contact in between and no support with pain management even though I've asked.”

Fibromyalgia

Medication

- 75%% (107) took medication for their fibromyalgia.

- 76% (82) of these respondents had faced challenges getting medication that worked for them. Challenges included:
  - Shortages.
  - Side effects e.g. hot flushes and gaining weight (but no support was provided on how to manage weight gain).
  - Finding medications and dosages that effectively controlled symptoms.
  - Medications were initially effective but not anymore.
  - Concerns around how addictive pain medication can be and how difficult it can be to taper off.



Fibromyalgia

Medication

“Shortage”
“Zapain shortage making it very difficult to stay on top of my pain.”

“Left with nothing”
“I was given every painkiller available including anti-depressants that might or might not work. They didn't! Eventually I was given Nefopam. My life changed. I was back on my feet, moving better, hurting less, sleeping better. I wasn't perfect. But compared to needing a stairlift to get safely up and down stairs, I could now feel more like me again. A mum, wife and friend. Then the prices shot up and I was left with nothing! It was vile and honestly, evil! I was diagnosed allergic to morphine so there was little else worth giving me. My life became a hell again. Four years later I was with a new surgery who happily supplied Nefopam for me. Sadly the damage was done and although it took the edge off on very bad days, it never worked the same again. Once again the price became and issue and I was dropped yet again. I currently take ibuprofen and cocodamol - when they aren't trying to stop me like I'm an addict - as and when I can't cope anymore. Which is rarely as I've lived like this for so long it's now just life!”

“I have given up”
“I have only been offered opioid painkillers. No alternative meds have been offered to me. I have given up and try to cope with the condition. All while working full time in a stressful job and being a single mum.“

“My life isn’t worth living”
“In the last three years I have been given morphine patches. Nothing else. In the last few weeks I have been given pregabalin 25 mg which have very little effect. All my surgery is interested in is my diabetes. What is the point of I can't sleep properly without pain, wake after a few hours and get out of bed. Have the energy to have a shower, do housework, go out with friends etc. I really don't care about diabetes if my life isn't worth living due to 24/7 pain. No one seems to care. No treatment offered at all.”

“Everything is blamed on being overweight”
“The medication given has known side effects of gaining weight with nothing given to counteract this. I then put on weight and then everything is blamed on being overweight. With the condition you can exercise much so it’s hard to lose the weight.”

Fibromyalgia

Medication

- One respondent highlighted some good practice:

"My medication is always available and ready from my GP when I need it. They are always happy to discuss my fibromyalgia and any extra pain relief that I need during flare ups. It's just a shame every situation is always put down to fibromyalgia when it may not be related to that."

Other treatment

- 45% (64) had been offered or received treatment outside of medication for their fibromyalgia.

- This included an online pain management course, physiotherapy, talking therapies, counselling and exercises groups. The majority found these fairly ineffective and in some cases just telling them information they already knew. A benefit of the support was meeting people in a similar situation.

"Pain management course it was to meet others but the rest was fairly useless to me."

"CBT therapy which didn't help, a course on how to cope with my pain that just went over what I was already doing."

"I've tried medication. It didn't work. I've had counselling and paid for any alternative therapies. They don't work. I'm just managing my pain alone most of the time."

"I recently completed an online pain course. It was completely useless. It was far too generic and assumed that you were doing absolutely nothing to support yourself or had no insight into your own pain."

"It was not specifically for fibromyalgia but had CBT after a bad depression, she understood that the fibromyalgia symptoms had caused a lot of my depression and so she taught me some pacing."

Fibromyalgia

Other treatment

"Positive and helpful"
"Walking group and exercise group at Galletly which led to exercise class at Bourne Leisure centre helping with condition gaining confidence and getting to know others in similar situations. Friendships made. Very positive and helpful."

"Important that mental health is managed"
"In my very early days, 11 years ago, I was very lucky. I got some counselling to help me get my head around my conditions as was struggling with that. Because when you get a life changing condition its very difficult and you kind of think they will give you a tablet and you will be fine. So when that doesn't happen you then have to get your head around the fact that your life was going to be this way. I was also sent to the pain clinic which at the time wasn't that helpful. At this time they were doing four-hour talks on pain and it was mainly for people who have isolating pain nothing for people with widespread pain. I wasn't able to take much onboard as i was in so much discomfort and pain all I could think of was getting home. I had some physio at this time which didn't help at all. Living with fibromyalgia etc has a big impact on your mental health so its really important that the mental health side of things is managed as when you live with chronic pain all the time it does have an impact on you mental health."

Fibromyalgia

Other treatment

- Respondents were also asked if they believed there would be any other treatments or support they would benefit from. By far the most common response to this question was that they were unaware of what other support could be offered or would be of benefit to them.

"Yearly check-up"
"I would definitely benefit from having someone to talk to about all the symptoms and continuous pain, but when you get to speak to a GP it's over the phone for a couple of minutes. A yearly check-up is definitely needed."

"Told to look it up on the internet"
"I have no idea. I was just told by two consultants I have it and not offered any help. Just told to look it up on the Internet as they no longer provide information. I have never looked it up as find it difficult."

"Learn to live with it"
"I don't know what's available, I just keep getting told I have to learn to live with it."

"Don't know what treatement is available"
"Counselling. A support group. Other than that I do not know what treatment is available. No one has ever told me. I have seen a doctor once in three years."

"Tips on relaxation"
"I am not aware of any other support available. I did go to a CFS group for so many sessions previously which explained the science and some tips on relaxation. The sessions were during my working day and were quite a drive from my home but I did this useful."

"Being let down"
"I have had no follow ups or referals or medication for fibromyalgia, and reading what others are receiving i sincerely think im being let down."

Fibromyalgia

Urgent and emergency care

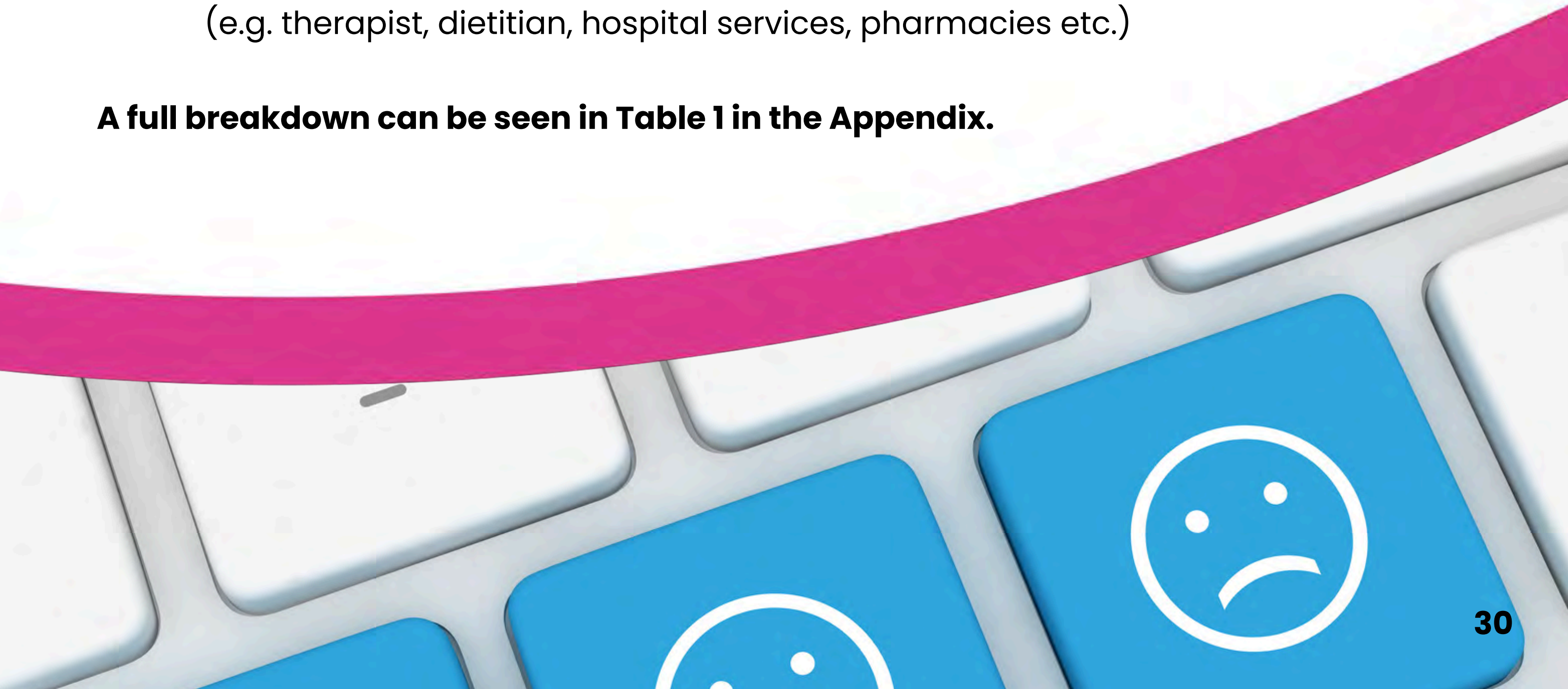
- 11% (15) of respondents had accessed urgent or emergency care in the last 12 months for their fibromyalgia. Experiences tended to be negative with professionals not having an understanding of the condition or saying there was nothing that could be done. The reasons for respondents accessing such care appeared to be due to unmanaged symptoms mainly pain.

> “My ankle gave way due to pain and resulted in me breaking my other ankle…”
>
> “Was told they could do nothing for me.”

Overall

- Respondents were asked to think about the care they receive for their fibromyalgia and rate a range of areas. Overall, the majority rated as **very poor:**
  - Being able to access care for your condition when you need to
  - Listening to you
  - Explaining tests and treatment
  - Involving you in decisions about your care
  - Offering you different forms of treatment not just medication
  - Treating you with care and concern
  - Addressing your needs or making plans to do so
  - Communicating with you clearly about your care
  - Providing you with information about your condition, treatment and care
  - Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)

A full breakdown can be seen in Table 1 in the Appendix.



Fibromyalgia

Overall

- When asked overall what works well and what could be improved about the care they receive for their fibromyalgia, the following was highlighted:

What works well?	What could be improved?
• Many responded along the lines of "**nothing**" or "**no support received**" to this question. Respondents repeated the fact that after a long road to a diagnosis they were just left to manage the condition themselves	• Listen to patients and be understanding • Greater knowledge of the conditions amongst healthcare professionals • Believe the condition is real • More information for patients on the condition, prognosis and management • A fibromyalgia centre/hub/clinic • Pain clinics • Support groups • Better pain management strategies • More and better mental health support

"To have a plan of how to be able to get a better quality of life. To have support from a consultant, not to just diagnose you then that's it no follow up we need help support and we are being failed becouse it's chronic pain."

"I was told by my GP that fibromyalgia is not a neurological condition. Over the years (30, not all in lincolnshire) I have relieved little or no recognition of this condition or support to manage it effectively. So perhaps training would be useful."

"Urgency. A sense of concern. I am in a lot of pain daily and I cannot walk long distances anymore and when I contact my GP about it I am treated like I am lying."

"Specific clinics and more support groups."

Fibromyalgia

Overall

“Finding help is difficult in a rural setting”
“I followed my surgery's advice when I called for mental health support and phoned the Lincolnshire mental health team who couldn't help me because it wasn't an acute case. Was given different signposting till I ended up back at my GP surgery. I was then told to phone the Lincolnshire Mental Health team. I found help for myself. I don't mind self referral if it works. What I wanted was long term support and possibly medication to help. I received none of that through my GP surgery. Finding help is difficult in a rural settings and it was only by chance that I found out about the social prescribing team.”

“Diagnosed and ignored”
“Nothing positive to say sadly, diagnosed and ignored. Most of the support I get is self directed.”

“Made to feel like a drain on resources”
“Nothing works well and I am not supported. I am made to feel like a drain on the resources if I ever try to get help.”

“Have to cope the best I can”
“Nothing works as don’t get any help whatsoever just have to cope the best I can on my own.”

“Medical professionals don’t believe in fibrolyalgia”
“I don’t think the medical professionals really believe in fibromyalgia.”

“Not aware of any care”
“I would like the condition explained to me not just told I have it. I would like to be told if any help available and how I could help myself. I would like to be told of any support groups. I am not aware of any care or management at all.”

“I worry about financial problems”
“Support groups. Keep pain clinics going. What options are available to help when the condition gets worse, I worry about financial problems if I have to keep reducing working hours.”

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Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)

- **13% (49) people shared their experiences of accessing care for ME/CFS.**

Diagnosis

- 63% (31) were diagnosed correctly first time with 37% (18) initially being diagnosed with something else.
- Diagnosis times varied but it took 71% (35) over 10 months to be diagnosed and for 43% (21) it took more than 18 months.

ME/CFS

Diagnosis

- Similar to respondents who shared their experiences of fibromyalgia, there were many recurring and overlapping themes in their experiences of getting a ME/CFS diagnosis:
    - Being told their symptoms were normal
    - Presenting at their GP surgery multiple times over months, if not years
    - Symptoms being put down to depression
    - Being told the condition does not exist
    - After a diagnosis, there was little support to manage symptoms or mentally coping with the fact they've got a life changing condition
    - Individuals shared the impact their symptoms, not getting a timely diagnosis or support had on their life:

"I must just be a massive failure"
I struggled for five years from onset aged 10 to diagnosis aged 15. When I was 14 and too ill to attend school, a consultant at Lincoln County Hospital asked what I thought was wrong with me. At 14, this should have been his remit. I said I didn't know, but my GP thought it may be ME. He responded by saying that people who say they have ME are just talking about themselves, we could all say we have ME - it's exactly what it says it is - it's all just 'about me'. This has stayed with me and as an adult who has had ME since childhood and never known a life without it, I question sometimes in my own head whether there is anything wrong at all, because of the constant stigma towards people with ME, or whether it is like the consultant told me, 'just me', in which case I must just be a massive failure of a person despite however hard I try.

Later, aged 17, when I became totally bedridden in a darkened room for four years, unable to chew food or toilet myself, my GP couldn't get a neurologist to do a home visit, even just to check that a terminal diagnosis hadn't been missed. Neurologists don't seem to recognise ME as a neurological illness.
It's incredibly difficult to find a GP who is supportive and is accepting of ME as a real illness and doesn't think it's anxiety. As such, going to a GP about anything, becomes somehow related to anxiety which I never had."

ME/CFS

Diagnosis

“The GP said, ‘I am diagnosing you with ME - I think it's a load of bollocks - but I can't find anything else wrong with you.’”

“No concerns where not taken seriously and still aren’t. I missed out on a lot of schooling and left at a young age.”

Waiting times

- 18% (9) of respondents were waiting for tests, treatment or additional diagnoses. Respondents were waiting for appointments with specialist and diagnosis of potential co-morbidities.

“I am waiting for a referral to the chronic fatigue specialist. The waiting time is 5-6 months. I have no additional support in the meantime.”

Medication

- 47% (23) took medication for their ME/CFS.

- 80% (20) had struggled to get medications that worked for them. These challenges included:
  - Side effects and allergic reactions
  - Access to effective medications
  - Side effects of tapering off medication

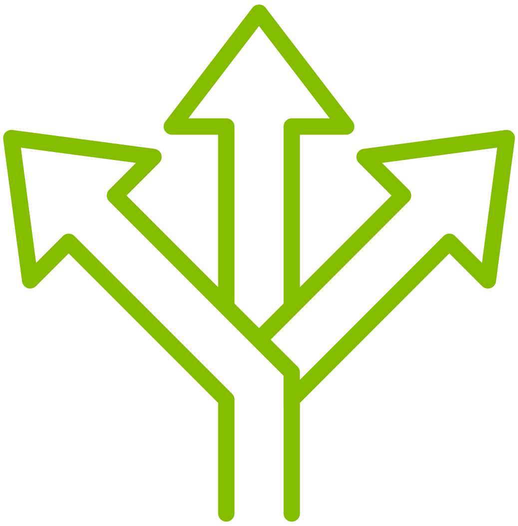
“A change of anti-depressants helped the ME, strangely. My biggest issue is getting the meds in a rural area without transport, if I remember to order them on a monthly basis.”

“When one medication stopped working, it was horrible coming off it. We then started the new meds too soon, which caused a serotonin storm. Not nice! There have been times when I've asked for support, but been denied a referral to the local clinic because of insufficient change. Waiting lists for clinics are long and last time I was discharged when I became too ill/unstable to follow their program. I have no backup now, since my GP left, no single point of contact within the surgery when things go wrong or I have a bad crash.”

ME/CFS

Other treatment

- 69% (33) had been offered or received treatment outside of medication for their ME/CFS. This included:
    - Support groups
    - Online courses
    - Pain clinic
    - Occupational therapy
    - ME/CFS clinic
    - Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET)
    - Group therapy and individual counselling



“No safety net”
“Had a six-to-eight-week online course with the Lincs ME clinic. Good people, but no ongoing support/community-based support. No safety net for someone to use in a crisis.”

“Sessions were too long”
“Group rehabilitation following initial consultation. I couldn’t do it because the sessions were too long in duration and too closely together.”

“Useful self care service”
“Was referred to an NHS ME/CFS Clinic in Grantham in 2014. I attended a 10 week in-person rehabilitation group in 2015. When this finished I was left to get on with life. In October 2023 I started feeling the signs of a crash. In April 2024 I asked my GP to refer me back to the ME/CFS clinic. In March I met online with an OT and was offered an eight-week online Compassion Therapy rehabilitation group. This was a very useful self care service but I am waiting to speak with an OT again and be offered a care plan.”

ME/CFS

Other treatment

- Similar to respondents with fibromyalgia, those with ME/CFS were unsure of what support is available. Respondents highlighted that support needs to be available locally as some were unable to travel long distances due to their condition and the pain.

- 31% (13) had accessed private care and this was due to long waiting and the lack of support available on the NHS.

Urgent and emergency care

- Two respondents had accessed urgent and emergency care for their ME/CFS. One individual shared they had to wait and were given painkillers.

Overall

- Respondents were asked to think about the care they receive for their ME/CFS and rate a range of areas.
  Overall, the majority rated as **very poor:**
    - Being able to access care for your condition when you need to
    - Listening to you
    - Explaining tests and treatment
    - Involving you in decisions about your care
    - Offering you different forms of treatment not just medication
    - Treating you with care and concern
    - Addressing your needs or making plans to do so
    - Communicating with you clearly about your care
    - Providing you with information about your condition, treatment and care
    - Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)

A full breakdown can be seen in Table 2 in the Appendix.

ME/CFS

Overall

- 23 out of the 35 individuals who responded to this question said something along the lines of “nothing” or “I get no support”.

What works well?	What could be improved?
• One individual praised the CFS service: “I know the individual CFS service is there to offer me support. It’s informative and tries to help give you the tools to manage your condition.”	• Single point of contact for concerns around ME/CFS • More support to help patients mange their symptoms • Training for professionals to better understand the condition, management strategies and the support available to patients • Better pain management • More specialist support and easier access to it

“More support and understanding. Practical advice and info on ways to access this. Train GPs on the condition as I've been told some really harmful, outdated things by my GP, who is otherwise a lovely, caring person.”

“Proper education of GPs who still think ME/CFS is mental illness or depression.”

“Greater communication between medical services to improve the outcome for patients.”

“I have not received any support in last 13 years apart from repeat prescriptions despite being housebound and frequently spending weeks stuck in bed.”

ME/CFS

What could be improved?

“A lonely, scary, devastating journey“
“Education and resources for clinicians and relevant others to diagnose and support those with ME and long Covid.
- Care pathways, care plans & flexible tailored support.
- Access to service that accepts the limits of this condition and can help me to address the consequences. E.g. Too tired to shop & cook/prepare food so I don't eat, don't eat well. It affects my health, at point of crisis what do I do not to follow a downward spiral which makes me worse. And of course within my financial means. Advocacy. I was an advocate for many years, and could do with one myself now! For myself it has been a lonely, scary and devastating journey. Someone at least to check in me, discuss concerns with. And the wellbeing service is not it. Help to access reliable & trustworthy services.”

“No real support”
“Something that helps deal with the long term incurable nature of ME. There is no cure, but there is no real support or suggestion from any service as to how to manage it. There is no follow up service, no one checking in, no annual review at the least. Something which represents ongoing care would be good.”

“At least an annual assessment”
“Anything would be an improvement on the current state of affairs. Every patient with this condition should at least have an annual assessment and a care and support plan.”

“Resentment towards your body”
“There's just not enough understanding of the condition. The groups focus on recovery, yet ME is a long term condition and there's no cure so it feel disempowering to suggest lifestyle changes (diet, meditation etc) can cure it, because when you then try these things and they don't cure you it further exasperates the feelings of resentment towards your body.
More support is needed. Practical assessments to improve quality of life in the home would be a big benefit. I cannot afford equipment which would help me in the home as I'm very limited to how many hours I can work, due to ME. It just feels like you're alone struggling with a daily battle that never ends.”

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Multiple Sclerosis (MS)

41 (11%) **people shared their experiences of having multiple sclerosis (MS).**

Diagnosis

- 71% (29) were diagnosed correctly first time with the remaining 30% (12) being initially diagnosed with something else.

- Diagnosis times again varied, for 44% (18) it took more than 18 months to get a diagnosis. Regardless of whether the respondent was diagnosed correctly first time or initially with something else, it took more than 18 months to get an MS diagnosis. For those initially diagnosed with something else it took all of them at least seven months to get a MS diagnosis.

- Experiences of getting an MS diagnosis varied. Some respondents were diagnosed quickly and only presented at their doctor once or twice before being sent for tests. For others it took months, in some cases years. In such cases symptoms were written off as normal or depression.

"When I was 25, **I was told I had mental health issues** and was making up being ill for attention. They now know it was MS. Just been diagnosed at 33."

"I was **diagnosed very quickly**."

"My neurologist didn't believe me, **dismissed me totally**. Even once all the tests showed I had the disease he was still very dismissive."

"My **diagnosis was quick and the care I received was outstanding** from the neurologist."

"I had sudden scary symptoms and went to hospital that day, where I had an MRI scan and its **results within a week**."

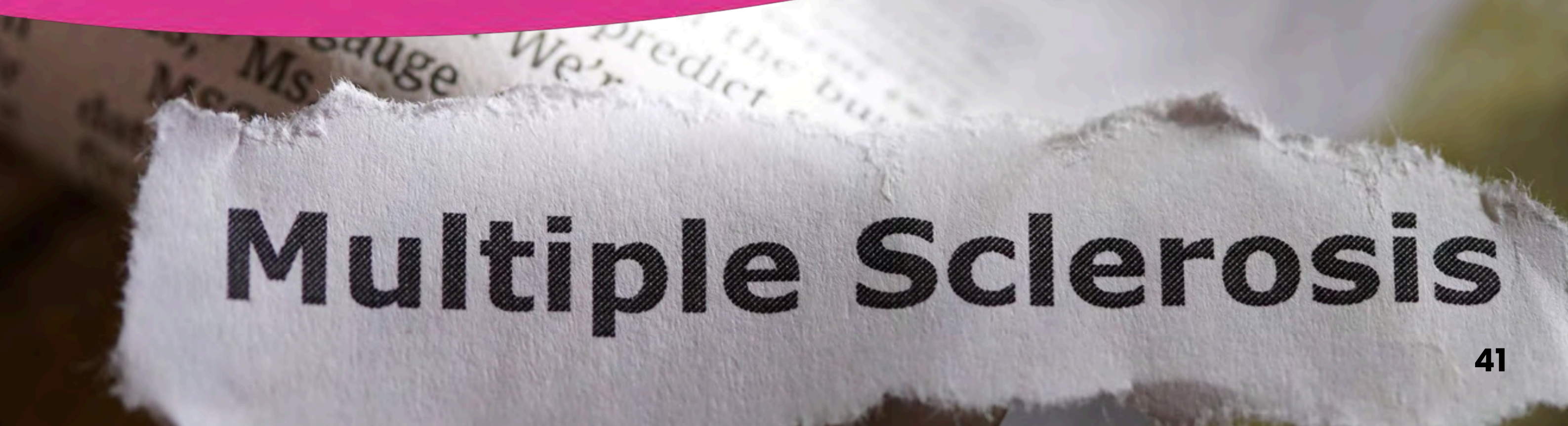
MS

Diagnosis

“Begged to be seen”
“It took nearly six years from my first visit to the GP with symptoms to getting diagnosed. I was diagnosed October 2021 with MS and barring an MRI scan in November 2022 I have had no communication with any MS team (neurologist or MS nurse) until July this year after I emailed and begged to be seen/have an appointment because I feel my symptoms have gotten worse and I have had no advice on my condition.”

“No guidance”
“Multiple issues not picked up as being linked to MS going back months. Still only preliminarily diagnosed via a head MRI. Have opted out of county but now still waiting on spine MRI and lumber puncture to fully confirm. Offered no guidance whatsoever. Done lots of my own research and the MS therapy centre (charity run) has been my only useful and helpful source of information and support. Mental health now suffering as a result as nowhere to go to ask questions. Left in the dark on what now appears to be a 14 week waiting list. Still not able to work after three months. Medication only for symptoms and no DMTs offered as yet.”

“Feel let down”
“I first saw a GP in 1984 with symptoms of numbness and was told “there was no logical explanation for what you're saying!” Because of this dismissal I didn’t go back to the doctor but was constantly ill and had a very poor sick record at work. In 2005 we moved to an army base in Cyprus. In 2006 I was unable to walk. I was admitted to the military hospital and after an MRI and lumbar puncture I was diagnosed with MS. I feel let down by that original GP.”



MS

Waiting times

- 27% (11) were waiting for additional tests, treatments or diagnosis relating to their MS.
- Respondents shared they were wating for a ocrevus infusion, MRI scans, lumbar puncture and neurology appointments.

“I have been waiting about eight months for two referals made by nurses at the Queens medical centre. There is **no possibility to have those referrals in the city where I live** even though Lincoln County has MS nurses. Apparently your consultant can't be in a different city to the nurses.”

“I am waiting for an MRI appointment. This has come about since I emailed my neurologist after **19 months of no contact with them**.”

“Betaferon auto injector broke in October 2023 **still waiting for new medication**.”

“Awaiting spine MRI and lumber puncture. Just had letter saying **no appointments currently available. No support** at all whilst waiting. Just told to go to A&E if needed!!”

“MRI. Was told I’d have one every year to monitor disease progression. **Last had an MRI in 2021**.”

“Several months with **no support**.”

MS

Medication

- 73% (30) took medication for their MS.

- 43% (13) of those that took medication for their MS had faced challenges getting medications that worked for them.

- Challenges around medication were similar to those faced by those with fibromyalgia and ME/CFS. The main challenge was finding medication that helped to somewhat control symptoms whilst balancing potential side effects.

- One respondent highlighted issues with getting medication that met their allergy requirements.

“I had to wait eight months to start it which was **incredibly stressful**. A nurse from Nottingham had to drive to Lincoln to show me how to self inject. I regularly have to go to the pharmacy two or three times because they don't seem to order things as soon as they get the prescription, and my meds are a little unusual.”

“Getting liquid Amatryptilline **took four months**. Couldn't take pills due to dairy allergies.”

“Took gabapentin but it made me sick, then moved to pregablin **without being told how addictive it is**. Came off that and now take carbamazepine when I can get it as there is a shortage and has been for months.”

“**Finding the level of meds needed**.”

MS

Medication

- For the respondents who hadn't faced any challenges getting medications that worked for their MS, they appreciated being able to have medications delivered to home. Medications being readily available and good communication between specialists and GPs was also praised.

"I have to travel quite far every four weeks to access my treatment but **the nurses are absolutely fantastic**. I cannot fault the nurses they are amazing."

"They get delivered every other month and **I can choose when**."

"My medications are **always ready on time.**"

"Available when I need them and **regular reviews** for effectiveness."

"Meds are delivered. **Really good communication**."

"**No issues** with medication. Neurologist has prescribed them and GP issues prescription."

MS

Other treatment

- 34% (14) had been offered or received treatment other than medication for their MS.
- Treatment other than medication included counselling, physiotherapy and rehabilitation.
- Respondents who had not been offered or received treatment other than medication shared what other help they thought would be beneficial. Physiotherapy, counselling and local support groups were the most frequently suggested.
- 12% (5) had chosen to access care privately. The reason for doing so included long waiting times on the NHS, limited care provided and accessing alternative therapies.

"**Therapy or local support groups** as it can be difficult to deal with and accept you have a chronic medical condition. It can feel very lonely dealing with an illness."

"A group where you **meet other sufferers**."

"It would be nice to see the MS nurse and neurologist every now and then as I **haven't seen a neurologist for 11 years** since first diagnosed and MS nurse is very difficult to access."

"**Psychological support is a must** when you diagnose someone with a life altering condition that frequently includes pain."

"I'm sure there would be but **I have no idea what is available** as I haven't been informed. I have researched myself for self help treatments/support but unsure what I need for my diagnosis."

"**Support while waiting for confirmed diagnosis is needed**. Brain MRI shows lesions and months of wierd leg weakness/sciatica/suspected but never diagnosed. Shingles clearly depicts MS. Stuck in a system that doesn't have effective resources to get effective preventative treatment, so A&E it will be!"

MS

Urgent and emergency treatment

- 20% (8) had needed to access urgent or emergency treatment for their MS.
- Some went on to discuss their experience in more detail and their subsequent stay in hospital.

“Felt in so much danger”
“I had a fall and after a call to 111, went to A&E. They couldn't give me an appointment slot so I just had to go and wait, but I felt in so much danger being surrounded by so many sick people whilst taking an immunosuppressant that I had to leave. I couldn't get an appointment with my GP because the online system said that I had to go to A&E. My hip is still causing me a lot of pain and it is clear that I did something too it, but can't get to see anyone.”

“Left in bed for too long”
“Terrible; on admission to Peterborough City Hospital was left in bed far too long which made me decondition due to lack of physio support. I was never taken to the gym facilities and discharged to rehabilitation where again there was no gym facilities.”

“Weak and useless”
“A&E did expedite quicker MRI through GP after CT scan was completed in A&E. Six weeks of barely being able to move nor get out of bed landed me weak and useless in A&E. Hadn't even been seen face to face by a GP.”

MS

Overall

- Respondents were asked to think about the care they receive for their MS and rate a range of areas. Overall, responses were mixed. The majority rated the following as **good**:
    - Listening to you
    - Explaining tests and treatment
    - Involving you in decisions about your care

- The majority rated the following as **poor**:
    - Being able to access care for your condition when you need to
    - Offering you different forms of treatment not just medication
    - Treating you with care and concern

- The ratings for the following aspects of care were **mixed**:
    - Addressing your needs or making plans to do so
    - Communicating with you clearly about your care
    - Providing you with information about your condition, treatment and care
    - Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)

A full breakdown can be seen in Table 3 in the Appendix.

MS

Overall

What works well?	What could be improved?
• MS nurses were repeatedly praised for their support and timely responses • One individual praised the MS registry and MS society • Another praised their GP for 'fighting their corner'	• Increase specialist support available for neurology and have more based in Lincolnshire • Shorter waiting times to access specialist support • Provide support whilst people are waiting to access care • A named point of contact • Support groups (not just in working hours either)

What works well?

"MS **nurses are brilliant and always accessible** by phone."

"**My GP is my one saving grace. He is amazing and fights my corner** when all around is chaos."

"I saw an OT before I was diagnosed with MS and **she was brilliant at getting me equipment** to make life easier for me."

"Visit from OT and making **adaptions to our home**."

MS

What could be improved?

“Days to get over the journey”
“Have a neuro department in Lincolnshire as I have to drive to Nottingham QMC for any appointments, and with my condition I am exhausted when I get back and it takes a couple of days to get over the journey.”

“Support groups”
“If there conditions were more recognised if the community, seeing support groups would be good.”

“Frankly terrifying”
“Just some contact would be nice. I never hear from anyone and have no idea if my MS is getting worse or not which is frankly terrifying.”

“Have to rely on people to take me to hospital”
“I would like to be treated at the hospital near me as I don’t drive and have to rely on people to take me to hospitals further away.”

“I feel lost”
“More communication about what treatment/review is needed for my condition, or how/who I get in touch with if I am concerned about anything to do with my condition. I have recently gone to my GP but I find this difficult currently as my mental health/depression has become worse since I feel lost with my diagnosis.”

“Nothing has happened”
“A point of contact. An MS nurse / consultant assigned to my wife would be a start. We have been told that we should have one, but nothing has happened.”

“Meet other sufferers”
“An MS group in my immediate area which would help get access to services and meet other sufferers.”

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Migraines

17 (5%) **people shared their experiences of having migraines.**

Diagnosis

- 53% (9) were diagnosed correctly first time.

- 35% (6) were initially diagnosed with something else.

- 12% (2) are trying to get a diagnosis.

- For those that had a diagnosis but were initially diagnosed with something else, it took all such respondents more than 10 months to be diagnosed with migraines. However, for those diagnosed correctly first time all but two respondents were diagnosed in under six months.

“Suffered, frequency increased, started keeping a log, had a couple of debilitating episodes, logged an online request with the GP 15th April 2024 and had a link to book an appointment. Saw a GP 26th April where she asked about symptoms and prescribed medication to take when they come on.”

“Been having issues that are migraine related for 50 years, been seeking answers for that time too. Was finally diagnosed two weeks ago.”

“The doctor didn't seem interested and I had to insist on being referred to a consultant. I was sent for numerous tests before diagnosis.”

“I was diagnosed quickly, but it took a long time to get the right medication, sometimes i was very debilitated and seeing some doctors was not taken seriously.”

Migraines

Waiting times

- 18% (3) of respondents were waiting for additional diagnoses and tests.

- Two individuals shared what they were waiting for and this included results from an MRI scan conducted in May and another had been waiting for 12 months to see a specialist only for their appointment to be cancelled.

Medication

- 93% (14) took medication for their migraines.

- 71% (10) of these individuals had faced challenges getting medications that worked for them.

- Challenges included shortages, difficulties finding medication or dosages that worked. Some felt they were given little support whilst navigating the latter.

“Initially prescribed painkillers the size of horse tranquilisers that were ineffective. Sumatriptan prescribed in six-tablet quantities, cannot get more than six per month so stockpile by getting a prescription each four-week cycle. Amitriptyline ineffective, no other treatment offered, **tiresome to keep asking** so I stop asking!”

“I tried several medications in my teens, none of which made any difference. Eventually I went on the pill for contraception which seemed to help. There seemed a complete lack of understanding and i was never referred to anyone. I feel I was **just left to get on with it**.”

“I have tried multiple medications until I’ve found one that works and now I have to stop it as it **costs too much**.”

“It **took a long time** to get the right medication that worked well.”

Migraines

Other treatment

- 20% (3) respondents had been offered or received treatment other than medication for their migraines.
- This included Botox, lidocaine infusions and pain management. One individual noted they had acupuncture which helped a lot but due to funding cuts are not available anymore.
- Other respondents who had not received any support other than medication felt that a local clinic or support group could be beneficial.

“A migraine clinic would be a good addition for Lincolnshire.”

“I think at the time I could have been given information about other options than medication I was led to believe that medication was the only treatment.”

“It would probably help to see a neurologist or a migraine specialist, but have been told not available in Lincoln.”

Urgent and emergency care

- 27% (4) respondents had accessed urgent or emergency care for their migraines in the past 12 months. The four experiences were mixed.
- Two praised that they were dealt with quickly but the remaining two faced long waits.

“I had to spend the night in A&E on a chair as there were no available beds, to wait for a scan, to be sent home next morning and have scan done as outpatient.”

“Very quick to respond to suspected stroke/TIA.”

“Brilliant when thinking its a potential stroke, once scanned and found no stroke, sent home with left sided weakness intermittently, with no idea of cause. Would have been nice if someone explained the potential of a migraine affecting my left side.”

Migraines

Overall

- Respondents were then asked to rate aspects of their care from very good to very poor.
  The responses were **mixed**, especially for the following:
  - Being able to access care for your condition when you need to
  - Listening to you
  - Explaining tests and treatment
  - Involving you in decisions about your care
  - Communicating with you clearly about your care

- However, the following aspects of care were rated **poorly** by the majority:
  - Offering you different forms of treatment not just medication
  - Providing you with information about your condition, treatment and care
  - Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)

Migraines

Overall

What works well?	What could be improved?
- Only **one respondent** shared a positive comment and that was they hoped their care would improve once their care plan was completed	- Providing support, not leaving people to their own devices - Quicker turn around of test results - Migraine clinic - Medication reviews - Acknowledgement that migraines can be very different for different people, tailor support appropriately

What could be improved?

“**Acknowledgement that it really exists** and each person experiences it differently. There should not be a scale of expectation of your suffering before you are listened to.”

“**Care is very disjointed** there is need for a while person approach where all symptoms are considered so problems can be sorted quickly, in not more than 12 months and not half a century as in my case.”

“I was told in A&E that I would be referred to a **migraine clinic, something that's not existing in Lincoln**.”

“A **dedicated migraine clinic** would be a massive help.”

Migraines

What could be improved?

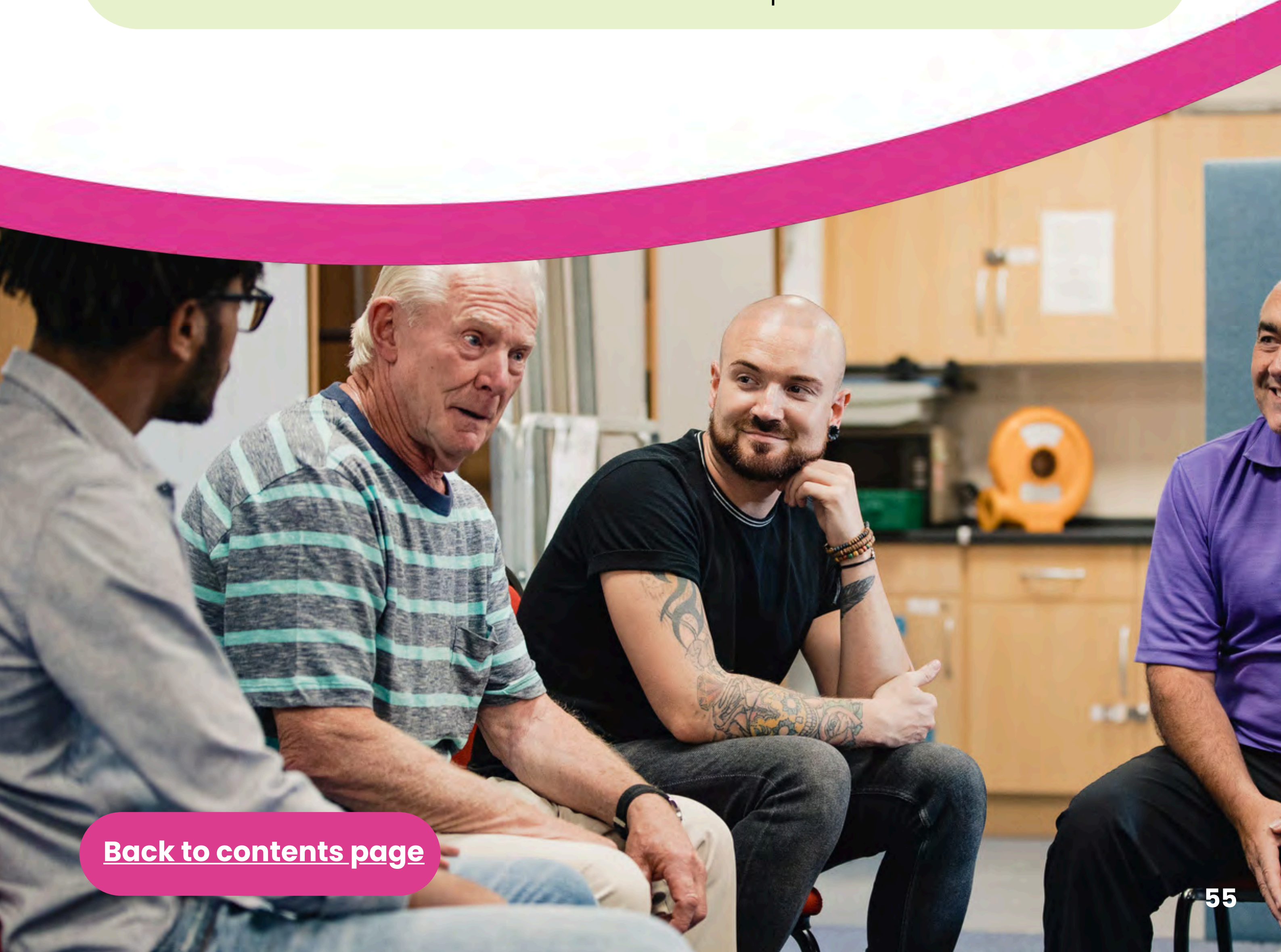
“To be **followed up regularly** and have my medication reviewed on a regular basis.”

“Some care and **management of any kind** would be an improvement to my current experiences.”

“I had an MRI scan in may and only received results beginning of July via a letter from my GP, with **terminology I don't understand** and have to wait until 17th July for an explanation phone call.”

“I have **had to fight for all the care and treatment** I have received and also paid privately, often doing my own extensive research.”

“**Results are too slow** which causes concern and impacts lives.”



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Epilepsy

15 (4%) **people shared their experiences of having epilepsy.**

Diagnosis

- 87% (13) were diagnosed correctly first time. Most commonly it took between 10 and 12 months to get diagnosed. All of these individuals were diagnosed within this time frame.

- For the remaining two respondents, one was initially diagnosed with something else and the other was trying to get a diagnosis. The latter had been waiting for 11 months.

- When discussing their experiences of getting a diagnosis, two individuals highlighted the lack of services in the county and another the poor transition between child and adult services.

"There was no paediatric neurologist in Lincoln, so took a long time to be diagnosed, waiting for scans, EEGs and ECGs."

"There were no specialist epilepsy services in Lincolnshire, so had to get appointment in Nottinghamshire."

"It wasn't until my son had a full blown seizure in front of medical professions that he was diagnosed with epilepsy."

"My concerns were always taking seriously whilst under paediatric neurology as I was diagnosed since the age of one as soon as I transitioned to adults at 16, this is when everything changed."

Epilepsy

Waiting times

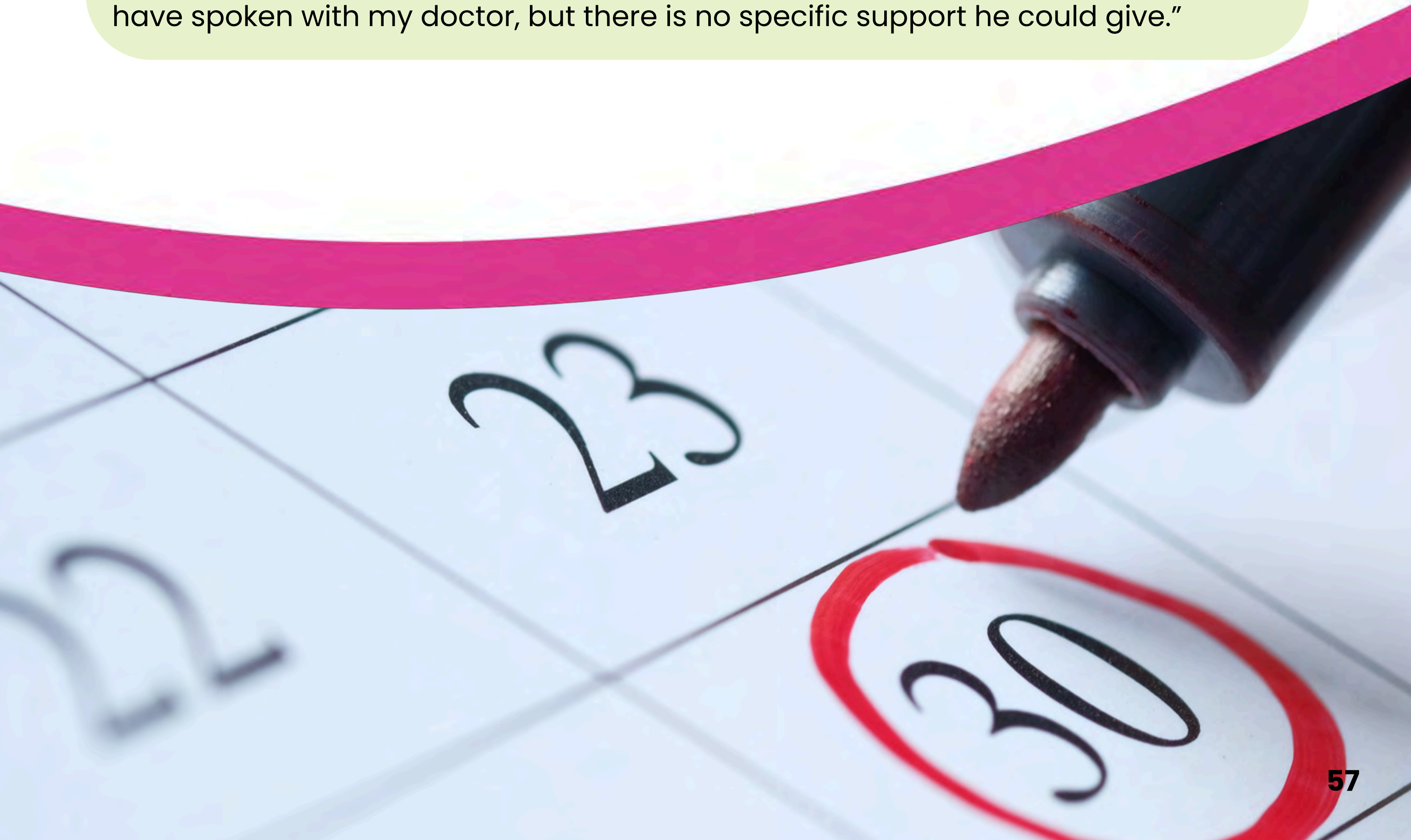
- 53% (8) of respondents were waiting for additional diagnosis, test or treatment.
- Three respondents had chosen to access private care, two citing long waiting times as being the reason.

I had a car crash due to having a seizure in February 2024. I had been seizure-free for two years at this point and had been stable on my medication before. As a result I was referred "urgently" to neurology at Lincoln hospital, to try and explore what is actually happening, yet I am still waiting to be seen, meanwhile **my life, university and job have been turned upside down** by my now uncontrolled seizures."

"We are waiting EEG, we have been waiting since May, **no support whilst waiting**, just keep being told long waiting lists."

"Follow up appointment after MRI, **been waiting seven months** so far."

"I'm **waiting to see a neurologist** about increased seizure frequency. I haven't seen one in about 20 years. I was told the wait maybe six months. Meanwhile I have spoken with my doctor, but there is no specific support he could give."



Epilepsy

Medication

- 80% (12) of respondents took medication for their epilepsy.
- 75% (9) of these respondents had faced challenges getting medications that worked for them.
- These challenges included shortages and being given substitute or different brands of medication which did not control symptoms as effectively. One respondent shared their frustration that their GP cannot change their dose without seeing neurology, but the waiting times to see a neurologist are long.

"**Not always consistently the same brand of medication** which I feel makes a difference."

"GP can't change dose without seeing neurology. Can't see neurology as it takes so long. So meanwhile **my life is left in limbo**."

"Getting the same brand has been challenging as advised by the neurologist as **different brands have different impacts**."

"I have been getting different brands which **goes against what my consultant told me** as different brands could have different impacts."

"**Brexit-related shortages** meant that I had to take substitute medication that put me at increased risk of seizures last month. It was scary."

"I'm on Epilim Chrono 500 and **we wanted try for a baby** so I had to by weened off Epilum several times as it was causing me to fit."

Epilepsy

Other treatement

- One individual had been offered and was waiting to receive other treatment, outside of medication. They were waiting for VNS.

- For others who had not received treatment other than medication, a support group, transition lenses for photosensitivity, a Lincolnshire based consultant were suggested.

"Maybe **a consultant in Lincolnshire would be nice** instead of having to go to Nottingham."

"Adaptive sunglasses (for light sensitivity). People's **awareness and understanding of epilepsy in general**, including differences between seizure types."

"A **local support group.**"

"As a child, I would've benefited from **peer support and better understanding of my condition not just leaflets**."

"**Transitions glasses**, suitable for photosensitivity."

"Support to help my memory. **Support to be independent**. Due to my uncontrolled seizures I now can't drive again, it's also not safe for me to go on public transport, ride my bike or be out in public on my own due to the risk of seizures, and the confusion/memory loss that happens afterwards, this leaves me extremely reliant on family, and means I have lost the majority of my independence."

Epilepsy

Urgent and emergency care

- 33% (5) of the respondents had accessed urgent and emergency care for their epilepsy in the past 12 months.

“You’re a Nottingham patient”
“Long waiting times to be seen, just checked over and said you're a Nottingham patient, we will have to contact them. Discharged and Nottingham is never contacted.”

“It was all very upsetting”
“After my car crash I went to A&E to get checked out, as I couldn’t remember the crash happening and I wanted to be safe. Whilst in A&E, I had repeated seizures, which my dad supported me through, until A&E decided to say all relatives must leave. So my dad was forced to leave me on my own, in A and E, knowing I was frequently having seizures, which came with memory loss and confusion. I have no recollection of what treatment I received, what tests I had done, or what I was told was my next steps of treatment, because of this. It is vital that people in this situation have a plus-one with them to retain any important information that the patient may not be able to. I even ended up waiting three hours too long in the waiting room due to not remembering they told me I could go home. It was all very upsetting, as I am also neurodivergent, and having had an unexpected seizure, a car crash, followed by multiple other seizures, I was expected to remain in an unfamiliar environment, where I suffered memory loss and confusion, alone and anxious.”

“Louth needs its A&E back”
“I ended up in Grimsby A&E after I hit my head during a violent seizure. Treatment there was very good. What could be improved would be having A&E in Louth, where it would be quicker. The number of times I have gone to Louth and they aren't allowed to do anything... Louth needs its A&E back.”

Epilepsy

Overall

- Respondents were then asked to rate aspects of their care from very good to very poor. The responses were **mixed,** especially for:
  - Being able to access care for your condition when you need to
  - Listening to you
  - Explaining tests and treatment
  - Involving you in decisions about your care
  - Communicating with you clearly about your care
  - Addressing your needs or making plans to do so
  - Providing you with information about your condition, treatment and care

- However, the following aspects of care were rated **poorly** by the majority:
  - Offering you different forms of treatment not just medication
  - Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)

- The majority rated being treated with care and concern as **good**.

Epilepsy

Overall

What works well?	What could be improved?
• Specialist services were praised but respondents noted they had to travel to get such support • However, five out of the nine comments shared sentiments along the lines of nothing or they do not get any support	• Local access to specialist neurology care • Waiting times to access specialist care • Joined up, holistic care • Medications to be available consistently

Epilepsy

What could be improved?

“There are too few neurologists, it seems to be about one person for the whole county. Drugs need to be securely available, with decent backup stocks. Brexit destroyed these supply chains, it wrecked our security for securing medicine stocks as part of the EU, and nothing has been put in place to ensure crucial supplies. I and 600,000 other epileptics could die without the right medication, so fixing this is **a matter of national security**.“

“There is **no service for epilepsy**.”

“To see a **neurologist in Lincolnshire**.”

“People who understand the effects of epilepsy, experts to give the right information, give choices and make sure care is taken place. Support from mental health services, SALT services. **Everything is disjointed** and waiting times for everything - to have an appointment you have to call daily. Care for a diagnose condition shouldn't be difficult between services.”

“Anyone with epilepsy needs to **automatically be allowed a plus-one** with them in A&E/hospital. Same for neurodivergent patients. This is for their own wellbeing, as well as retaining information regarding their treatments and any test results etc. Waiting times need to be shorter. An urgent referral shouldn’t take over six months. I also know people that are 22 months overdue a “12 month check up” too, which fills me with little faith that even once I am seen that anything will be followed up with in a timely manner.”

“I know there are very long wait periods for new patients to get their official diagnosis which has a **massive impact on their lives** so reducing wait time needs to be addressed. I feel care itself once you are diagnosed is brilliant and can always get hold of [my epilepsy nurse] but ahead of this care is very poor.”

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Functional Neurological Disorder (FND)

14 (4%) **people shared their experiences of having functional neurological disorder (FND).**

Diagnosis

- 50% (7) were initially diagnosed with something else.
- 36% (5) were diagnosed correctly first time.
- Diagnosis times varied, with a quarter (3) being diagnosed in less than a month but for 50% (6) it took more than 13 months.
- 14% (2) were trying to get a diagnosis. These respondents had been trying for 4-6 months and more than 18 months to get a diagnosis.
- Two respondents had positive experiences being diagnosed - being taken seriously and diagnosed quickly. However, for the other respondents they often had to present to their GP practice multiple times over months and years and were not taken seriously. As a result of the latter some sought a private diagnosis.

> "I repeatedly presented at the GP with unexplained dizziness, feeling off-balance and fatigue. I was under 25 and **no-one was taking me seriously** on the impact it was having on my life. I could barely go to the toilet without feeling like I was going to fall over. They just kept putting it down to anxiety and gave me antidepressants which made my anxiety so much worse. I went private, they then referred me for an MRI on the NHS to rule out a schwannoma. Nobody knew what was wrong and they just kept telling me it was anxiety. In the end FND was thrown around as a possibility, but I was never officially diagnosed or never really found out what was wrong. I'm still two years later being left to manage my symptoms myself. It feels like no one cares or takes it seriously."

FND

“My child was diagnosed with FND age 9, it taken different professionals with there own misdiagnosis to then diagnose FND, there was the professional who said your child just doesn’t want to go to school. There was the professional who said there’s nothing wrong, **you’re just wasting our time**.”

“Repeated trips to the GP who kept doing bloods and no onwards referral. I was told it was probably something to do with menstrual cycle even though I don't have periods, or it was depression. I felt like **I had to over-justify myself** constantly and that I wasn't being taken seriously.”

“I was diagnosed quickly after my main symptoms began (in a different area). I was taken seriously, but often told there was ‘nothing they could do’ and that I’d **have to go home and learn to live with it**.“

“CAMHS were helpful, It's unfortunate ICB, PALS were **unwilling to investigate** why 2017 EEG was not followed up or ever questioned.”

“It took about three years I was **made to feel like a fool** didn't take me seriously and I suffered because of it and I find it difficult to trust any professional.”

“It took **12 years to get a diagnosis** as no-one had heard of Functional Neurological Disorder.”

“Have spoken to neurologist about FND but there **does not appear to be the resources to investigate**/offer any help.”

FND

Waiting times

- 29% (4) were currently waiting for tests, treatment or additional diagnosis.
- This included waiting to see a neurologist or other specialists.

"Waiting for neurology appointment. I've been on the waiting list for seven months now and **no idea of likely timescales**."

"I am waiting on an inpatient stay on Lishman unit in London. It took a long, long time to be referred and **the wait after assessment is up to TWO YEARS**. In the meantime I just have email access to a consultant response clinic at QMC, but no ongoing appointments with neurology."

"ULHT have agreed to see son next week, though **it took multi-level complaint**s to achieve."

Medication

- 43% (6) took medication for their FND.
- Half of these individuals had faced challenges getting medications that worked for them.
- Two of these individuals felt that the medications didn't have a huge impact. One called them a "sticking plaster" whilst another felt they "only skim the surface".

Other treatment

- 50% (7) had been offered or received treatment other than medication for their FND.
- This mainly included counselling.
- Others who had not received any other support wished they had been given more advice and support on how to manage their condition.

FND

Other treatment

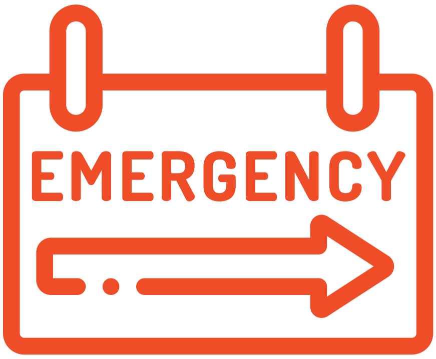
“Help with it all instead of **just been given a web address** and told to research it.”

“I'm not sure I was diagnosed but the neurological consultant and left to deal with it **no advice or support** been let down I'm in constant pain and struggling daily.”

“There is **no FND service in Lincolnshire**, so I can't access neuropsychology or talking therapies.”

Urgent and emergency care

- 21% (3) of the respondents had accessed urgent and emergency care for their FND in the past 12 months.
- The three experiences were quite negative with healthcare professionals having a poor understanding of FND being the main issue.



“Nearly discharged home with no additional help or investigations despite having lost the use of my legs. Discharge lounge then took me seriously and **bounced me back in to the hospital system**. I then periodically also lost use of my arms. Most doctors and nurses were fine while I was in, but a few didn’t really understand.”

“The doctor at the hospital didn't even know about FND or how it effects the patient was **left on trolley for 16 hours**.”

FND

Overall

- Respondents were then asked to rate aspects of their care from very good to very poor. The majority of respondents rated all aspects of their care as **very poor**:
    - Being able to access care for your condition when you need to
    - Listening to you
    - Explaining tests and treatment
    - Involving you in decisions about your care
    - Offering you different forms of treatment not just medication
    - Treating you with care and concern
    - Communicating with you clearly about your care
    - Addressing your needs or making plans to do so
    - Providing you with information about your condition, treatment and care
    - Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)

- When asked what works well about the care they receive for their FND, none of the respondents had anything positive to say, with nearly all 13 saying nothing or they either didn't receive any support.

What could be improved?

- Listen to patients
- Follow-ups, ongoing monitoring of symptoms
- Greater awareness of the condition amongst professionals
- Provide patients with advice and support

FND

What could be improved?

“Just to actually listen to people, stopping putting everything down to anxiety and there may be an underlying condition or something causing the anxiety.”

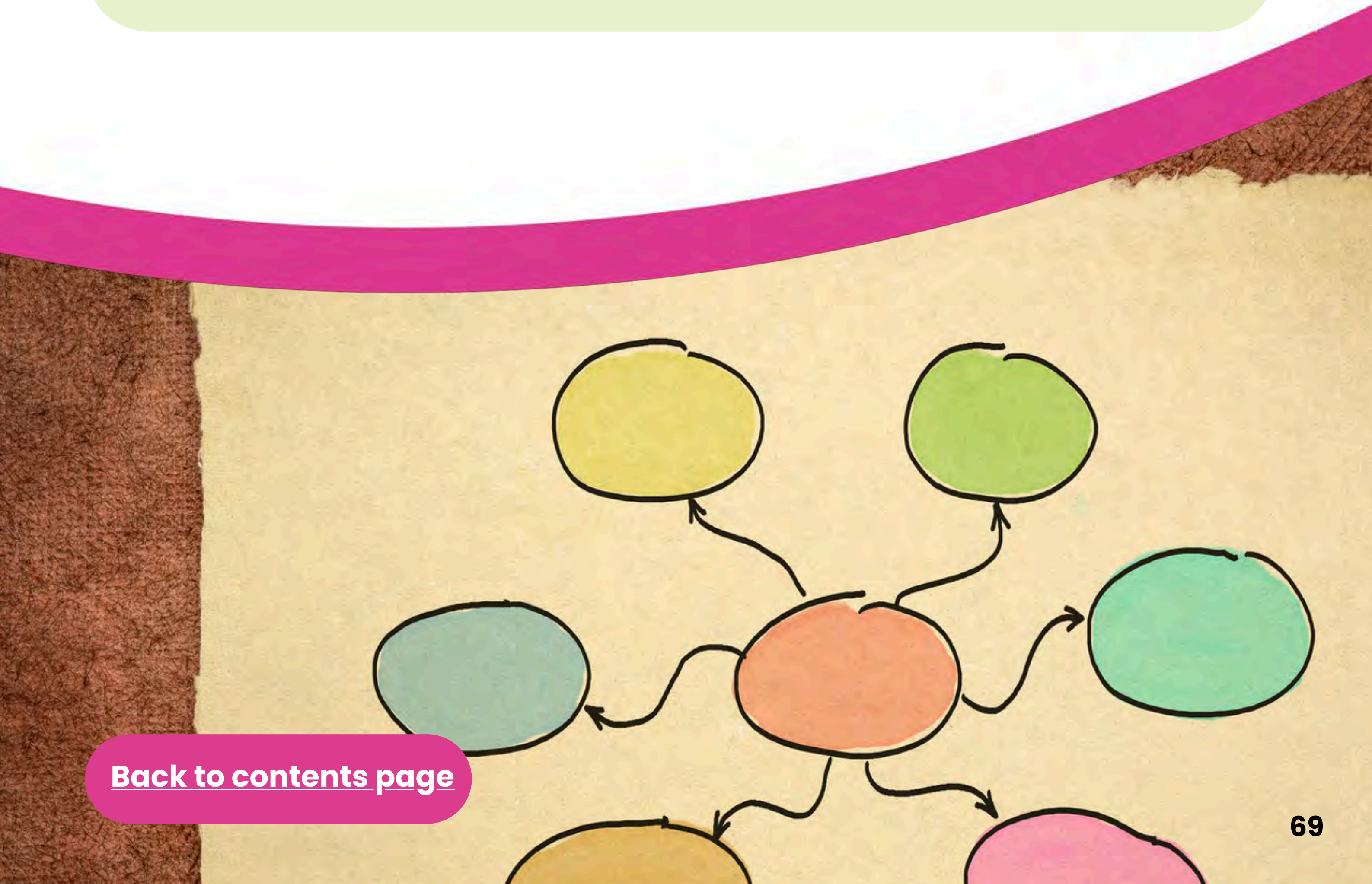
“Nothing as soon as you have issues it seems the staff think it’s all in your head made up.”

“They just don’t understand it, Lincolnshire doesn’t seem to be commissioned to work with the condition so there’s no treatment available.”

“For there to be more readily available FND help, resources and professional acceptance.”

“To have resources to actually see someone who’s prefer to make a different to someone with the condition.”

“To be listen to properly and listen and treat my condition and have knowledge of it.”



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Chronic pain

13 (3%) **people shared their experiences of having chronic pain.**

Diagnosis

- 69% (9) were initially diagnosed with something else.
- 31% (4) were diagnosed correctly first time.
- It took all respondents at least four months to get diagnosed, but for 77% (10) it took more than 13 months.
- Experiences of getting a diagnosis were poor, with respondents having to wait years and not being taken seriously. It took one individual 26 years to be diagnosed. Respondents were often passed from person to person and felt no one was interested.

> “Took me over 26 years to be diagnosed. Prior to that I was **constantly told I had musculoskeletal problems.** No help or explanation.”
>
> “In 2011 I presented at A&E in severe pain in my neck. I was diagnosed with a trapped nerve. This was diagnosed by a doctor pressing his thumb into my neck. I spent six months back and forth in pain before my GP finally sent me to have an MRI. This revealed a slipped disk and compressed spinal cord. Since then I have suffered chronic pain and been battling for help. I now have another disk issue and am **getting passed around with no actual treatment offered**.”
>
> “Back & leg pain. Seeing GP, specialists, physiotherapist, MRIs, back to GP and repeat more than **eight years until I was finally diagnosed** and pain was taken seriously.”
>
> “Took years on waiting lists and got to point where **permanent disability** had occurred.”

Chronic pain

"For years I was told I was in pain because I was obese and told to lose weight. I was admitted to hospital with crushing chest pain and once it settled I was left for three days then sent home. I was then diagnosed with high cholesterol and over two weeks lost over two stone. I was ignored the weight kept dropping off I went from 16.5st to 7.5st the pain got worse I was sent to a rheumatologist who said I had fibro and exercise like an athlete, you will be cured. So I did which made everything worse I have never been pain free. Connect health never helped they only saw the words fibro and was told to come off all meds and retrain my brain. I have chronic pain in my low back and c5/c6 and frozen shoulder that has nothing to do with fibro I have chronic migraines that remain untreated and now have trigeminal neuralgia."

Waiting times

- 62% (8) were waiting for tests, treatment and additional diagnosis relating to their chronic pain.

"Four years waiting, repeated cancellations and staff shortages no support provided."

"Months have had surgery last June and November self paid June due to desperation."

"For a disc in my neck to be looked at properly, bone spurs in five vertebrae to be sorted out and the severe pain to my arms head and neck to be fully investigated."

- Four individuals had chosen to access private care due to long waiting times and the limited support available on the NHS.

"Pain was so bad and limiting quality of life."

"Yes before I committed suicide!! NHS waiting times were 8 months!!"

"I was offered it as a way of getting faster treatment than waiting for NHS treatment list."

Chronic pain

Medication

- 92% (12) took medication for their chronic pain.

- 100% (12) had faced challenges get medications that worked for them.

> "I've been on high doses since 2011 unchanged. I've been asking for a full review and change ti meds as they are no longer working for me. I've been ignored. Pain management are only interested in removing meds or telling me to meditate and think myself better. (Useless)."
>
> "GP in Lincolnshire ignoring consultants' advice and diagnosis."
>
> "My GP is not interested and tells me to contact the pain clinic, who take forever to do anything."
>
> "GP stopping them against consultant's advice and guidance."

Other treatment

- 77% (10) had been offered or received treatment other than medication for their chronic pain.

- This included physiotherapy, counselling and referrals to pain clinic. For some respondents none of this was very effective.

> "Pain management and therapy sessions online to manage pain through meditation (utterly useless) if I could think the pain away I'd be fine!"

Chronic pain

Urgent and emergency care

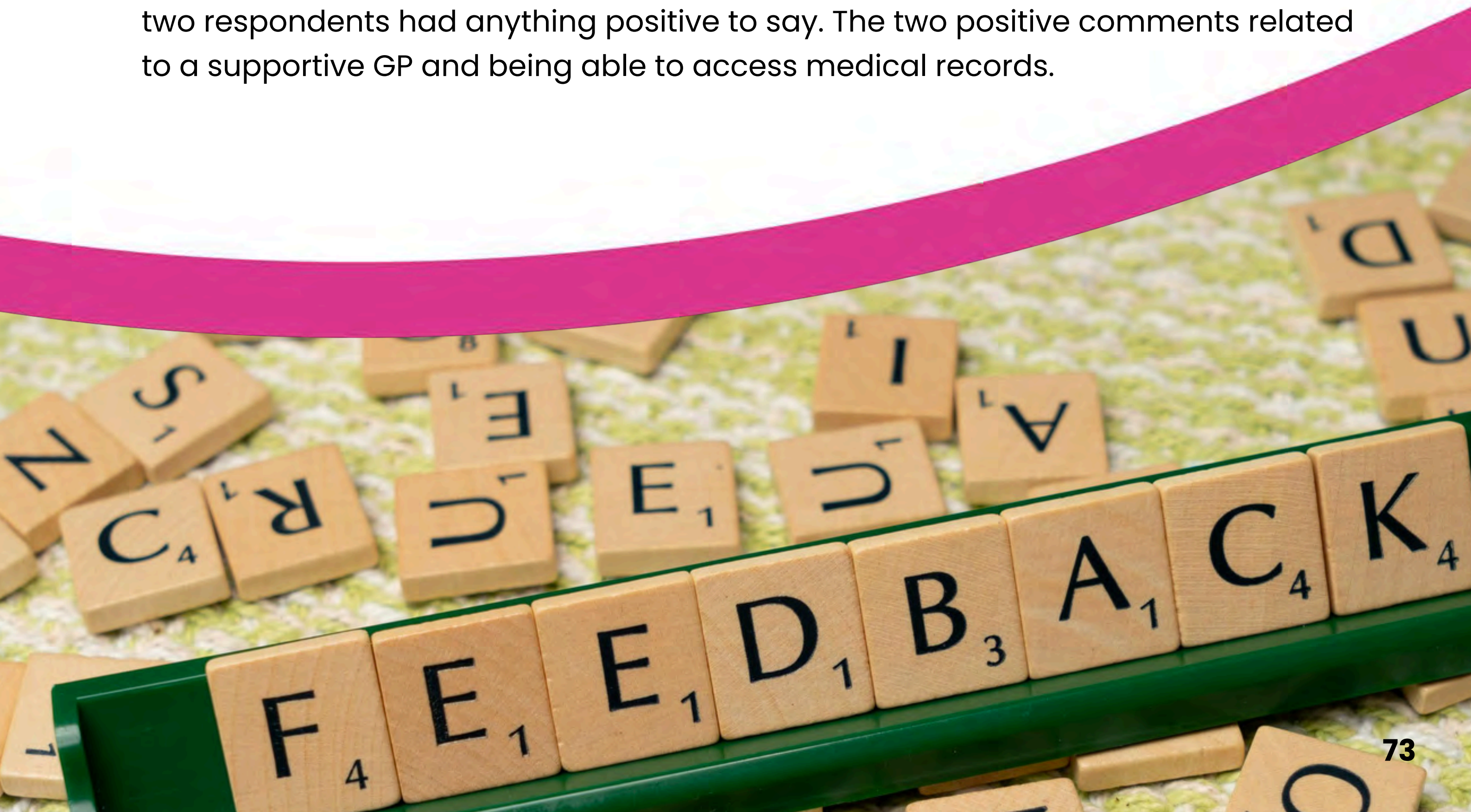
- 67% (8) had accessed urgent and emergency care for their chronic pain.

- Experiences tended to be poor including long waits, being told they just had anxiety or having to travel out of county to access out of hours GP care.

Overall

- Respondents were then asked to rate aspects of their care from very good to very poor. The majority of respondents rated all aspects of their care as **very poor**:
  - Being able to access care for your condition when you need to
  - Listening to you
  - Explaining tests and treatment
  - Involving you in decisions about your care
  - Offering you different forms of treatment not just medication
  - Treating you with care and concern
  - Communicating with you clearly about your care
  - Addressing your needs or making plans to do so
  - Providing you with information about your condition, treatment and care
  - Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)

- When asked what works well about the care they receive for their chronic pain, only two respondents had anything positive to say. The two positive comments related to a supportive GP and being able to access medical records.



Chronic pain

What could be improved?

What could be improved?

- Listen to patients
- Better communication between services
- Actually getting some support
- Holistic, personalised support

"I'm not being supported as I have been told what do you want us to do about it. I end up in tears every day. I'm in so much pain. I'm human but I'm not treated nice."

"Computer systems that connect from GP to hospitals, keeping me informed about tests and not having to explain each time I visit a health 'professional' what is wrong with me. They should know as they have diagnosed me. Have given up even trying to see a GP."

"Everyone treats you as per their department and not as a whole person with varying symptoms."

"Getting any type of care in Lincolnshire would be an improvement."

"Unable to get care and management in Lincolnshire."

"For people to realise that fibro chronic pain migraines tremors twitches are not the same in everybody some might be able to cope with no analgesia and meditation works for them but not everyone should be treated the same."

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Stroke

9 (2%) **people shared their experiences of having a stroke.**

Diagnosis

"A&E **scanned within 20 mins of arriving** and sent to QMC."

"I suffered a stroke back in 2014, whilst on the way to work, my colleague called 999 and an ambulance was there within 10 minutes, blue lighted to Lincoln and **was seen within the four-hour window**."

"999 called, first response arrived 45 minutes after call first made ambulance arrived 15 minutes after that. Taken from Skegness to Lincoln County Hospital A&E. Was transferred to a meningitis ward in the night then after lunch the next day taken to the stroke ward. I believe the first MRI/CAT scan was done the day after that. So **stroke Saturday pm, scan Monday pm**."

"Emergency ambulance to A&E, had **CT scan to diagnose within 30 mins** of onset."

Waiting times

- One individual was waiting for a referral to a psychiatrist. They had been waiting for more than two years.

"Referrals to psychiatrist that should have been done over two years ago. I need to chase it up to see what is going on. Neurologist, had my first appointment 03/22 was supposed to be seen six months later but **still haven't heard anything** from them."

Stroke

Medication

- All nine respondents took medication after their stroke.

- Five had faced challenges getting medications that worked for them. This included access issues.

> "**Shortages**. Pharmacy always trying to change to a different brand without speaking to a doctor."
>
> "Have had **difficulty getting medication** and getting changes to medications following appointments with consultants. GP may read letter and highlight what needs changing but fails to action it."

Other treatment

- Eight of the respondents had been offered or received other treatment.

- This included counselling and physiotherapy.

> "I have not had an recent physiotherapy input. I still have some problems and really feel that I could manage some more rehabilitation but I've been told that I had treatment at the time of the stroke and there is nothing more that can be done for me. There is. I tried going for physiotherapy through the GP and they said **we don't treat stroke patients**, it does not fall into our contract. They also said there is no-one else offering this post stroke rehabilitation."

Urgent and emergency care

- Three of the respondents had accessed urgent and emergency care in the past 12 months. All three experiences were poor.

> "Really poor, **15 hours in a chair** then discharged fell at home on return two weeks in hospital."
>
> "At Lincoln A&E it was a poor experience, I was **accused of not having a stroke** when I did. Consultants / doctors actually doing what they should do, patient care and interests always comes first."

Stroke

> "Terrifying in Pilgrim A&E in April 2024. Absolute carnage in the waiting room. It has left my husband and I suffering with anxiety. Nothing worked well, nobody listened to me, I knew my husband was having a stroke, it is time critical and we was meant to just sit and watch him deteriorate until I lost it and shouted loudly and he had a CT scan. **Absolutely appalling**, completely desensitsed staff."

Overall

- Respondents were then asked to rate aspects of their care from very good to very poor. The majority of respondents rated all aspects of their care as **poor**:
  - Being able to access care for your condition when you need to
  - Listening to you
  - Offering you different forms of treatment not just medication
  - Addressing your needs or making plans to do so
  - Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)

- The rating for the following aspects of care were very **mixed**:
  - Explaining tests and treatment
  - Involving you in decisions about your care
  - Treating you with care and concern
  - Communicating with you clearly about your care
  - Providing you with information about your condition, treatment and care

- When asked what works well about the care they receive for their stroke, two respondents praised their consultants.

Stroke

What could be improved?

What could be improved?
• Clear communication between services and to patients • Care 3-4 years post stroke • Point of contact for concerns

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Brain injury

9 (2%) **people shared their experiences of having a brain injury.**

Diagnosis

“The patient I was working with was diagnosed within Lincolnshire acute hospital services. The patient was then transferred to a rehabiliation ward. The patient continues to require psychological, emotional and practical support in a specialist neurorehabilitation unit to enable adjustment and to develop coping and self-management strategies. **A funded six-week stay would make all the difference to the patient**. Sadly he was discharged to a care home. Come on Lincolnshire. Specialist brain neurorehabilitation services for people with acquired and traumatic brain injury need to be planned, organised, delivered and available.”

“**Diagnosed eight months after an accident** at work.”

“Was diagnosed in another county. Moved to Lincolnshire and apart from a very proactive surgery there’s **very little support locally** for people with brain injuries.”

“A&E **completely disregarded** what was being told them after my mother was attacked. No scan. We had to pay privately for a scan. Mum was diagnosed with a subdural haematoma which consequently burst a couple of weeks after the attack. Had she been scanned at the time the outcome would have been different.”

Brain injury

Waiting times

- Five respondents were waiting for additional tests and treatment.

- This included neurorehabilitation, neuropsychology and results from scans.

"Rehab and neuropsychology - waiting times in excess of one year. No support other than local brain injury charity, **Headway**."

"The patient is waiting for specialist brain neurorehabilitation. In the first instance the patient is waiting for someone in the Lincolnshire healthcare system to take responsibility to properly help him. Unfortunately at present, I think the **patient will be waiting a long time and may not ever receive the specialist help**."

"Waiting for results of CT and MRI scan to see if his narrowing of the windpipe can be improved - been **sent to wrong clinic**, tests repeated by different clinics and have to ring up to make sure he finally gets appointment with the right person."

Medication

- Four respondents took medication for their brain injury.

- Two individuals had faced challenges getting medications that worked for them. These challenges were shortages and being given incorrect medication.

Other treatment

- Five of the nine respondents had been offered or received treatment other than medication for their brain injury.

- This included counselling and neurorehabilitation.

"Counselling support through Headway Lincolnshire."

"Received 12 weeks in a neuro rehab unit."

Brain injury

Other treatment

- When asked if there was any other treatment they would benefit from, respondents highlighted:

> "Yes, some kind of neurophysio would be helpful. Access to counselling would be helpful too. Fatigue and pain management also."
>
> "Specialist brain neurorehabilitation services, specifically a funded six-week inpatient stay."

Overall

- Respondents were then asked to rate aspects of their care from very good to very poor. The majority of respondents rated all aspects of their care as **poor:**
  - Being able to access care for your condition when you need to
  - Listening to you
  - Involving you in decisions about your care
  - Offering you different forms of treatment not just medication
  - Treating you with care and concern
  - Addressing your needs or making plans to do so
  - Communicating with you clearly about your care
  - Providing you with information about your condition, treatment and care
  - Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)

- The rating for the following aspects of care were very **mixed:**
  - Explaining tests and treatment

- When asked what works well about the care their receive for they brain injury, none of respondents shared anything positive.

Brain injury

“After going to brain injury support groups and hearing the woes of people who come for help **not much help or support is around**. Health authorities advocate go to the right place, at the right time, for the right treatment but this doesn't happen. If it did money would be saved and patients would have a better outcome. As one in six people have a neurological condition something needs to be done.”

“The patient needs everyone to pull together and for **someone to take responsibility** to help to secure funding for a six-week inpatient stay at the regional specialist neurorehabilitation centre.”

“Brain Injury services are a **black hole in Lincolnshire**. Those that there is are very limited with very long waiting lists.”

What could be improved?

What could be improved?

- More support for neurological conditions in Lincolnshire.
- Holistic support including pain management and mental health support and to patients.
- Neurological services have been poor for years, with one respondent highlighting that nothing had improved since 2018 when the neurological needs assessment (discussed in the introduction of this report) highlighted the poor service provision.

Brain injury

“Back to square one”
“Put neurology back on the ICB agenda and take note of some of the enclosed documents eg clinical pathway for TBI, HARG summary report, Headway statistics (I was a member of Headway Lincs for 30 years and neuroglial alliance), JSNA information (the JNSA for neurological conditions 2018 was not acted upon but was included in the latest JNSA) which I understand they are the already source which services and equalities should be based on. They see to be disregarded at the moment. Also pathway for rehabilitation and Healthwatch's previous findings, which were not acted upon. After such a bad experience in hospital and so-called rehab I have campaigned for over 25 years for better services and staff to have better knowledge of TBI. But when you think you are getting somewhere its another change in authorities and back to square one and start again.”

“Funded referral route”
“A clear funded referral route to specialist brain neurorehabilitation service.”

“More support in Lincolnshire”
“Communication between departments. More support for neuro conditions in Lincolnshire.”

“Only because of Headway”
“A more holistic approach. I have received the right help eventually when specifically asked for it but not knowing what help you need makes it difficult to do this. It is only because of Headway Lincolnshire i have been able to access the necessary treatment which was after a long delay since my injury.”

“Emotional support”
“I’d like some kind of emotional support due to the complexities of my situation. Pain management too.”

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Parkinson's disease

9 (2%) **people shared their experiences of having Parkinson's disease.**

Diagnosis

- Seven of the respondents were diagnosed correctly first time.
- Two respondents were initially diagnosed with something else.
- Diagnosis times varied, five out of the nine respondents were diagnosed within six months or less.

"My husband went the GP and was referred to a neurologist re Parkinson's after waiting over 15 months and hearing nothing we decided to pay for a private consultation and were seen within two weeks. The diagnosis was immediate but he needed to have scans and a DaTscan to confirm. These were done on the NHS so took another four months. September 2021 his diagnosis was confirmed and medication started properly. Since then only seen a neurologist once but have spoken on telephone about every six months. How can they assess mobility and dystopia by telephone?! We both feel quite **alone and ignored**. I know if we could continue to pay privately he would be seen more regularly but we can't."

"**Had to go privately** to see neurologist far too long a wait with NHS DaTscan had to be taken in the NHS."

"Was correctly diagnosed and prescribed medication. However the statement given that "it won't bother you in your lifetime" was **totally misjudged**. 73 years old, 18 months on can no longer drive, walk very far, have fatigue etc."

Parkinson’s disease

Waiting times

- One respondent was waiting for additional tests and treatment.
- They shared they were waiting for an MRI scan that had been delayed by four months.

> “I am waiting for a MRI scan, as when I had a scan for DBS surgery they found something my in my head. I was supposed to have a scan after 12 months so I’m now nearly four months over time.”

Medication

- All nine respondents took medication for their Parkinson’s disease.
- Five out of the nine had faced challenges getting medications that worked for them.
- Challenges included shortages, being given the incorrect medication and side effects.

> “Medication causing adverse side effects, own GP unable to change medication unless on consultants say so. Waiting seven months for appointment, A&E three times over two weeks with related side effects, nothing pinpointed. Finally staff member at Pilgrim advised us to access the Frailty ward there. Fabulous facility, sorted us out during the one day, and assured of follow up in one month.”
>
> “I was repeatedly given incorrect medication for over two years at which made my condition much worse, throughout this period I saw by only neurological Doctor throughout this period, who despite me reporting serious side affects he repeatedly tried 3 different types of the medication group dopamine agonists. I was so ill I gained over five stone had major psychosis was hallucinating deluded having nonsensical imaginary conversations, hyper sexuality. Chronic constipation and insomnia. I had to pay for a private neurologist who diagnosed Dopamine Dysregulation Syndrome.”

Parkinson’s disease

Medication

“My husband is on medication four times a day and a sleeping pill at night. There have been several occasions when they haven’t been able to get his Co-Beneldopa 50mg and ran out one time causing him lots of **stress and worry**! We have also had to visit many chemists to try and get the meds. He now keeps extra pills to avoid this happening again.”

Other treatment

- Five of the respondents had been offered or received treatment other than medication.

- This included physiotherapy and occupational therapy.

“Lincoln City Foundation Charity offer brilliant weekly physio sessions but we **found out about these by chance** and not via either consultant or GP who I guess were nor aware of the existence of these weekly sessions.”

- Three respondents suggested that more physiotherapy and speech therapy would be beneficial.

“I don’t know as I don’t know what I need but I do know (from people we know) in other parts of the country Parkinson's patients are given speech therapy, physiotherapy, six-monthly meetings with a Parkinson’s specialist. In this region **we do not appear to have this at all**.”

“**Physiotherapy** or structured exercise class.”

“The speech therapy was a bit sparse feel would like to see more of our **Parkinson's nurse she is incredibly helpful** I know I can call her if things are wrong but would like her to come round more often.”

Parkinson's disease

Urgent and emergency care

- Two of the respondents had accessed urgent or emergency care in the past 12 months for their Parkinson's disease. One individual went on to share their experience in more detail.

> "A&E Lincoln three times, did not recognise the symptoms as being adverse side effects from the Parkinson's medication as the right questions were not asked, and presumably there was no one qualified, as at Pilgrim, to spot the overlap in the tablets prescribed."

Overall

- Respondents were then asked to rate aspects of their care from very good to very poor. Ratings for the following aspects of care were **mixed**:
    - Being able to access care for your condition when you need to
    - Listening to you
    - Explaining tests and treatment
    - Treating you with care and concern

- The majority rated the following as **poor**:
    - Offering you different forms of treatment not just medication
    - Addressing your needs or making plans to do so
    - Providing you with information about your condition, treatment and care
    - Communicating with you clearly about your care
    - Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)

- Whilst the majority did rate being involved in decisions about their care as **good**.

Parkinson’s disease

Overall

- When asked what works well about the care they receive for their Parkinson’s disease, one respondent highlighted their GP and another the aftercare after receiving deep brain stimulation (DBS). Others shared they felt they got little support.

What could be improved?

- More Parkinson’s nurses
- Equitable offering of care and support
- Regular meetings and follow-ups
- Inform patients of what support is available

“**Nothing works well.** There are no regular meetings to assess me and my condition, I have not been seen by neurology for over a year. I have seen a Parkinson’s nurse a long time ago who is based in Skegness, there does not appear to be PK Nurse at Lincoln hospital that I know of.”

“**More communication** so that everyone in Lincolnshire suffering from Parkinson’s has the same opportunity to receive the same standard of good care.”

“More consultant input and information from neurology about my condition. **Regular reviews for medication and disease progression**. Involvement of support services ie speech therapy, physio etc.”

“More support. Regular face to face meetings. As my husband’s condition worsens we need more equipment but don’t know where to access? No support for carers either! **A very lonely illness**! Our GP and surgery are just not interested and even when the neurologist writes to say support this patient with medication they totally disregard.”

“Being offered a referral not having to ask. We **didn't know who to turn to**.”

Other neurological conditions

50 (13%) **people shared their experiences of having other neurological conditions.**

- 50 individuals chose to share their views about neurological conditions that were not listed among our provided answer options. The conditions included autism spectrum disorder, restless leg syndrome, trigeminal neuralgia, Chiari malformation and dementia.

- Due to the limited number of responses for each individual condition included in the 'other' section, we have opted to focus on general themes, highlighting what is working well and what could be improved overall.

- Regardless of the condition, many of the same issues were raised in relation to diagnosis, what is working well and what could be improved about care for neurological conditions in Lincolnshire. Many of the issues raised were the same as those that have already been discussed in this report such as not being believed, poor knowledge of conditions amongst healthcare professionals, a reluctance to refer to specialist services and long waiting times to access the latter.

"I have had the condition my entire life. Countless investigations on NHS which produced either no result or wrong diagnosis. NEVER TAKEN SERIOUSLY. The condition had a serious effect on both my business and domestic life. At the age of 78, in **absolute desperation**, I sought private treatment. The NHS had completely failed me. I had never been referred to a specialist consultant neurologist. Upon seeing a private specialist, I had a diagnosis in half an hour. I understand that the particular combination of conditions I have is rare, and the average GP may never even see it, but there is absolutely no excuse for not having referred me to a specialist headache consultant many years ago.
I am fortunate in that I can afford private treatment, but I should not have to."
Respondents who has cluster headaches talking about their journey to getting a diagnosis

Other neurological conditions

“The GP looked up a diagnostic tool online and I completed it in the surgery with him. It showed I had moderate to severe Restless Legs Syndrome. I am **grateful my concerns were taken seriously** as the illness was adversely affecting my quality of life, i was getting very little sleep, was exhausted and struggling to concentrate at work.” ***Respondent with restless leg syndrome share their positive experience of getting a diagnosis***

“I have been suffering for over nine years with very little local or national support. I have only in the last six months had support from neuro outreach, and speech and language service for the brain injury that the leak caused nine years ago. We are **abandoned** with this condition. We are left to manage ourselves as a family.”
Respondent with Cerebrospinal Fluid leak share their long, difficult journey to trying to get support

Two respondents shared their difficulties getting an ADHD assessment and the impact this was having on their lives:
“Unsatisfactory. I have a busy working week and feel tired at the weekends, I spent a lot of time completing their online assessment only to be told they couldn’t see the text! **No offer of help** either.”

“Waiting for ADHD. Having huge issues at work, and have had many **mental health issues** trying to unpick what is wrong. This appears to be the cause and trying to explain to my manager, and her manager, that I can't 'just let things go'. Has been very stressful.”

“Only given pain relief. **No referral to pain clinic or specialists**. No follow up or named professional I can turn to when things are more difficult. No referral to support groups or where to look for help and/or support.”
Respondent with Dementia sharing their experience of accessing medications

Other neurological conditions

"My Lincolnshire based GP did communicate with various specialists in Sheffield and was prepared to refer me to them. Again I have fear that a lot of GPs in Lincolnshire are not prepared to do this. During the course of the treatment for my neurological condition I did at times feel as though various specialist fields did not treat me as an individual, it was also more do as I say not say as I do, I was channelled down avenues of treatment that would have proven to be inappropriate essentially after a long period of time it was discovered that I was experiencing some pretty debilitating side effects from my medication that were not functional in nature. My specialist was hard to reach even my GP found it hard to get hold of him. At times I really felt as though I was being treated with what could be deemed a lack of respect, I appreciate that epilepsy can have comorbidities with learning difficulties and other cognitive problems but it is wrong to treat you in the aforementioned way. Without my academic background and excellent GP I would not have asked the appropriate questions and **I dread to think of what else could have happened** if I didn't have these at my disposal. Again I can imagine that there are many patients with neurological conditions in Lincolnshire that have the problems that I faced or even worse than me and having to live with the consequences of a wrong diagnosis and treatment."
Respondent with an undisclosed condition share their experience of receiving out of county care

"Lack of follow up for my condition, I have **not seen my consultant for two years.**"
Respondent with myasthenia gravis share their experience of poor follow up care

"My GP tries to support me when I ask for assistance but they say that my condition is 'above my paygrade' so they can't do much. They tried referring me to other services but I keep being rejected as they all deem me to complex for them and they all appear to work in 'silos' **no one wants to take overall care** of me unfortunately. The one team that have done some recently are the neuro outreach team, at least they gave offered some support and advice, which has helped. But it might have been better to have seen them nine years ago, when I first experienced my brain injury."
Respondent with Cerebrospinal Fluid leak share their experience of accessing care

Other neurological conditions

“The consultants are amazing but can't help with day to day problems. Knowledge the GP have of conditions they don't even know what is it, least whether symptoms I am having are normal or not. Just want to talk to someone who can ease your worries without to wait for email replies or long appointment waits.” -
Respondent with CFS and Chiari malformation

“I would like to see every surgery have a dedicated, specially trained ADHD/autism (as there are often overlaps) team rather than having to farm it out to private companies. I don't know what the waiting times are like for children's referrals, but obviously the sooner they can be diagnosed and helped the better, rather than suffer the low self-esteem and self doubt that blighted my own childhood.
I know times were different then; many of us are now **grieving for those lost years** ("You've got a high IQ but if only you could concentrate!", "Dolly Daydream", "Could do better"...) but now we know better we need to ensure it doesn't still happen to the current generation.”
Respondent sharing what could be improved in ADHD care in Lincolnshire

“Better **communication between service providers**. Shorter wait times for consultations.”
Respondent waiting for a diagnosis shares how they felt the process could be improved

“Better established links between neurological centres in Sheffield, Nottingham, Leeds and perhaps Cambridge and Leicester in Lincolnshire based hospitals and GP practices. Effectively **better communication**.”
Respondent who previously had a neurological condtion shares how their experience could have been improved

“I would like **a more holistic service**, one that encompasses rare condition and pain management, regardless of how completely the condition is. They only appear to deal with 'simple/common' conditions.”

Other neurological conditions

"**Greater knowledge** and the ability to hear how it impacts on the individual as different things affect neurological conditions in variable ways for people."
Respondent with neuromyelitis optica spectrum disorder and myasthenia gravis shares how their care could be improved

"Joined up care that looks at the **whole person** their illnesses treatments and social needs."
Respondent with restless leg syndrome shares how their care could be improved

"I would like to see the pain team change and how my conditions are dealt with. To be told there is nothing they can do for me is **ridiculous** whereas I see a private specialist and they said it might not even be fibromyalgia pain."
Respondent with trigeminal neuralgia and fibromyalgia share how their experiences could be improved

A health care professional working in the community sector to support those with neurological conditions:
The challenges services face: "Reach and engagement, communication from statutory services, lack of interest from primary care, lack of shared data and information. **Statutory services lack specialist neurology knowledge** and lack of specialist neurologists and neurology services"

What could be improved? "Better coordination, more support, increased funding, **better engagement and communication**."

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What works well?

Overall, when asked what works well about how health and social care services are supporting them for their neurological conditions, few respondents sadly highlighted any positives. The main positive was:

Specialist care, including MS nurses and CFS service

What could be improved?

Some improvements and suggestions have been explored throughout the report. The most frequently suggested improvements are outlined below:

Listening to service users and taking them seriously

Improve knowledge of these conditions amongst healthcare professionals

Establish local specialist centres/clinics /hubs

Provision of more information around causes of conditions, prognosis and management. This included holistic support to complement medication

Establish local support groups

What could be improved?

Reduce waiting times for specialist support and provide support to help people to "wait well"

Offer holisitic support, recongising individuals are affected in different ways

Improve pain management and access to pain clinics

Ensure joined-up care with coordinated services

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Final Thoughts

We would again like to thank all those who took the time to share their views. Common themes persisted throughout this report, spanning conditions such as fibromyalgia, MS, ME/CFS and epilepsy.

Key headlines were:

Diagnosis

- Symptoms being ignored and/or normalised
- A lack of knowledge of neurological conditions among professionals
- Long waiting times to be diagnosed which had an negative impact on an individual’s health and ability to work
- As a result of these factors, some sought a private diagnosis

Waiting Times

- Regardless of the condition or what they were waiting for, respondents shared they had often been waiting for months, with little communication or support offered in the meantime

Treatment and Management

- Challenges getting medications that worked included side effects of medications, finding medications and dosages that helped manage symptoms, shortages and needing a specialist’s input to change dosages
- It was apparent that signposting to support and referrals to other services appeared to be inconsistent. Also, service users appeared to be unaware of what support is available and what could be beneficial

What works well?

- Those who accessed specialist care, including MS nurses and consultants, praised its quality, this was not the case for everyone
- Repeat prescriptions

Final Thoughts

What could be improved?

- Listen to patients and show understanding
- Increase healthcare professionals' knowledge of neurological conditions
- Provide clear information for patients on diagnosis, prognosis, and management, ensure this is consistently done
- Establish local specialist neurological centres, hubs, or clinics
- Improve access to pain clinics and better pain management strategies

The findings from this survey reiterate many of the issues highlighted in both our 2022 survey and the 2018 HNA, including:

- Delays in diagnosis
- A lack of understanding of neurological conditions among healthcare professionals
- A lack of local services
- A lack of information about services available to support those living with neurological conditions.

Workshop

To share the survey results, we held a workshop with health and care professionals and service users to foster a collaborative and co-production approach to enhancing neurological health in our community. Attendees were invited to comment on our findings, as well as to share their insights and initiatives. The first part of the workshop was a presentation of our findings, which is available to watch on our YouTube channel HWLincs:

Click the picture to watch our presentation

Neurological Health Research Workshop

In this presentation, we share the findings of the Healthwatch Lincolnshire research project on neurological health as part of a workshop designed to improve the experiences of those accessing care for conditions such as:

- Brain injury
- Chronic pain
- Epilepsy
- Fibromyalgia
- Migraines
- Multiple sclerosis
- Myalgic encephalomyelitis or chronic fatigue syndrome
- And many more neurological conditions

Neurological Health Survey Findings Webinar

Workshop attendees included service users and an individual from a national neurological charity.

Below is an anonymised summary of what was discussed in the second part of the workshop.

A service user shared they had been diagnosed with fibromyalgia and FND. They explained that when they visit their GP surgery many of the professionals they see have never heard of FND and look at them “gone out”. They discussed how they feel their symptoms are not connected, with their symptoms and conditions being seen as mutually exclusive. They are not looked at holistically.

When asked what would improve their care, they highlighted a need for more training for professionals on neurological conditions including their symptoms and management . It took them over 20 years to get a diagnosis despite being told they had probably had it all their life. Their diagnosis came later in life and still their conditions are not really being recognised.

Workshop

Attendees also discussed the impact neurological conditions can have on mental health and how the mental health needs of those with neurological conditions are often poorly considered and addressed. **An issue highlighted in detail in the "Together for the 1 in 6: UK Findings from My Neuro Survey" report from the Neurological Alliance.**

The report presents the findings from the "My Neuro Survey" where over 8,500 individuals across the UK living with neurological conditions shared their experiences of accessing care, treatment and support. Some key headlines from the report include:

- Delays in treatment and care - more than half of the respondents experienced delays in accessing routine neurologist appoints, leading to deteriorations in health.
- Mental wellbeing and support - 67% reported that their mental wellbeing needs were only met to a small extent or not at all, highlighting a critical hap in mental health services for this group.
- Information at diagnosis - nearly 40% were not provided with any informational resources, leaving many without essential guidance.

Many of these findings were echoed through the data we collected. Click here to read the full report: **"Together for the 1 in 6: UK Findings from My Neuro Survey" report from the Neurological Alliance.**

Recommendations

Key improvements that can be implemented in the short-term across all services for the benefit of residents.

1. Improve listening and acknowledgement

- **Evidence from the report:**
    - **Diagnosis issues:** Many respondents felt that their symptoms were dismissed or not taken seriously by healthcare professionals (p.21, 23, 40 & 41).

- **Potential solutions:**
    - Support professionals to better understand neurological conditions incorporating symptoms and management.
    - Create and share case studies with healthcare professionals who face these scenarios to promote best practice.

2. Increase awareness and knowledge of neurological conditions

- **Evidence from the report**:
    - **Lack of knowledge among healthcare professionals:** The report highlights a lack of knowledge and awareness among healthcare professionals regarding neurological conditions particularly conditions such as fibromyalgia, ME/CFS and FND. Respondents shared instances where professionals had thought the conditions did not exist and underestimated the effect the conditions can have on daily life (p. 31, 69, 83 & 93).

- **Potential solutions:**
    - Launch an awareness campaign targeting healthcare professionals to bridge the knowledge gap regarding neurological conditions.
    - Create an information resource for dissemination across health, care and community service providers.

3. Improve the support available to patients while they wait for tests or treatment, and ensure they are informed about these resources.

- **Evidence from the report:**
    - **Impact on patient wellbeing:** The report mentions that long waits often left patients without support or information on how to manage their conditions (p. 24, 35, 42, 45, 57, 63, 70 & 75)

Recommendations

- **Potential solutions:**
    - Review how patients are supported while waiting for tests or treatment to ensure they have sufficient resources to 'wait well.'
    - Ask those with lived or living experience to review resources available to patients while waiting and how they are communicated with during this time.
    - If needed, collaborate with people who have lived or current experience to co-produce materials that will better support patients during their wait for tests and treatment.

Considerations

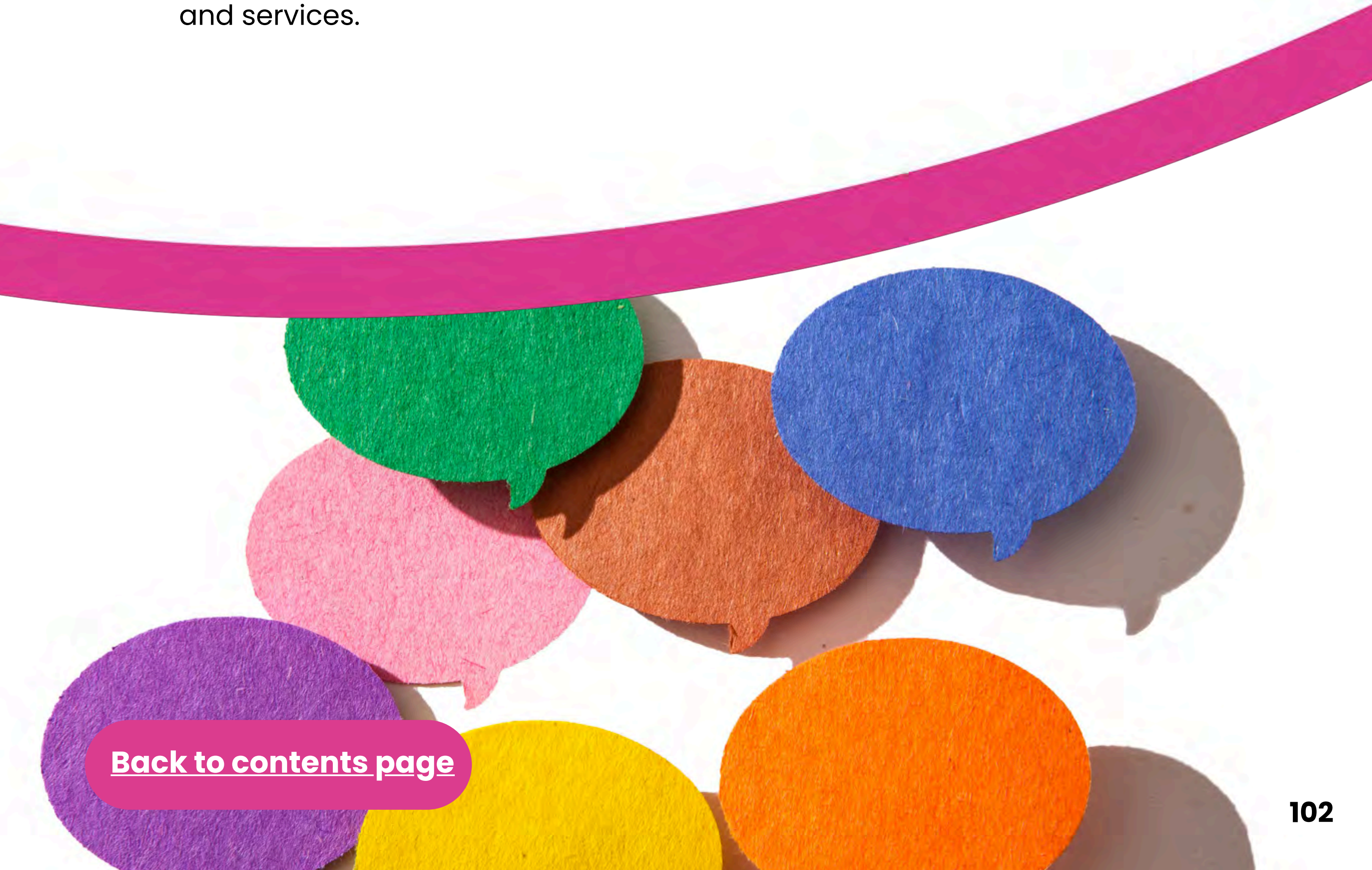
These are to inform future planning, development and improvement of services for long-term benefits to be realised for residents.

1. Review and develop training

- Establish comprehensive educational campaigns targeting the public, particularly in seldom-heard communities, using social media, print, and digital resources to raise awareness on these health conditions.
- Offer training for healthcare professionals directly or indirectly involved with people who may access services for neurological conditions.
- Develop a toolkit with ongoing resources for professionals and the public, incorporating digital tools, webinars, and community workshops to ensure sustainable long-term impact.

2. Develop a consistent approach to providing accessible information and services

- Create a one-stop shop where individuals can access information and support for neurological conditions. This information should be holistic. The information could be presented in the form of a signposting directory created by those with lived or living experience to cover information such as condition management, mental health support and alternative therapies. The directory could be on a webpage with copies in alternative formats to meet different needs. Professionals could direct individuals to this information. Launch an awareness campaign targeting the public regarding neurological conditions information and services.



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Demographics

Demographic	Percentage (number)
Age Under 18 18 – 24 25 – 49 50 – 64 65 – 79 80+ Prefer not to say	 1% (2) 1% (4) 28% (92) 50% (163) 16% (52) 2% (6) 1% (4)
Gender Male Female Non-binary Prefer not to say	 13% (41) 86% (278) 1% (2) 1% (2)
Have you gone through any part of a process, or do you intend to bring your physical sex appearance, and/or your gender role, more in line with your gender identity? Yes No Prefer not to say	 1% (3) 97% (305) 2% (5)
Ethnicity Asian / Asian British: Bangladeshi Mixed / Multiple ethnic groups: Asian and White White: British/English/Northern Irish /Scottish/Welsh White: Any other White background Not known	 0.33% (1) 0.33% (1) 93% (286) 6% (18) 0.33% (1)
Area of Lincolnshire Boston City of Lincoln East Lindsey North Kesteven South Holland South Kesteven West Lindsey Other	 8% (26) 12% (37) 19% (61) 15% (46) 8% (26) 15% (54) 17% (53) 4% (13)

Demographics

Demographic	Percentage (number)
I have MORE THAN enough money for basic necessities and A LOT spare that I can save or spend on extras or leisure. I have MORE THAN enough money for basic necessities and A LITTLE spare that I can save or spend on extras or leisure. I have JUST ENOUGH money for basic necessities and little else. I DON'T HAVE ENOUGH money for basic necessities and sometimes or often run out of money. Prefer not to say	4% (13) 31% (98) 31% (98) 15% (49) 19% (16)
I am a veteran	3% (11)
I work in farming/agriculture	1% (2)
I work in health and/or social care	13% (50)
I am a new parent	1% (2)
I am a carer	12% (43)
I belong to the LGBTQ+ community	7% (27)
I have a long-term health condition	79% (294)
I consider myself to be neurodiverse	13% (49)
I have a disability	48% (178)

Appendix - Additional Data

Table 1: Fibromyalgia

Respondents were asked to think about the care they receive for their condition and rate them in a range of areas. Overall, the majority rated the following as:

Overall	Very good	Good	Poor	Very poor	N/A or Prefer not to say	Overall
Being able to access care for your condition when you need to	4% (5)	19% (25)	30% (40)	45% (59)	2% (3)	**POOR 75% (99)**
Listening to you	7% (9)	18% (24)	31% (41)	41% (54)	2% (3)	**POOR 72% (95)**
Explaining tests and treatment	5% (7)	28% (37)	28% (36)	33% (43)	5% (7)	**POOR 61% (79)**
Involving you in decisions about your care	9% (12)	25% (33)	25% (33)	34% (45)	7% (9)	**POOR 59% (78)**
Offering you different forms of treatment not just medication	2% (3)	14% (18)	28% (37)	50% (66)	6% (8)	**POOR 78% (103)**
Treating you with care and concern	10% (13)	24% (32)	25% (33)	37% (49)	4% (5)	**POOR 62% (82)**
Addressing your needs or making plans to do so	5% (7)	18% (24)	30% (39)	41% (54)	5% (17)	**POOR 71% (93)**

Table 1: Fibromyalgia (continued)

Overall	Very good	Good	Poor	Very poor	N/A or Prefer not to say	Overall
Communicating with you clearly about your care	5% (7)	22% (29)	28% (37)	40% (52)	5% (6)	**POOR 68% (89)**
Providing you with information about your condition, treatment and care	5% (6)	14% (19)	30% (40)	47% (67)	4% (5)	**POOR 77% (107)**
Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)	2% (3)	11% (15)	31% (41)	46% (61)	9% (12)	**POOR 77% (102)**

Table 2: ME/CFS

Respondents were asked to think about the care they receive for their condition and rate them in a range of areas. Overall, the majority rated the following as:

Overall	Very good	Good	Poor	Very poor	N/A or Prefer not to say	Overall
Being able to access care for your condition when you need to	2% (1)	7% (3)	18% (8)	60% (30)	5% (2)	**POOR 78% (38)**
Listening to you	5% (2)	20% (9)	32% (14)	43% (19)	0% (0)	**POOR 75% (33)**
Explaining tests and treatment	2% (1)	20% (9)	27% (12)	34% (15)	16% (7)	**POOR 61% (27)**
Involving you in decisions about your care	5% (2)	25% (11)	16% (7)	39% (17)	16% (7)	**POOR 55% (24)**
Offering you different forms of treatment not just medication	5% (2)	11% (5)	11% (5)	59% (26)	14% (6)	**POOR 70% (31)**
Treating you with care and concern	7% (3)	23% (10)	30% (13)	36% (16)	5% (2)	**POOR 66% (29)**
Addressing your needs or making plans to do so	2% (1)	11% (5)	27% (12)	50% (22)	9% (4)	**POOR 77% (34)**

Table 2: ME/CFS (continued)

Overall	Very good	Good	Poor	Very poor	N/A or Prefer not to say	Overall
Communicating with you clearly about your care	2% (1)	16% (7)	30% (13)	42% (18)	9% (4)	**POOR 72% (31)**
Providing you with information about your condition, treatment and care	2% (1)	16% (7)	18% (8)	57% (25)	7% (3)	**POOR 75% (33)**
Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)	2% (1)	5% (2)	20% (9)	52% (23)	20% (9)	**POOR 72% (32)**

Table 3: MS

Respondents were asked to think about the care they receive for their condition and rate them in a range of areas. Overall, the majority rated the following as:

Overall	Very good	Good	Poor	Very poor	N/A or Prefer not to say	Overall
Being able to access care for your condition when you need to	2% (1)	37% (15)	37% (15)	17% (7)	7% (3)	**POOR 54% (22)**
Listening to you	12% (5)	44% (18)	29% (12)	15% (6)	0% (0)	**GOOD 56% (23)**
Explaining tests and treatment	7% (3)	51% (21)	27% (11)	10% (4)	5% (2)	**GOOD 58% (24)**
Involving you in decisions about your care	13% (5)	48% (19)	28% (11)	10% (4)	3% (1)	**GOOD 61% (24)**
Offering you different forms of treatment not just medication	2% (1)	15% (6)	46% (19)	27% (11)	10% (4)	**POOR 73% (30)**
Treating you with care and concern	7% (3)	23% (10)	30% (13)	36% (16)	5% (2)	**POOR 66% (29)**
Addressing your needs or making plans to do so	5% (2)	44% (18)	29% (12)	17% (7)	5% (2)	**GOOD 49% (20)**

Table 3: MS (continued)

Overall	Very good	Good	Poor	Very poor	N/A or Prefer not to say	Overall
Communicating with you clearly about your care	10% (4)	39% (16)	27% (11)	20% (8)	5% (2)	**GOOD 49% (20)**
Providing you with information about your condition, treatment and care	2% (1)	41% (17)	34% (14)	17% (7)	5% (2)	**POOR 51% (21)**
Communication between professionals within the service and external services (e.g. therapist, dietitian, hospital services, pharmacies etc.)	5% (2)	27% (11)	39% (16)	17% (7)	12% (5)	**POOR 56% (23)**

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healthwatch
Lincolnshire

Contact Us

Healthwatch Lincolnshire
Rooms 33-35, The Len Medlock Centre
St Georges Road
Boston
Lincs
PE21 8YB

www.healthwatchlincolnshire.co.uk
t: 01205 820892
e: info@healthwatchlincolnshire.co.uk
@HealthwatchLinc
Facebook.com/healthwatchlincolnshire

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