

Chronic Pain Experiences 2022



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Appendices of each individual anonymous response to the survey are available on request - contact details for Healthwatch Derby are at the end of the report.

Background of the report

Chronic or persistent pain is pain that lasts longer than 12 weeks, and affects a patient constantly or intermittently despite receiving treatment or medication. Some Chronic pain can be caused by inflammation or damage to tissues or nerves in the body or underlying medical conditions, however some pain can be a condition in it's own right.

The Health Survey for England (NHS Digital – 2017) discovered that **34% of the UK population are affected by chronic pain** - 28 million people - and accounts for up to **5 million GP appointments per year**. This has far reaching affects on quality of life of these patients, with limited ability to carry out regular daily activity leading to an increase in mental health issues and job losses. The situation affects more women (37%) than men (31%) and the numbers increase with age. (Appendix 6). Each year in the UK **97,200 Google searches are made for the term 'Chronic Pain'** and a further **8,640 made for 'Chronic Pain Management'** (Wordstream Google Keywords Tool - 2022). (Appendix 7)

With the prevalence of those experiencing Chronic Pain being so high in numbers and the large amount of internet searches of those who are looking for help around Chronic Pain, Healthwatch Derby have designed this survey to discover what is happening in 2022 to support these patients, how they are coping with their pain on a daily basis, and whether improvements can be made.

Our survey was open between 5th April and 12th July and we received a total of 309 responses.

We anticipate that this research will be useful to those in pain – to be listened to, understood and heard, and to make a journey through pain slightly more bearable for someone else in future by telling their story. This research will be useful to organisations and peer support groups working with people with pain, to know that they are catering for what people with lived experience have told us works well for them. This research will be useful to medical and clinical professionals – to raise awareness of the broad spectrums of chronic pain and presenting symptoms, to consider implications of a chronic illness diagnosis on a patient's mental health, overall well-being and lifestyle options, and to have quality, whole-person centred conversations at the first point of contact to enable a swift and meaningful diagnosis or progress plan for that patient.



Summary of findings

Over the course of 13 weeks, and with prior and subsequent promotion by ourselves and supportive external individuals and groups, our survey was answered by a total of 309 respondents.

Conditions

Our respondents are living with many different conditions, with 2.5x more responses than respondents – which signals that many of our respondents are suffering from more than one illness concurrently.

Aside from 'No diagnosis', there were a total of 122 different illnesses or conditions listed. Living with and experiencing ongoing or Chronic Pain extends beyond what is categorized or defined as a pain condition.

Pre-Diagnosis

- 87.5% of respondents surveyed have been living with pain for over 3 years with 21% having been living with pain for over 20 years.
- The majority of respondents initially sought support from their GP practice.
- 48% of all respondents experienced a trauma or life changing event which they feel has contributed to or caused their subsequent condition. Of these respondents, the highest noted trauma was bereavement.

Diagnosis

- The most commonly stated time period for diagnosis was between 0-2 years.
- 14% of respondents don't have - or are still waiting for - an official diagnosis.
- The most commonly stated diagnostic tests used were blood tests, MRI scans and X-Rays.
- The sentiments of the majority leaving additional information were mostly negative, with the most common theme being that when seeking advice and attending with symptoms, they felt repeatedly dismissed or unheard and they attributed their delay in diagnosis to this.

Support from Healthcare providers

- 32% of respondents were given medication to support them with their condition.
- 11% of respondents felt that their medication helped.
- 53% of all respondents do not currently feel – to some extent – supported by the healthcare professionals involved in their care.
- 5.7% mentioned support from healthcare professionals when stating what they felt helped them live well.

Quality of Life - current impact

- 27% of respondents directly noted a poor quality of life physically or mentally when asked in Q12 to tell their story in their own words.
- 79% of respondents stated that they struggle with various aspects of their daily life.
- 34% of respondents stated that they cannot work at all.
- 7% of all respondents stated in Q10 that they are not living well with pain.
- The mental health aspect of living with a physical health problem was mentioned as one of the greatest struggles, however mental health support was offered to less than 5% of patients during their route to - or eventual - diagnosis.

Quality of Life - Improvements

- 10% of respondents feel that the greatest improvement that could be made to help them to live better with pain is to be heard and understood by their GP.
- 6% of respondents feel that an increased general level of understanding of pain conditions within the public and professional arenas would help them to live better.

Our Audience

In addition to promoting this project through our online platforms and volunteer newsletter, we visited and made connections with various support groups and charities to access their in-person and online audiences, and offer these people a way to feed back their experiences with pain. It was also broadcast amongst various meetings and events we attended within the scope of our usual job roles that included representatives from NHS, council, business and 3rd sector professionals.

We don't hold demographic data for people that we have spoken to about the project as this was not asked at the time, however respondents of the online survey and (paper copy thereof) were all given the option to leave demographic data.

The following groups and organisations helped us to encourage responses for our project by inviting us to attend their groups or be a guest speaker at their event:

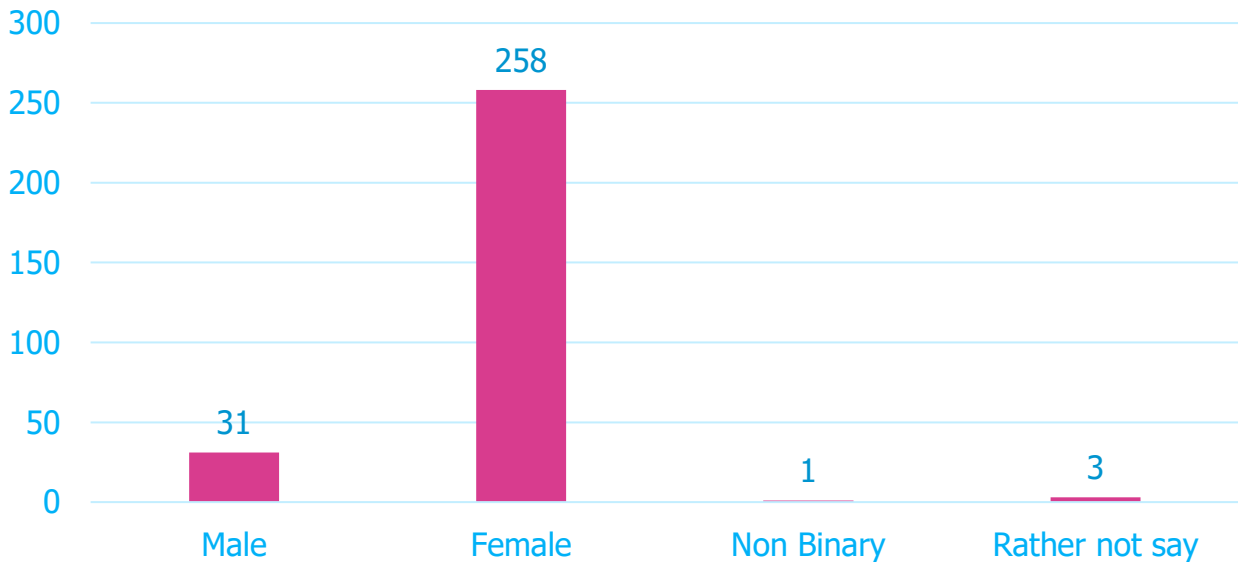
- Better with Friends Pain Support group, Alvaston Derby
- Lister House PCN – Let's Live Well With Pain
- Lilian Prime MS Centre, Derby
- Opioids Safety Improvement Programme (NHS E&I)
- HOLD Pain Management Workshop (EMAHSN & JUCD)

The following groups, practitioners and organisations helped us to encourage responses for our project by promoting it to their online audience or newsletter:

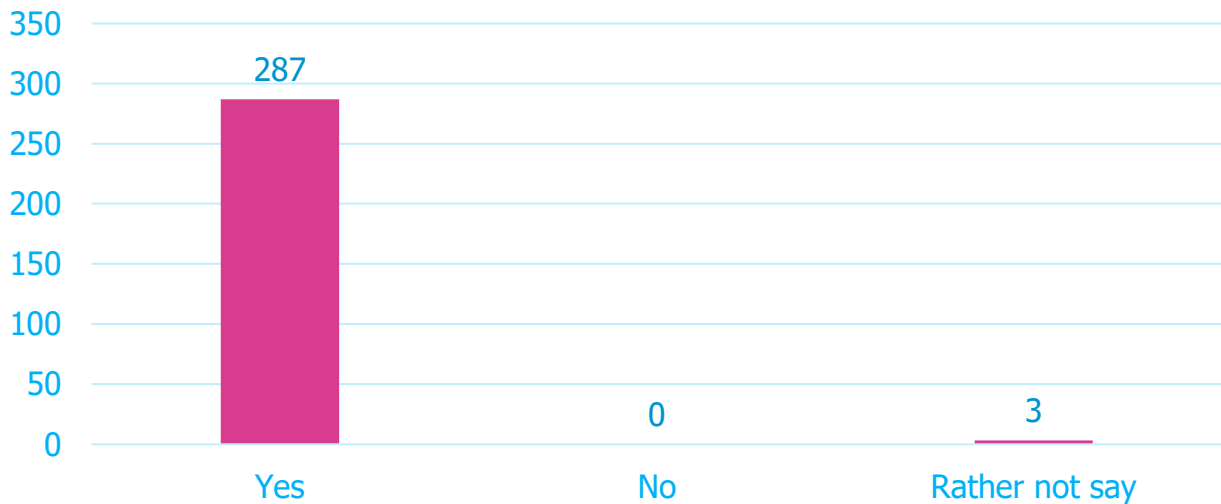
- Arthritis Action
- Erewash Voluntary Action & Derbyshire Voluntary Action
- East Midlands Academic Health and Science Network & Public Face newsletter
- Derby and Derbyshire CCG - Weekly newsletter
- Derby Fibromyalgia Group
- Healthwatch Derbyshire & Healthwatch Staffordshire
- Victim Focus – Anti Victim Blaming Trauma Informed Network
- James Bacon – Pain and Rehabilitation Coach
- Frances Brown, Nightingale Design Research
- Margaret Curtis, Healthwatch England
- Warwick University Sleep and Pain Lab
- Lupus UK
- Anna Finn – Hypnotherapist
- Livewell Derby
- Kuku Connect & Catena business networking groups, Derbyshire and Nottinghamshire

Who we spoke to – Gender Identity

Which of the following describes how you identify yourself?



Does your gender identity match the sex you were registered with at birth?

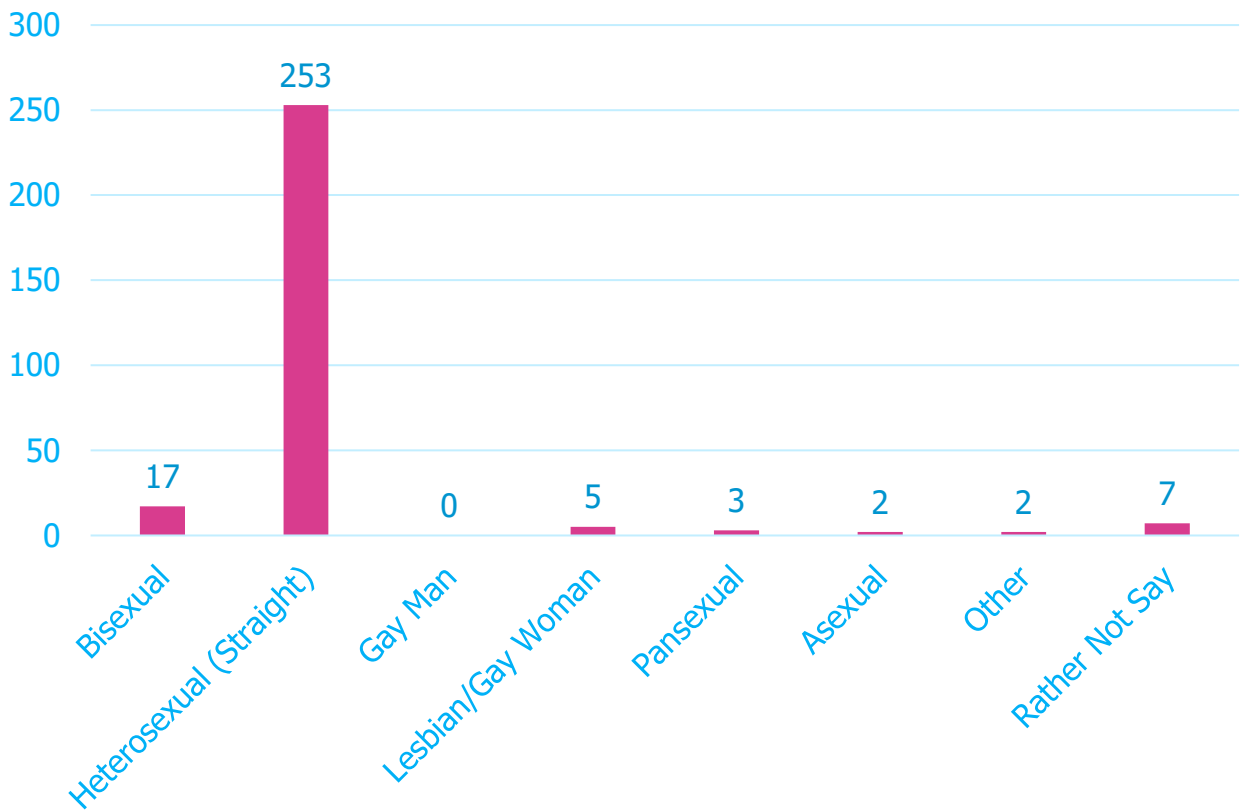


88% of respondents identified as Female.

99% of respondents stated that their gender identity matches the sex they were registered with at birth.

Who we spoke to – Sexual Orientation

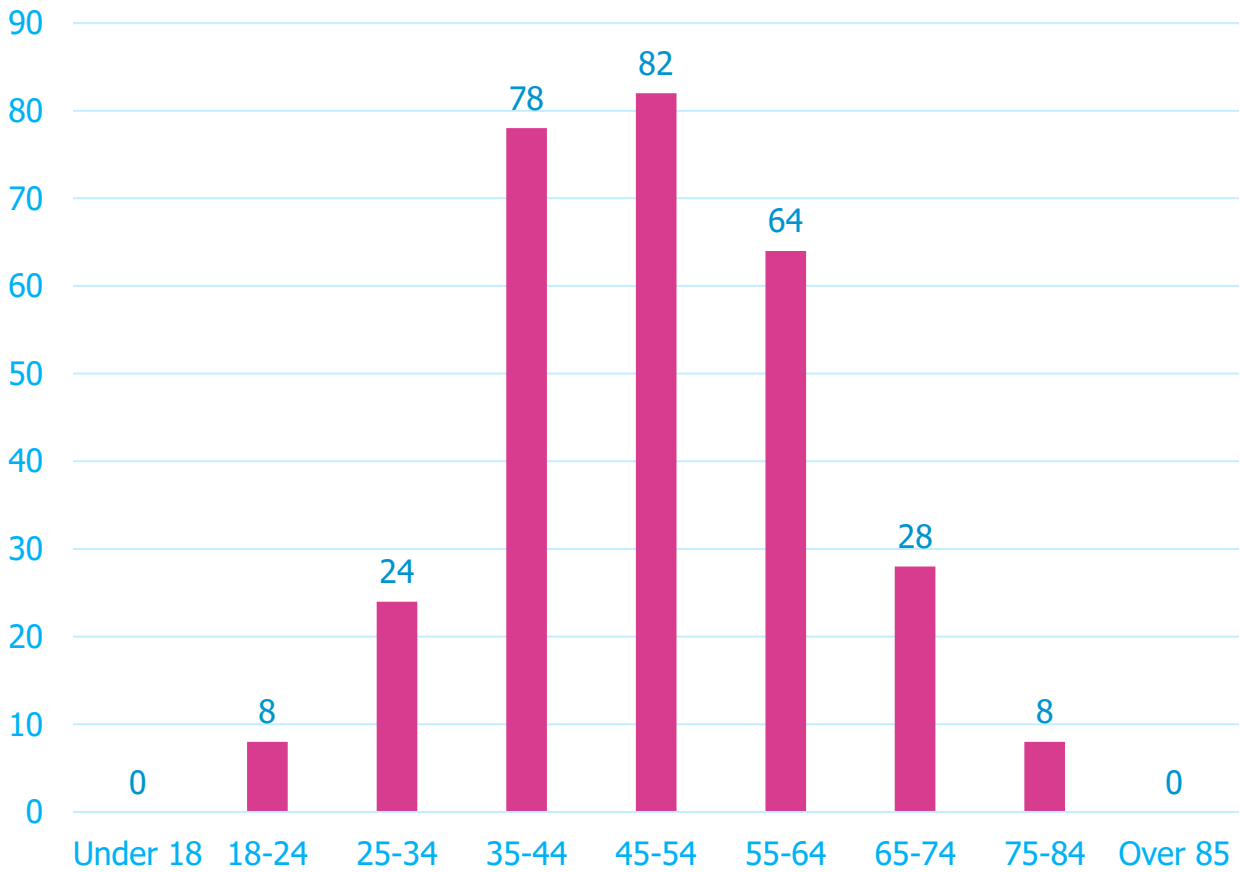
Which of the following describes how you identify yourself?



88% of respondents identify as Heterosexual.

Who we spoke to – Age

What is your age range?

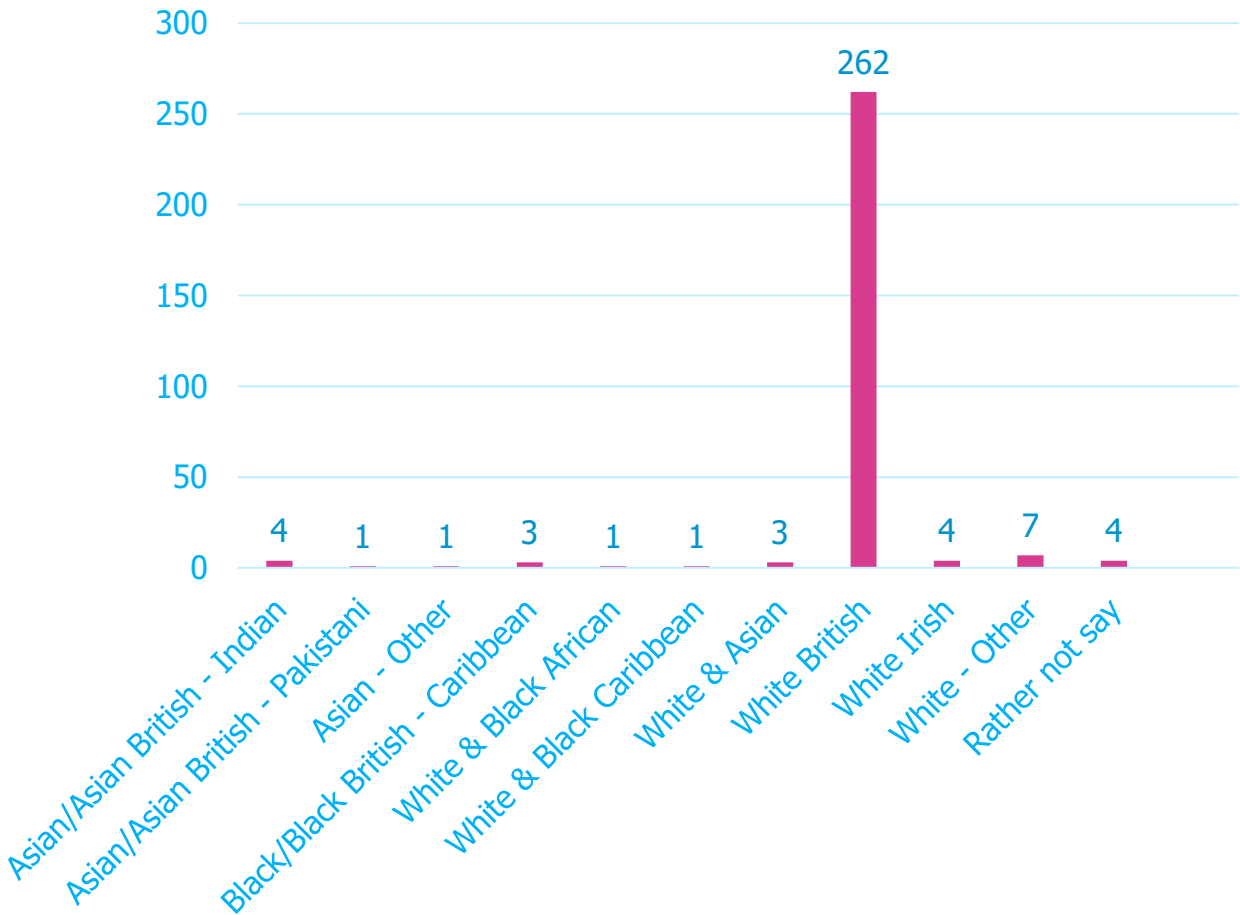


We had a wide mixture of ages take part in the survey with the majority aged between 45-54 (28%), 35-44 (27%) and 55-64 (22%).

All other outlying groups amounted to 23% in total.

Who we spoke to – Ethnicity

What is your ethnic origin?

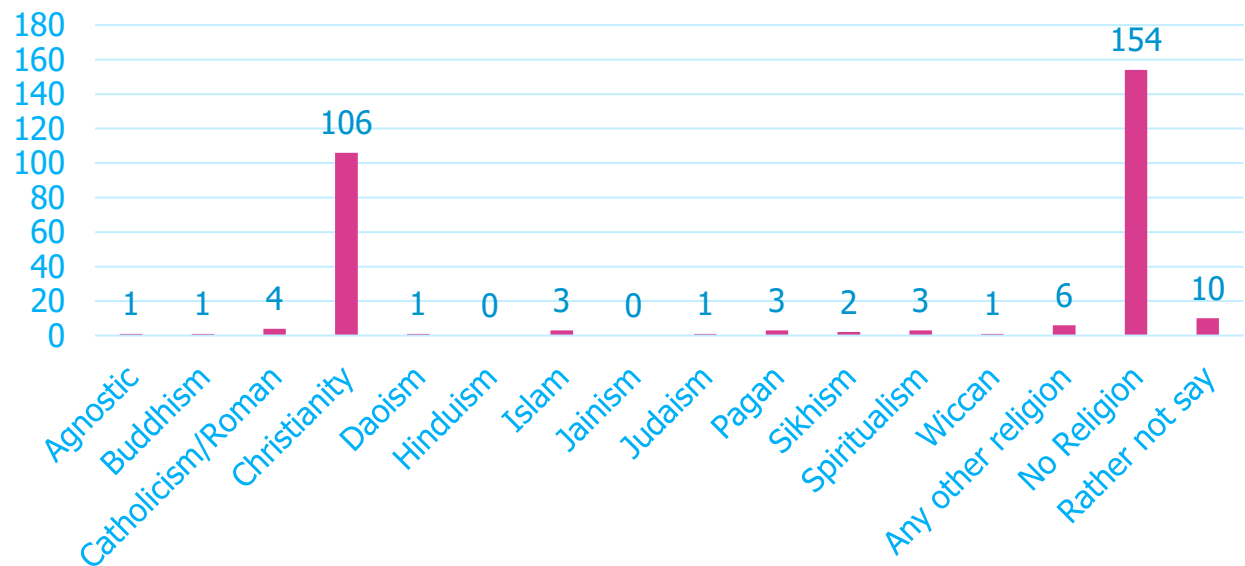


90% of respondents stated that their ethnic origin was White British / English / Welsh / Scottish / Northern Irish. Other responses are listed as above. All other ethnicities received zero responses and as such are not listed above.

1 respondent who stated Asian Other gave further detail as “Central Asian”.
1 respondent who stated White Other gave further detail as “British Italian”.

Who we spoke to – Religion

What is your Religion or Belief?

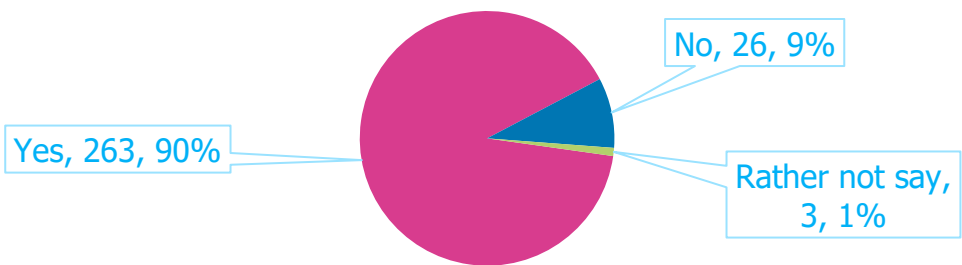


52% of respondents stated they had no religion, 36% of respondents stated their religion was Christianity. Other individual responses for religion and belief are listed as above.

1 respondent who stated No Religion gave further detail as "a new age mishmash".
1 respondent who stated No Religion gave further detail as "Nature is god".

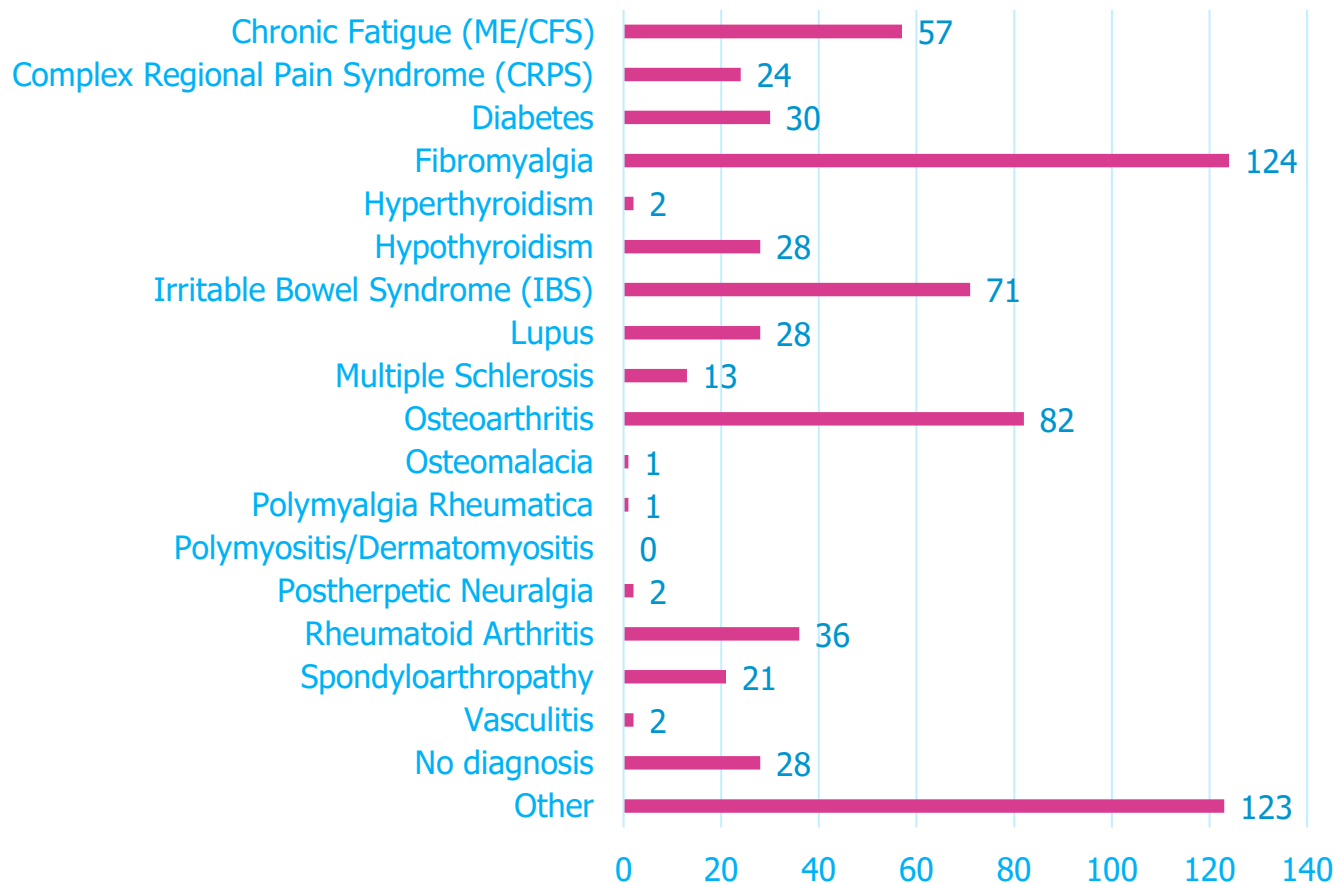
Who we spoke to – Long term health conditions

Do you consider yourself to have a disability or long term health condition?



Given the nature of the project and theme of the survey, it was unsurprising that 90% of respondents considered themselves to have a disability or long term health condition.

Question 1 – Which of the following Chronic Pain conditions do you consider yourself to have had for at least 12 weeks, constantly or intermittently?



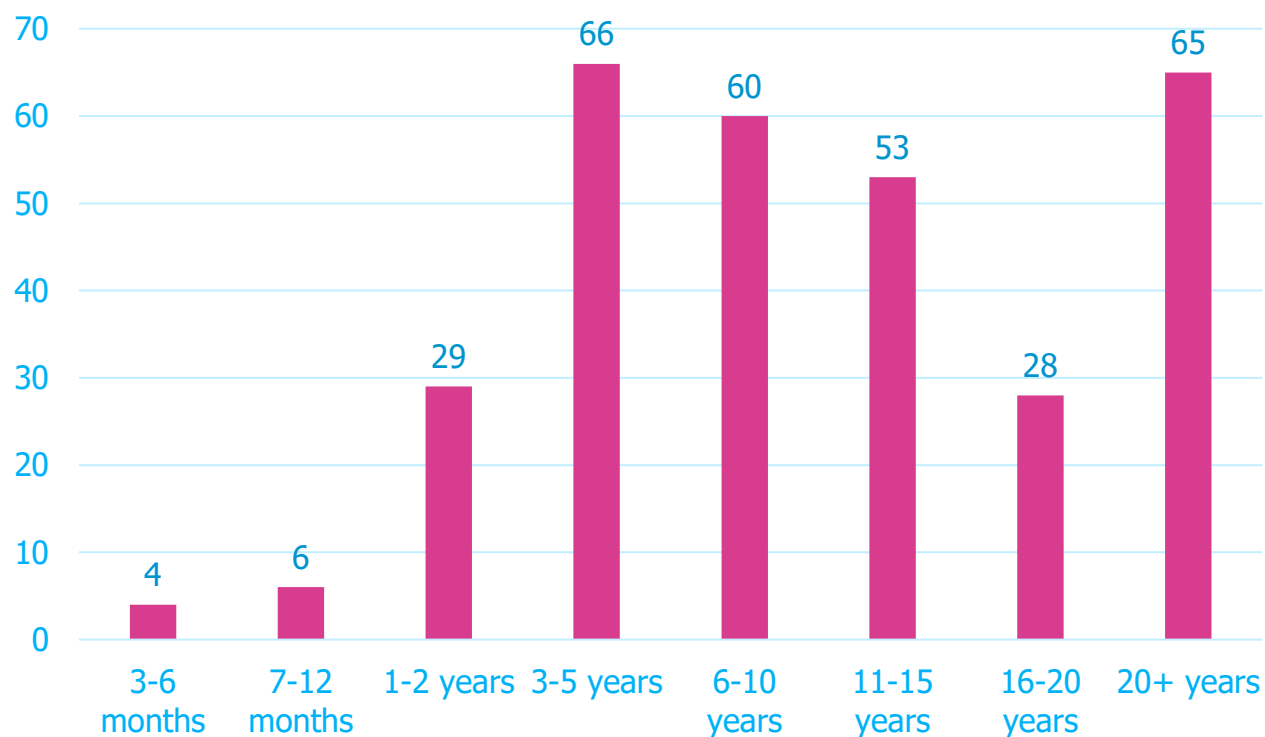
There were 739 responses given to this question by 294 respondents. 550 responses have been listed above, and an additional 123 respondents selected ‘Other’ – there were 188 responses of Other Illnesses, and many respondents stated that they had more than one illness, including those named above and others.

17% of all responses have Fibromyalgia. 11% of all responses have Osteoarthritis. 9% of all responses have IBS. 8% of all responses have Chronic Fatigue Syndrome (ME/CFS). All other illnesses listed were individual or selected by respondents at a rate of less than 5%.

The highest listed illnesses in “Other” were Chronic Back Pain (1.4%), Functional Neurological Disorder (1.2%), Psoriatic Arthritis (1%) and Chronic Migraines (0.8%). All other illnesses were individual or selected by respondents at a level of less than 0.7%.

A full list of illnesses listed is recorded at the end of this report as an appendix. (Appendix 1)

Question 2 – For how long have you been living with Chronic Pain?

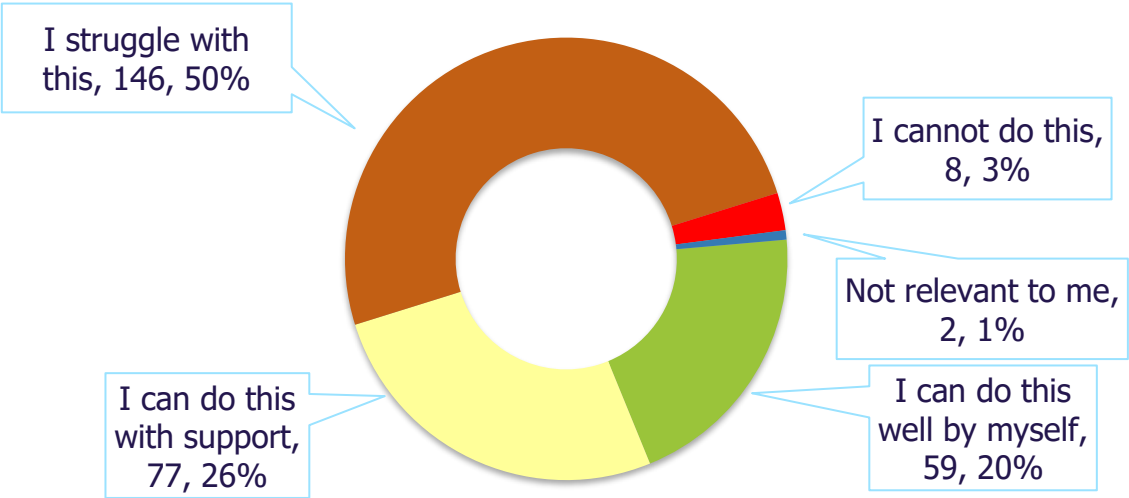


There were 311 responses and 87% of all respondents had been living with Chronic Pain for over 3 years. This demonstrated that the people speaking to us as part of this project have been in pain for a long time.

The largest grouped majorities of respondents had stated that they had been living with Chronic Pain for 3-5 years (21%), or 20+ years (21%).

Question 3 – How does your Chronic Pain directly affect your ability to live well?

Ability to look after my mental health and physical wellbeing



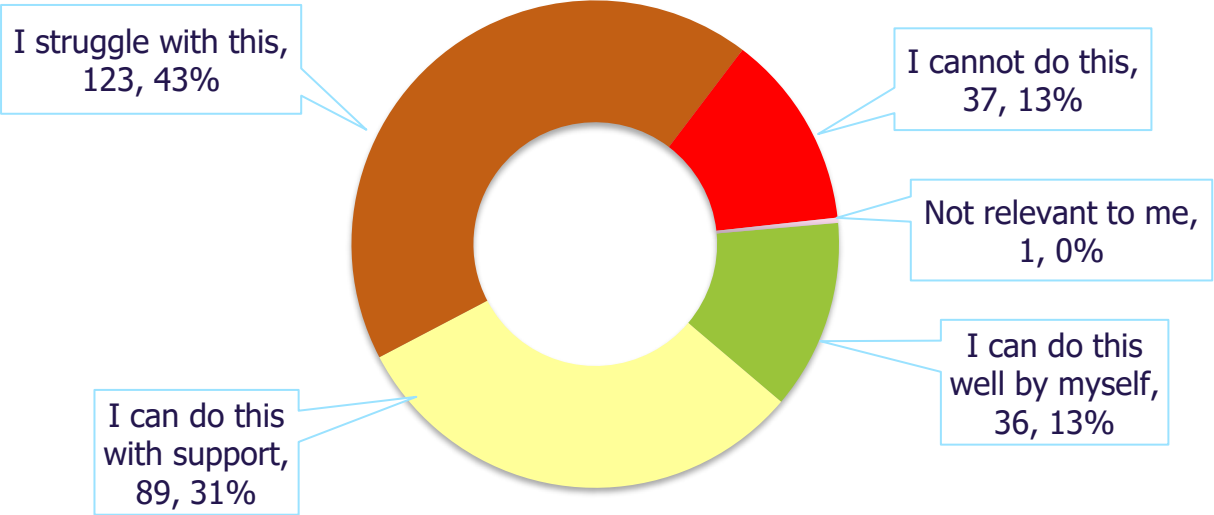
79% of 292 responses to this question stated that to some extent, their ability to look after their mental health and physical wellbeing is affected due to their ongoing pain.

50% of respondents struggle with this and a further 26% stated they needed support from someone else to be able to manage this.

3% of respondents – 8 people – are entirely unable to do this.

Question 3 – How does your Chronic Pain directly affect your ability to live well?

Ability to look after my home/household



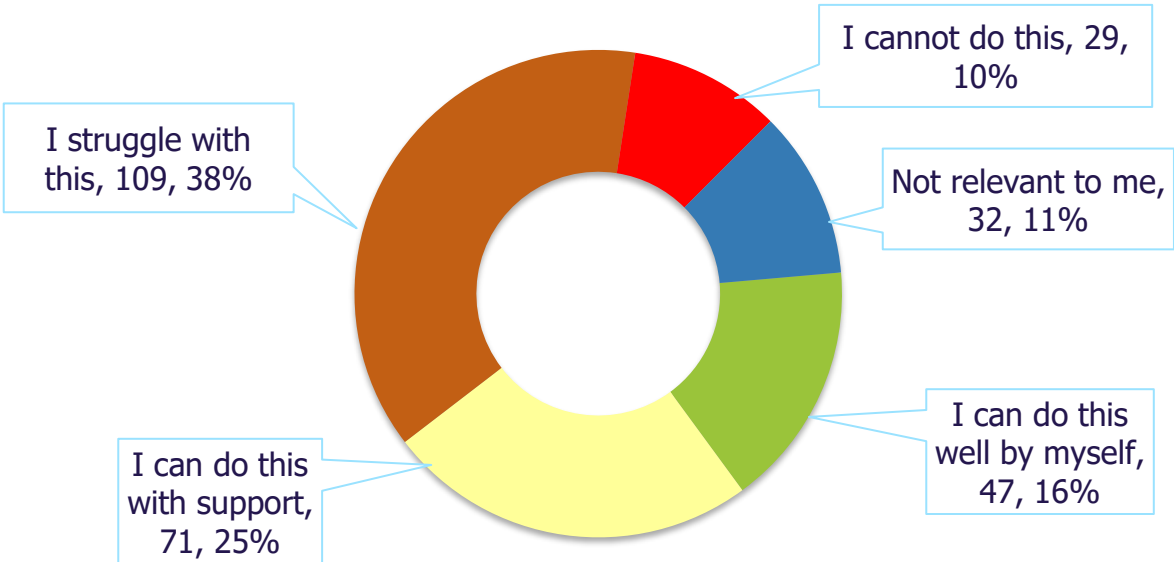
87% of 286 responses to this question stated that to some extent, their ability to look after their home or household is affected due to their ongoing pain.

43% of respondents struggle with this and a further 31% stated they needed support from someone else to be able to manage this.

13% of respondents – 37 people – are entirely unable to do this.

Question 3 – How does your Chronic Pain directly affect your ability to live well?

Ability to care for others



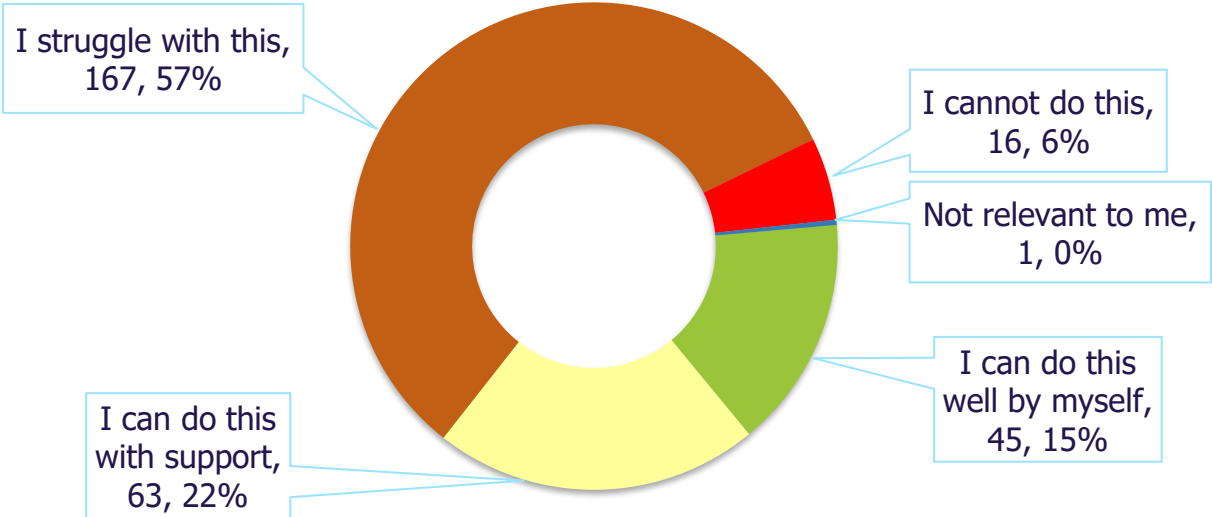
73% of 288 responses to this question stated that to some extent, their ability to care for others is affected due to their ongoing pain.

38% of respondents struggle with this and a further 25% stated they needed support from someone else to be able to manage this.

10% of respondents – 29 people – are entirely unable to do this.

Question 3 – How does your Chronic Pain directly affect your ability to live well?

Ability to carry out daily activities



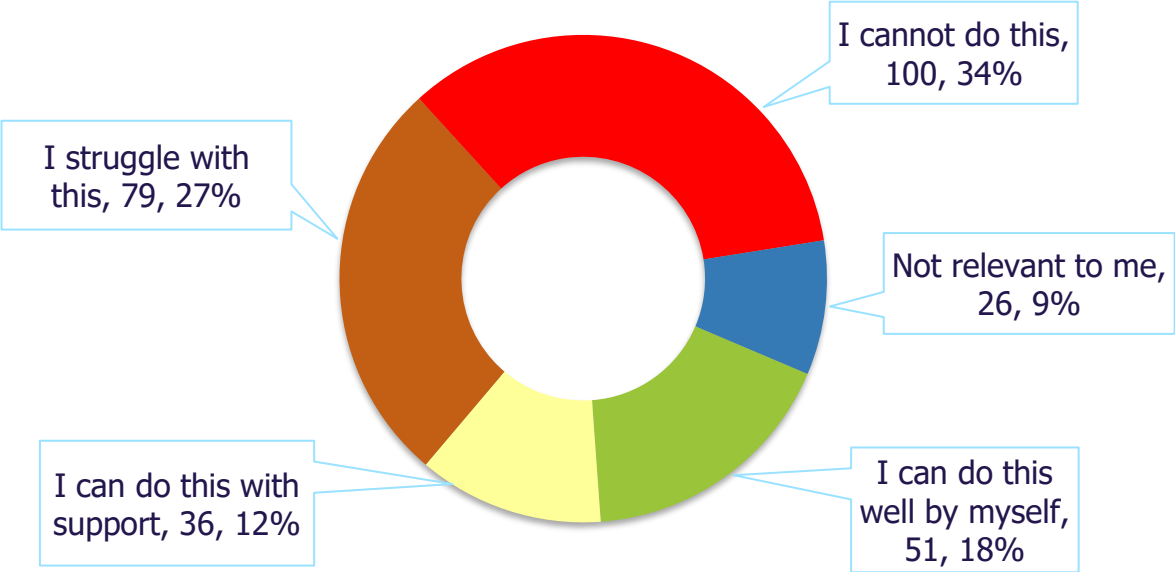
85% of 292 responses to this question stated that to some extent, their ability to carry out daily activities is affected due to their ongoing pain.

57% of respondents struggle with this and a further 22% stated they needed support from someone else to be able to manage this.

6% of respondents – 16 people – are entirely unable to do this.

Question 3 – How does your Chronic Pain directly affect your ability to live well?

Ability to work

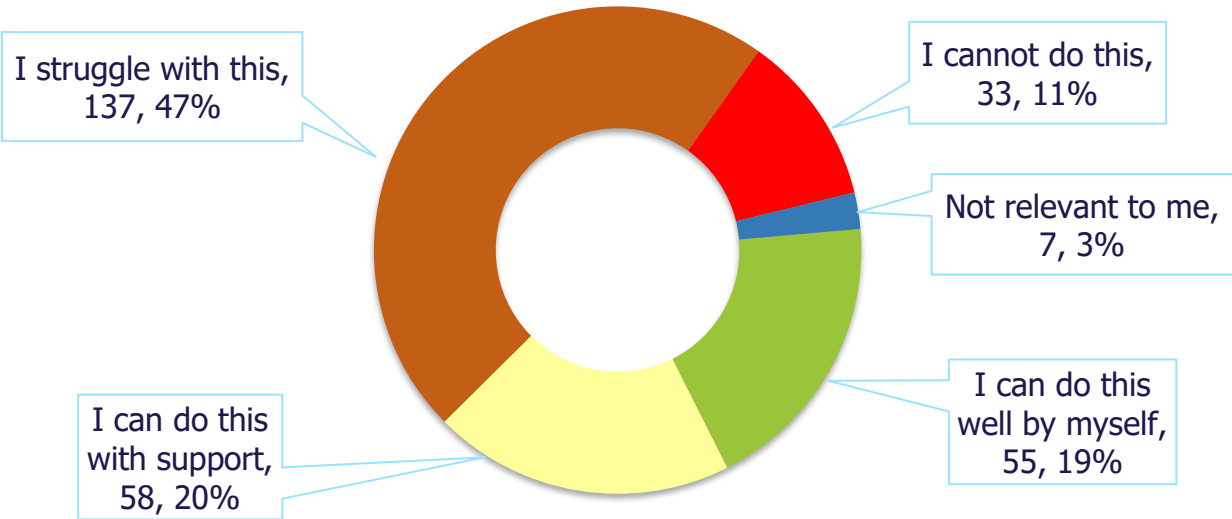


73% of 292 responses to this question stated that to some extent, their ability to work is affected due to their ongoing pain.

34% of respondents are unable to work at all, and a further 27% struggle with this.

Question 3 – How does your Chronic Pain directly affect your ability to live well?

Ability to socialise

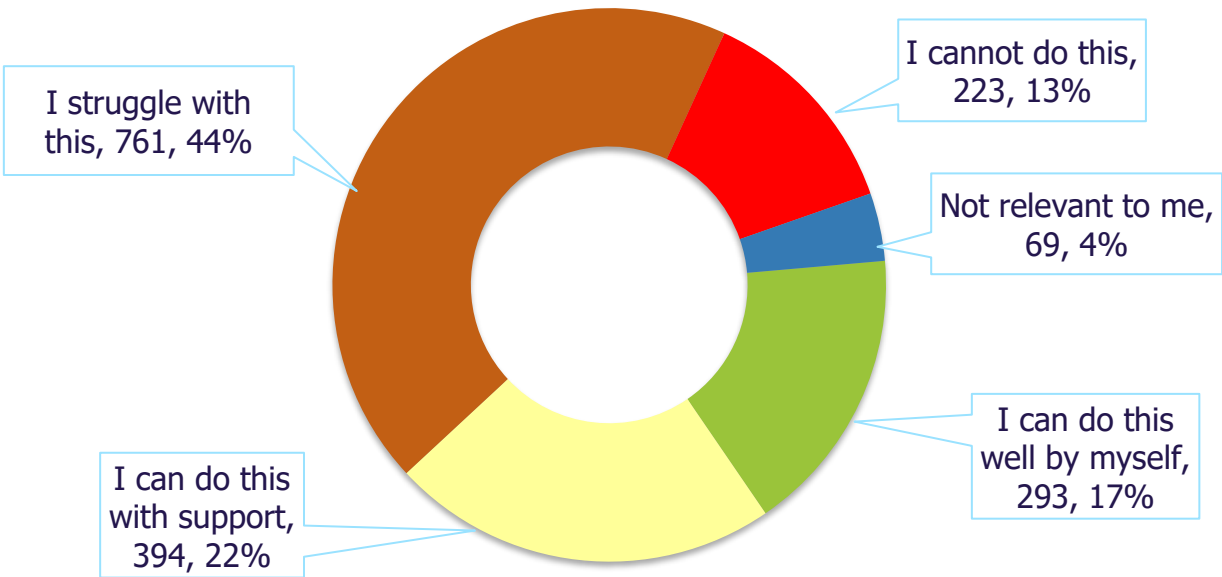


78% of 290 responses to this question stated that to some extent, their ability to socialise is affected due to their ongoing pain.

47% of respondents struggle with this and a further 20% stated they needed support from someone else to be able to manage this.

11% of respondents – 33 people – are entirely unable to do this.

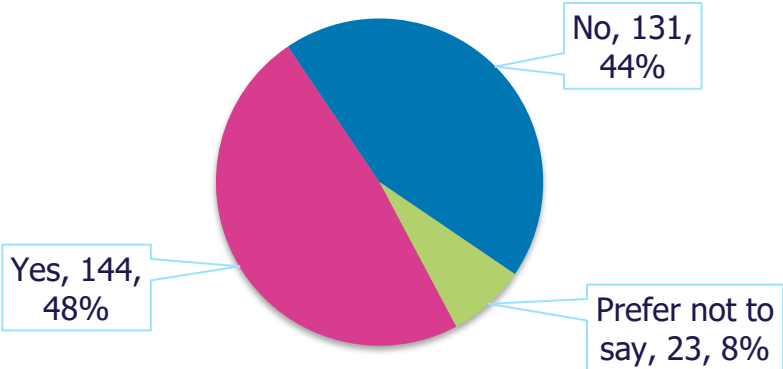
Question 3 – How does your Chronic Pain directly affect your ability to live well?



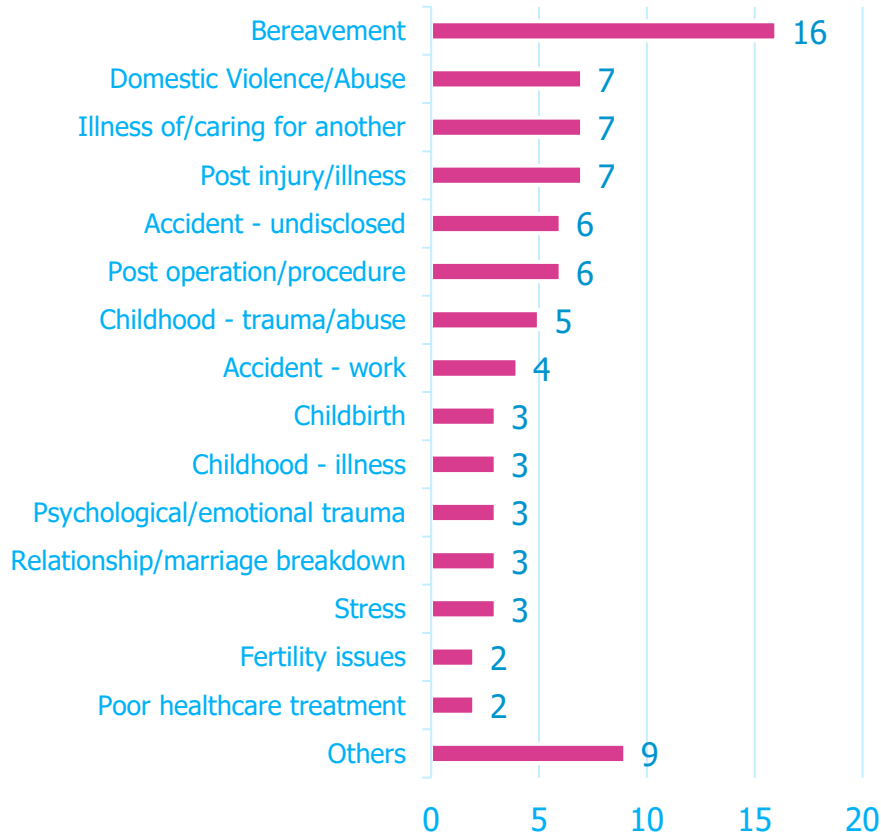
Of the 1468 collective total responses to all elements of Q3, 79% of respondents cannot to some extent, live well with Chronic Pain. This breaks down to 44% of respondents struggling to live well and a further 22% needing support from someone else to undertake activities.

13% of respondents cannot complete the activities at all, and so their quality of life is currently severely impacted.

Question 4 – Have you suffered from a trauma that you feel has contributed to your Chronic Pain condition?



The response was split between those respondents who had and those who hadn't felt that they had suffered from a trauma which they felt had contributed to their Chronic Pain condition, although narrowly more respondents said Yes (48%) than No (44%).



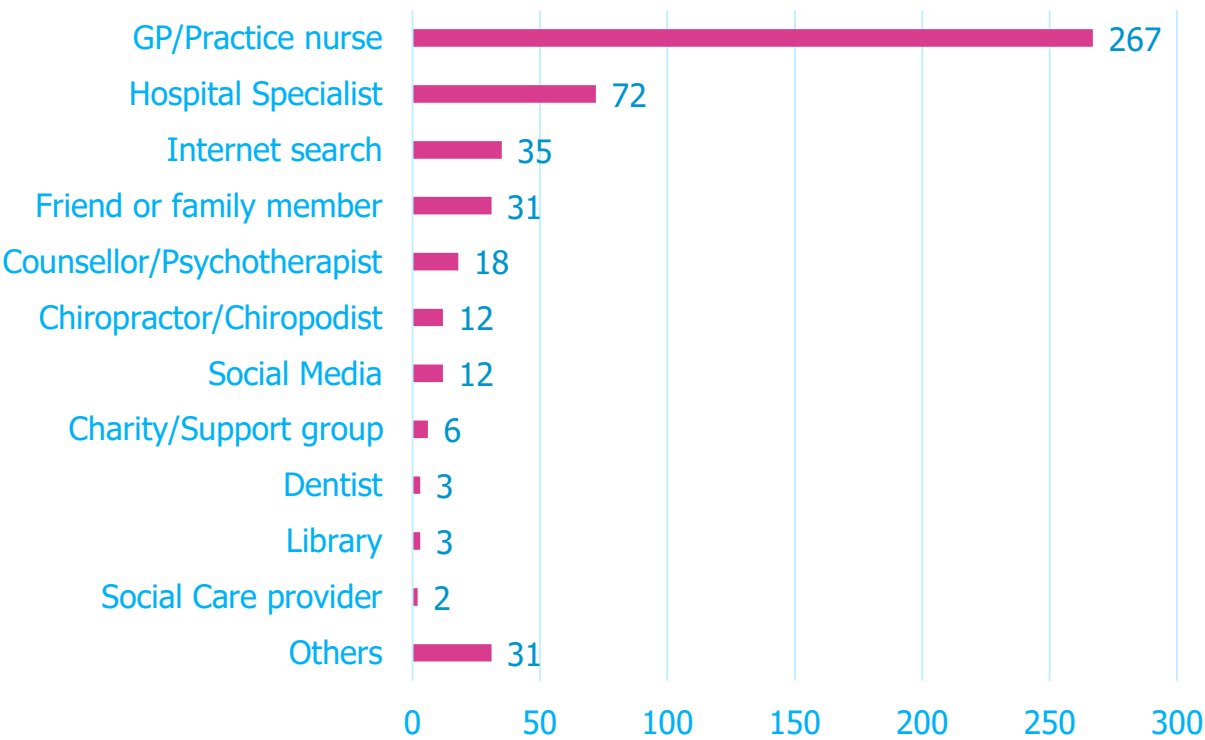
Of 298 responses, 89 gave us extra detail.

Of those 89 extra detailed responses, 18% stated that they felt suffering a bereavement had contributed to their Chronic Pain condition.

The next highest factors stated at 8% of responses each, were experiencing domestic abuse, caring for or the impact of an illness of a close relative/partner, or that their Chronic Pain developed following a different injury or illness.

Other individual traumas (1 per) are as follows in the respondents own words: car accident, EMF & rollout of 5g towers, family breakdown, hereditary, hormonal, hospital admission, medication, overexertion of retirement, undisclosed physical trauma.

Question 5 – When you first experienced symptoms of your condition where did you seek support?



50% of 522 responses to this question - answered by 293 respondents - stated that they sought advice from their GP or practice nurse when they first experienced symptoms of their condition.

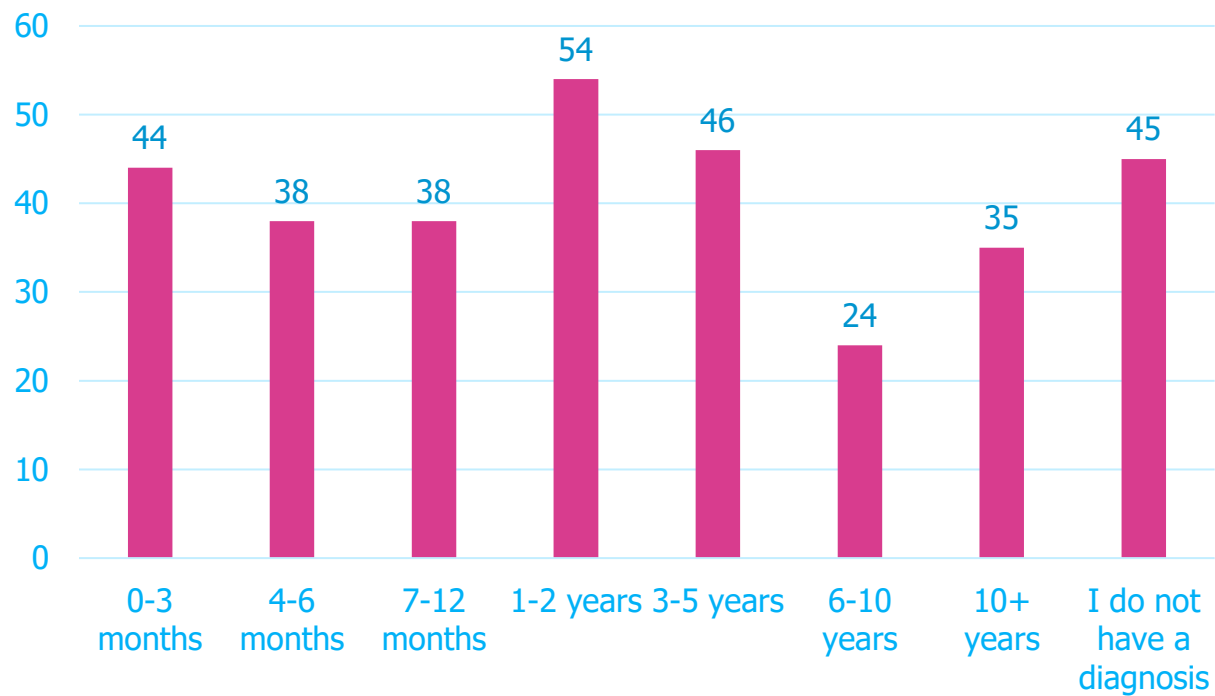
14% of responses stated that they had sought advice from a hospital specialist, and 12% sought advice from the internet or social media.

Of the responses that stated “Other” the most commented places or people from whom advice was sought are as follows:

- Physiotherapist (9)
- A&E (3)
- Osteopath (3)
- Walk in Centre, Derby (3)
- Acupuncture Therapist (2)
- Midwife (2)

Individual responses (1 per) sought advice from 999, Health Visitor, Hospice, Naturopath, Occupational Therapy, Pharmacist, School Staff, Sport Massage Therapist, Union at work.

Question 6 – How long after first seeking support from a healthcare professional did you receive a diagnosis?



297 respondents answered this question with 324 total responses.

Of the 279 responses that had received a diagnosis at any point, the collective groups between 0-1 year were the largest selected diagnosis period with 43% of diagnosed responses. 1-2 years was the next most selected with 19% of diagnosed responses.

14% of all responses do not have a confirmed diagnosis for their condition, and many of these are awaiting appointments or tests.

Question 6 – How long after first seeking support from a healthcare professional did you receive a diagnosis?

51 respondents left additional comments about their journey to diagnosis or further detail about how different illnesses had different timescales. Of those who left further sentiments in their own words, these were split into comments and themed.

Of these 38 descriptive sentiments, the most noted sentiment was that 34% of comments were stating that they believe their diagnosis took so long due to not being heard or listened to when attending with symptoms. 24% were still waiting for a diagnosis in general or on a waiting list to be seen. 16% said they had a diagnosis but either their healthcare professionals - or they themselves – did not feel this was a true or accurate diagnosis. 16% stated that they received good service and felt heard.

Other individual comments included having to wait for pain to become chronic before being able to access medication, not being able to access an appointment, having to go private to receive a diagnosis, or different practitioners not communicating together to see the whole situation of a person instead of treating individual symptoms.

Some of these positive and negatives sentiments are listed below in the respondents' own words. A full list of individual comments is available upon request.



"I was lucky, I got a locum that listened to me and was very attentive"

"GP was very good and when I started getting recurring pain referred me for X rays which were clear and then he had a hypothesis so referred me to Rheumatology."

"The medical profession didn't believe me when I kept telling them about the pain I was experiencing. They kept telling me it was in my mind."

"It took so long to get a diagnosis or for anybody to even really listen to what I was saying."

"GP kept saying it was other things for a few years."

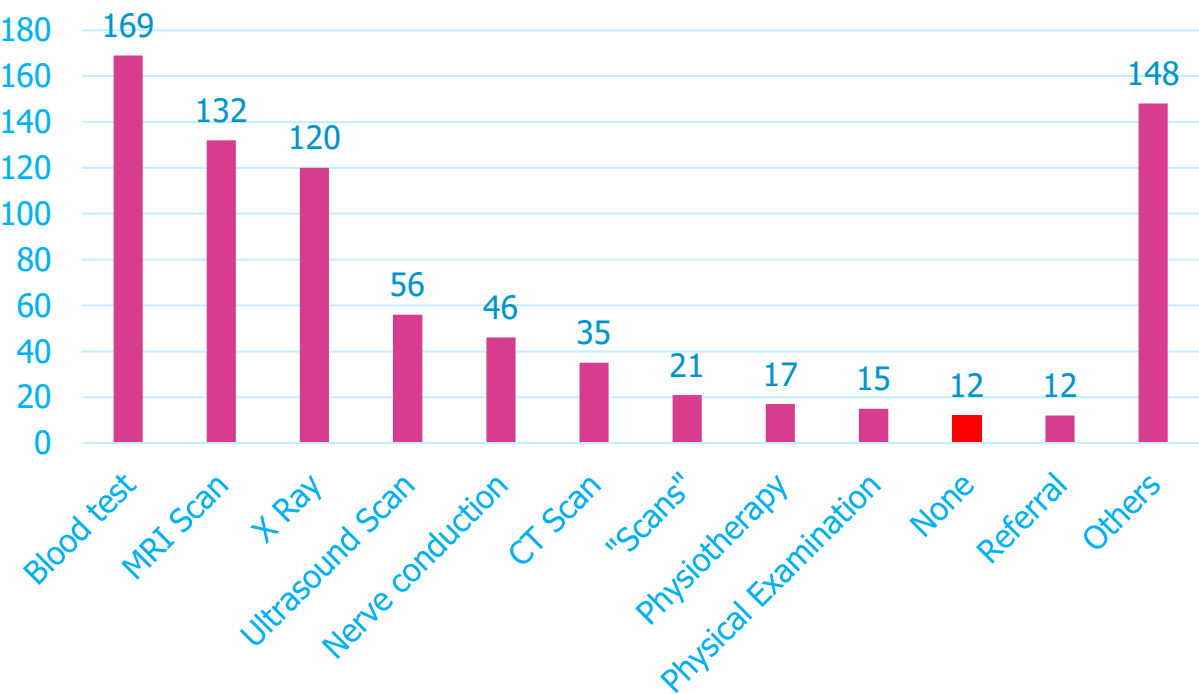
"Not being heard by the GPs, and not getting the help I needed pushed me to give more than I was able to, and I believe that is what has caused my pain."

"No one can tell me why I get pain everywhere"

**"Diagnosis wasn't a firm one, just a case of
"its probably fibro, because of your hormones"."**



Question 7 – What type of diagnostic tests/procedures did you receive under the guidance of your physician to enable them to come to a diagnosis?



21.5% of 784 responses to this question - answered by 272 respondents - stated that they were given a blood test to ascertain the diagnosis of their condition. 17% of responses were given an MRI scan, and 15% were given an X Ray. All other responses were selected at a rate of less than 8%, as shown above.

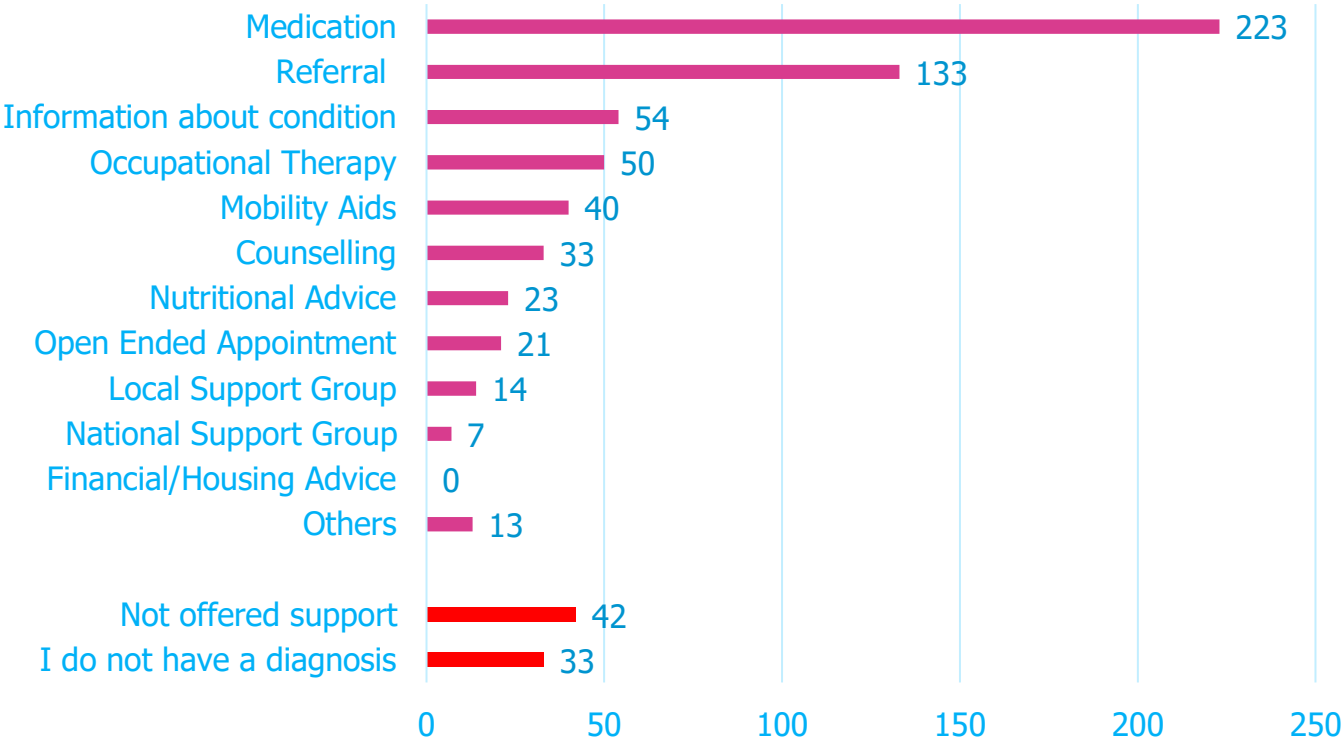
Of the responses that stated "Other" the most commented treatments and tests given are as follows:

- Pressure point test (9 – 1.1%)
- Lumber puncture (9 – 1.1%)
- Colonoscopy (8 – 1%)
- Endoscopy (8 – 1%)
- "Injections" (6 – 0.77%) ("Cortisone", "Steroid" or not specified)

All other responses were stated 5 times or less (> 0.63%).

A full list of treatments and tests stated is available as an appendix. (Appendix 2)

Question 8 – At the point of diagnosis what support were you offered to help you with your Chronic Pain/condition in the short or long term?



32.5% of 686 responses to this question - answered by 303 respondents - stated that they were given medication to help them with their condition and 19% of responses were given a referral to a different specialist or department. All other responses were stated at a rate of less than 8% each and are listed above.

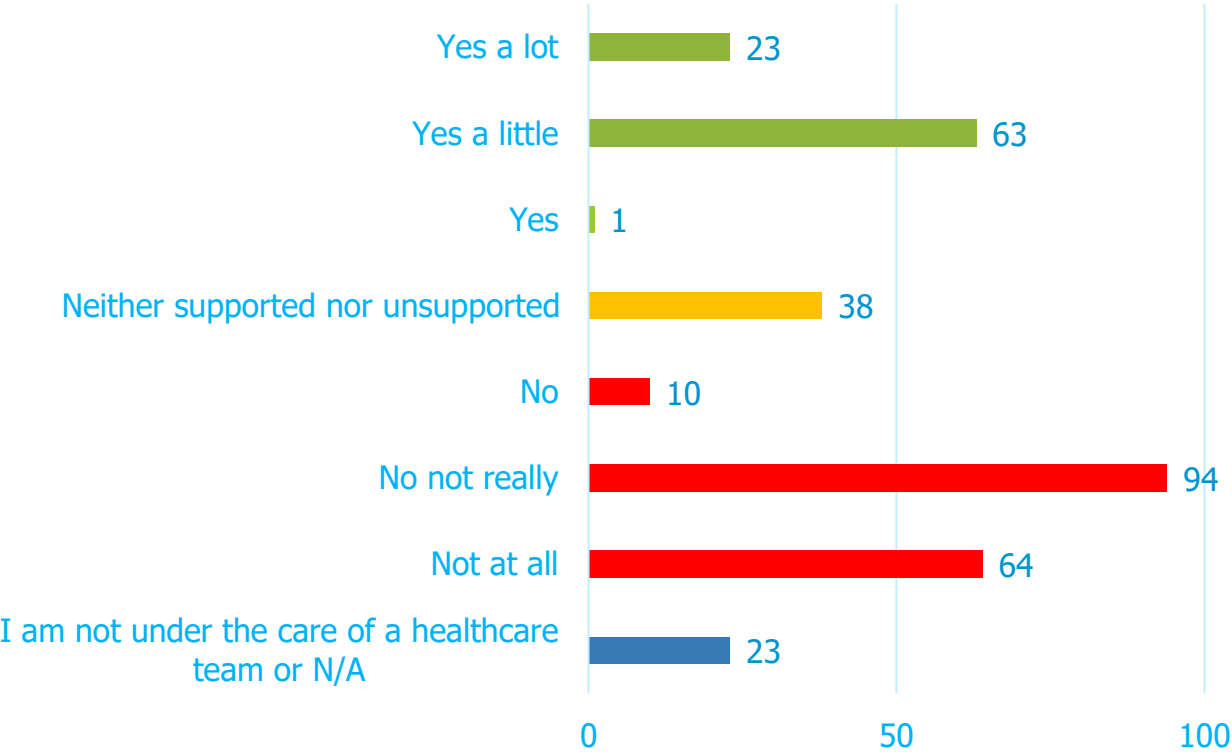
6% of all responses stated that they were not offered any support and 5% do not yet have a diagnosis to be offered support with.

Of the responses that stated “Other” the most commented treatments and tests given are as follows:

- Medical procedure/Operation (3 - 0.4%)
- Suggested Private treatment (2 – 0.3%)

All other responses were stated only once (0.1%) – Acupuncture, Advice to avoid phone usage, Advice to move house to another area, helpline, Hypnotherapy, immediate hospital admission, Mental Health support, Pain Management course.

Question 9 – Do you currently feel supported by the healthcare professional/s in charge of your care?



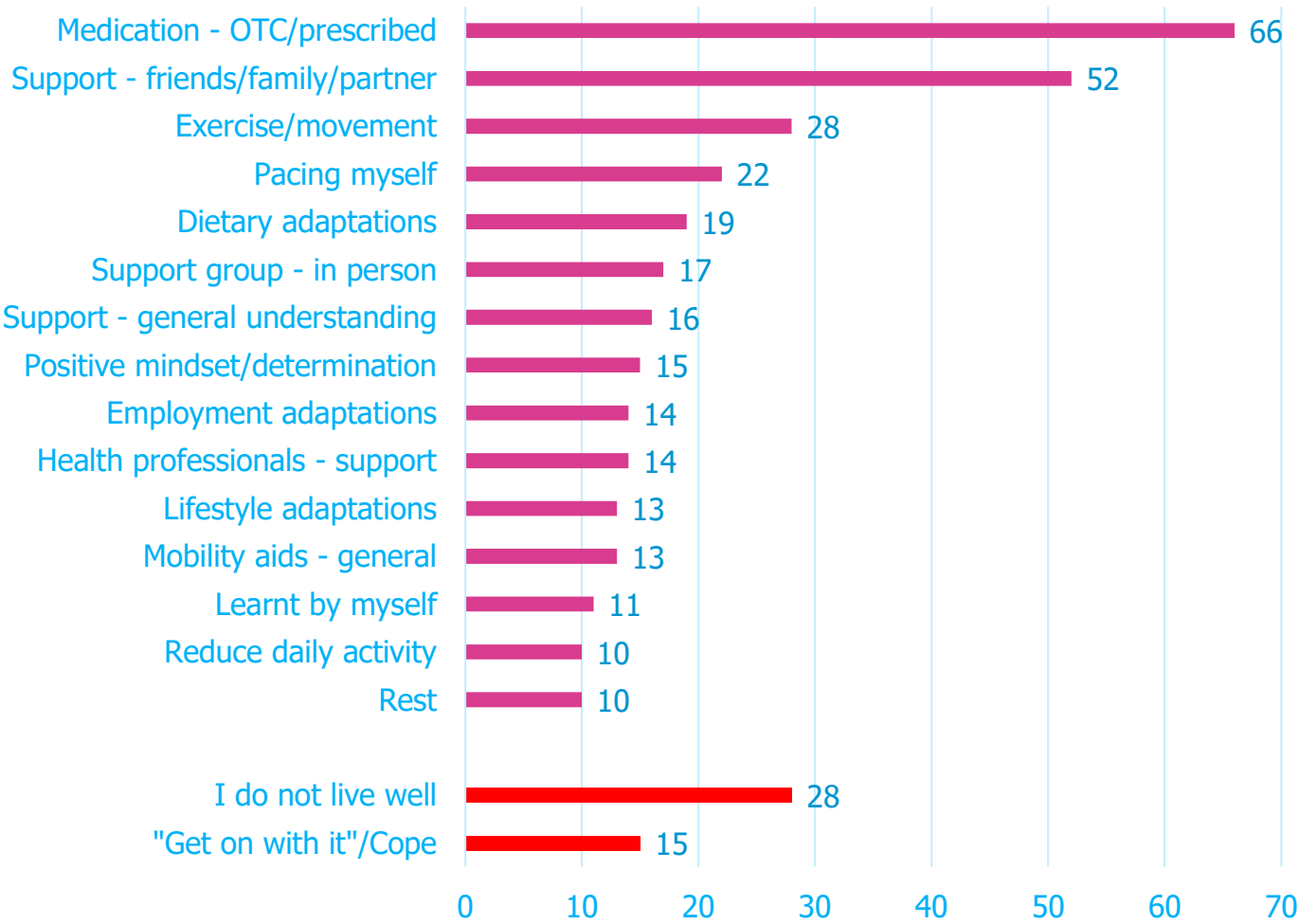
53% of 316 responses to this question - answered by 304 respondents - stated that **No**, they to some extent did not feel supported by the healthcare professionals in charge of their care – 20% stated that they did not feel supported at all.

27.5% of responses stated that **Yes**, to some extent they felt supported by their healthcare team, with 7% feeling that they were supported a lot.

12% of responses felt that they were neither supported nor unsupported, or experienced support and lack of support across a variety of professionals leading them to vote both ways.

7% of responses stated that they were not currently under the care of a healthcare team or stated N/A for another undisclosed reason.

Question 10 – In your opinion, what helps you to live well with Chronic Pain?



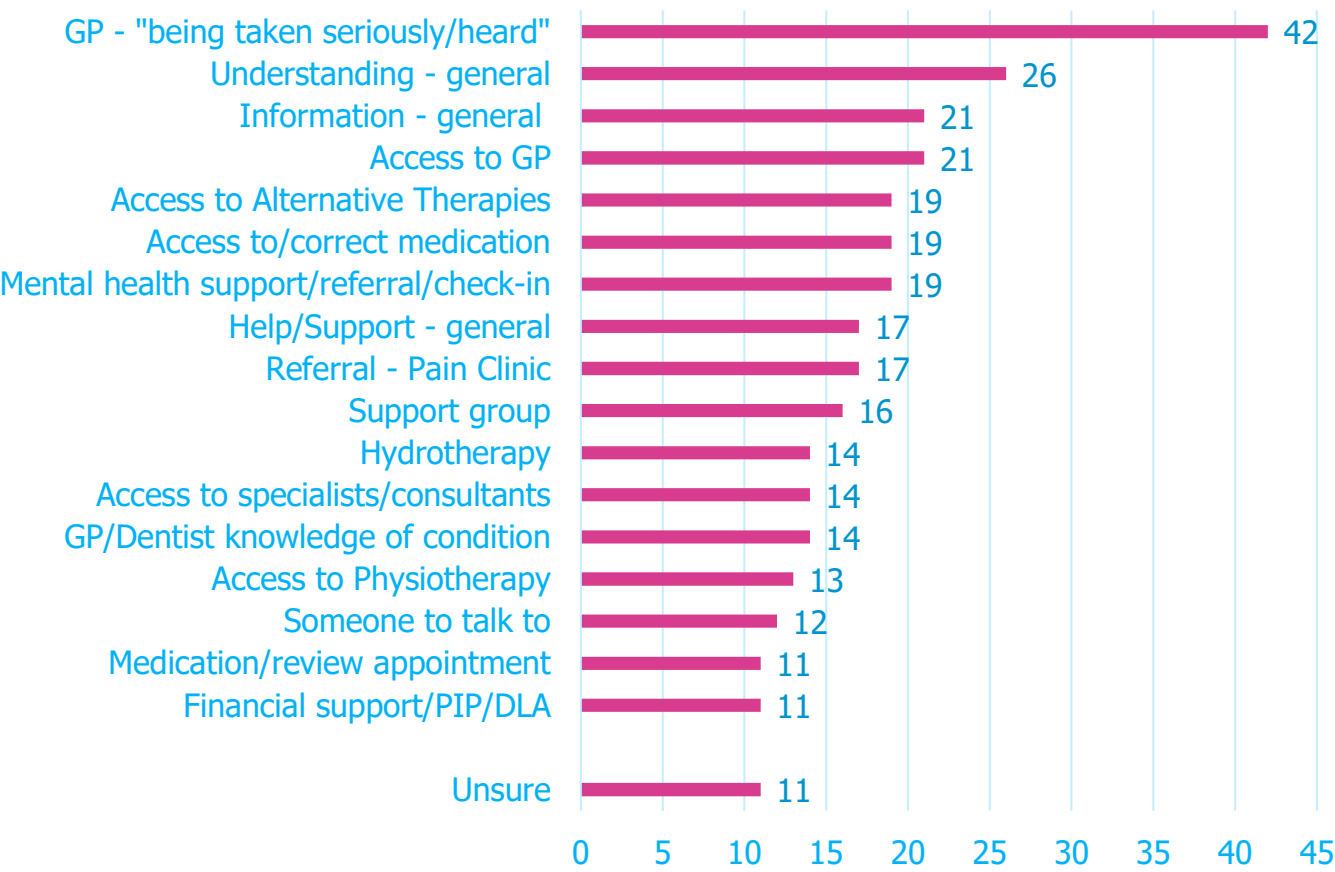
There were 610 responses to this question, answered by 247 respondents. The most popularly mentioned support mechanisms are listed above. **(There were 247 others, listed at a rate of lower than 10 responses each (>1.5%) which are not listed on the chart above.)**

The total of these above equates to 52% of the total responses. The two highest support mechanisms were Medication – OTC or prescribed (11%) and Support – family/friends/partner (8.5%).

43 responses (7%) stated that nothing helped, they do not live well with their pain at all or that they are ‘coping’ or ‘just getting on with it’.

A full list of choices stated is available as an appendix. (Appendix 3)

Question 11 – What support would you like to be easily available that would enable you and others to live better, whilst experiencing Chronic Pain?



This was a free text question and so the answers in the respondents own words have been collated and themed, and listed in the chart above.

There were 428 responses to this question, answered by 234 respondents and the most popularly mentioned options for support that people would like are listed above. **(There were 111 others, listed at a rate of lower than 7 responses each (>1.6%) which are not listed on the chart above).**

The total of these above equates to 74% of the total responses. Of these responses, the two highest requests were “Being taken seriously/heard/listened to by my GP” (10%) and General Understanding from professionals and the public (6%).

11 responses (3%) stated that they don’t know what would help.

A full list of response totals is available as an appendix. (Appendix 4)

Question 12 – Tell us your story - case studies

As noted in Question 11, the most important thing for people who are living with pain, is their need to be heard, understood and listened to by medical professionals, social support networks and the general public and for a wider understanding and conversation surrounding what it is like to live with pain on a daily basis.

This question – as the others – was optional, but there were many respondents who wanted to use this opportunity to be heard. The case studies have been broken down into comments and themed. This question has been separated into positive and negative themes. A full compilation of the responses to this question is available separately upon request. **Please note that these experiences are written in the respondents' own words and may contain upsetting, distressing or triggering information.**

Positive sentiments of experiences

The case studies of 117 respondents who answered this question were separated into individual experiences, and themed. Of the 395 comments, 16% were positive in sentiment.

The key points mentioned that were positive were:

- I have learnt to cope with my condition (14 - 3.5%)
- I received good service/support (8 – 2%)
- I had a medical procedure that helped (7 – 1.7%)
- I was given medication that worked (6 – 1.5%)
- I paid for private treatment and had good service (5 – 1.3%)
- My friends and family are supportive (4 – 1%)

Other points mentioned were at a rate of 3 responses or less (>0.76%). These are available as an appendix. (Appendix 5)

Below are some positive experiences in the respondents' own words.



I walked in to the walk-in centre on london road and explained I wasn't a minor injury but nobody would listen to me and I didn't know where else to go. I was taken to a side room where a lovely male nurse who I'll never forget, suggested fibromyalgia and explained that my symptoms fitted it. He sent a note through the system to my GP (who said I was depressed) to refer me to the rheumatology at derby royal and a few weeks later during my appointment there I was given the diagnosis of fibromyalgia and more appropriate medication. I wasn't offered any further support, but by this point I was really grateful that I finally had a diagnosis I could work with and learn about, and medication that would be more likely to work and that someone had listened and understood what I was saying was hurting and that I wasn't making it up or just depressed.



Question 12 – Tell us your story, case studies

Positive sentiments of experiences



Then years later I was sent to the pain clinic which was good to be able to talk to others with the same as I had this made me feel I was starting to feel understood at last. After this course finished I then kept in touch with a few of the people in this course and we now have a group and we meet up every fortnight which helps you to not feel alone. I'm now 51 and really wish I could have a pain free day but at least I have friends and family that are so supportive.

I accept my pain and acknowledge it. Its just part of me now and I have bad days when I struggle to function but I just take some paracetamol and think well, tomorrow is another day. Its the only way I can exist as a meaningful member of society. I have a positive attitude towards my health issues though they do stop me from doing a lot of things, I cant do anything about that so I just get on with it. I meditate and have had CBT, and I dont let it define me.

No medication seemed to take the pain away, physically or mentally, so for 4 years I lived in a world filled with the complexities of both.. I was very close to ending my life and had to make the decision of that or find something within me I could still do, my love of art came to me, day by day I would try and train myself to do a little, develop my drawing and watercolour skills. ... I still have so much pain and my mobility can be awful at times but having that structure and a sense of purpose, an identity helps life to be bareable again.

I discovered a chiropractor in the village and under his care I have been far more active sometimes walking upto 9 miles a day.
It seems I have a choice between being very active and sitting around all day. I have found a fairly happy medium but don't drive any more.

I am very grateful to the help I have been given. .. Most of the people I have seen have always been kind and they do what they can.

I do think realising that if you have multiple layers of types of pain they can confuse and mask each other i.e my regular migraines and persistent pure and simple headaches were three things: my MS, my work (!) and then my teeth grinding and clenching. Once they were unpeeled and dealt with individually I made headway and with progress that gave me confidence and hope. I still have bad days but things more manageable.

Being able to vent one's frustration with pain that cannot be and will never be resolved is important - leg spasms drive me nuts - hooking into someone who gets that helps not with the pain but controlling the utter madness that can come with helplessness.

I felt very supported during the initial diagnosis and treatment.



Question 12 – Tell us your story, case studies

Negative sentiments of experiences

The case studies of 117 respondents who answered this question were separated into individual experiences, and themed. Of the 395 comments, 84% were negative in sentiment.

The key points mentioned that were negative were:

- Poor quality of life (physically/practically) (57 – 14.4%)
- Poor quality of life (mentally) (48 – 12.2%)
- Health professional did not believe me/listen (33 – 8.4%)
- I have had no help/support (33 – 8.4%)
- My medication does not help/makes it worse/side-effects (25 – 6.3%)
- My referral/appointment/operation took too long (20 – 5.1%)
- My diagnosis took too long (13 – 3.3%)
- I was given medication and sent away (12 – 3%)
- There are no answers to help me (12 – 3%)
- Health professional made unsupportive comments (12 – 3%) – of these 6 were related to the patient's weight and 6 were told to 'deal/get on with it'

Other points mentioned were at a rate of 9 responses or less (>2.3%). These are available as an appendix. (Appendix 5)

Below are some negative experiences in the respondents' own words.



I was under the care of derby royal for around 2 years, had three operations, I could write a book on all the complications and mistakes made by the hospital it's shocking, I now have permanent nerve damage. I am currently under Liverpool hospital, but unfortunately haven't found a treatment for my chronic pain.

I'm a 20y/o female with PCOS, I've been struggling with this for nearly 8 years and have only received a diagnosis in the last month. I'm 5ft3 and 7st6 and the only advice my doctor gave me was to lose weight. Now I've battled an eating disorder for years now and that comment doesn't help when I know I'm the correct weight for my height. Doctors need to start taking young females seriously and not just brushing it off as 'normal' or 'common' for our age.

Months later I had another appointment saying the fatigue was still there, the pain is still there, and I was told I was depressed. I said I wasn't depressed I was upset due to living in constant pain, but the doctor wouldn't accept what I was saying and prescribed me anti-depressants, which made me more tired and I was feeling hopeless that nobody was listening to me I was just being given medication and sent away.



Question 12 – Tell us your story, case studies

Negative sentiments of experiences



I was referred to a Neuropsychologist but there is a 2 year wait. Rang GP after this diagnosis for medication for my pain, but was told my condition is all in my head and if I see a psychologist I will be cured. He told me that no medication would help me. I feel totally ignored and let down by the Health Service.

The mental repercussions of my back pain is worse than the actual pain sometimes. I'm more irritable, the slightest thing can make me more irritable because I'm already feeling uneasy anyway.

There is only a few people who help me everyday through all of this and keep me upbeat. None of those people are within the medical field.

I'm now steroid dependent. Had to give up work, now have a carer 20 hours a week but without them and my husband I don't think I would function at all physically or mentally. I can spend many days/ hours in bed, Sleeping and resting my life away due to pain. I'm in the Process of trying to get out of going to work as I don't want to spend the rest of my life Sleeping my life away. Chronic pain has had 19 years of my life, its not having anymore.

Since September 2020 I've been fighting the NHS for treatment & it became so overwhelming that my body broke & had an FND episode.

Living with pain messes up my life, my memory, speech, social life etc

I wish this condition would be taken seriously. Its painful and its upsetting to be isolated as it is a condition that will not be acknowledged. It is acknowledged in other countries but nothing is being done to support people here in Derby or the UK

Right now I'm so tired - I live with chronic pain and mental illness as well as other medical issues but it feels like I'm just existing and waiting to die. I feel as though I have no power or control over my life. I can't go out without support but there isn't enough funding to pay for someone to take me out. It feels like I'm living in a prison cell with no rights or self-autonomy and I cannot get any help from anyone.

Chronic pain is miserable. I cannot remember the last time I woke up not in pain. I have no way of managing my pain and feel like I am isolated with no one willing or interested in helping me. .. I just have to try and live like this, which in itself is really quite depressing.

If it wasn't for my children I would kill myself. My daily struggles are barely worth living for. Daily excruciating pain, aches, exhaustion, anxiety, depression, ibs, weight gain. .. I feel cursed. I don't like to burden the doctors as I feel they can't/won't help anyway. I take pain killers and anxiety medication but nothing really helps.



Question 12 – Tell us your story, case studies

Negative sentiments of experiences



I was so annoyed when I read where one doctor had written "I will not request an MRI as it will not change how I deal with this lady" This was despite the previous doctor that I saw saying that if I was still in pain at my next appointment he would have an MRI done.

I've had to live with pain for a long time and have had no help because of useless doctors who have no clue on what to do, any time i call the GP i either cant get through, cant get an appointment in person or on the phone and when i eventually do get through they ask me what i want them to do rather than actually suggesting things to me or listening properly so much so that i feel like i want to die most of the time because life became too hard

I had a few years of semi good health where I was able to have a child. The birth of my child should have been consultant led but it wasn't and therefore I suffered massively and ended up in high dependency for 5 days. I am writing this from a hospital bed, two weeks after a procedure that's meant to help.

I live alone and I'm getting really depressed and anxious. Struggle on a day to day basis, lost my self esteem. Constantly fatigued and in huge amount of pain in my back. .. Most days I'm running scared and struggle to cope. The pain is to much for me.

Finally I went for the scan, 3 weeks of pain by this point. .. I then had to await an op and be kept in hospital. This could of been done keyhole but since it had been left and got cellulitus set in, it become a bigger op. .. 4 years later I still have a wound that's failing to heal and lots of pain. It stops me doing things I should be able to do and is a constant worry of infection.

I now understand that the debilitating pain, fatigue and other symptoms are all related to me flitting in and out of the pre-diabetic zone. My GP could have been more understanding and less judgemental when he said I was overweight by actually informing me how I could change it and why I was experiencing chronic pain, etc. I have lost all confidence in GP.

When I was a child with CFS, I was told I had growing pains. I was then told I had a low pain tolerance like 'most teenage girls do'. I would sit in a GP surgery bleeding profusely and almost being sick from pain and I was told 'get used to it, that's periods for you'. I feel like I have had a long line of being told my pain isn't real, that I was over dramatic, to deal with it etc and I started to believe it was true which got me very anxious and depressed. When I finally got all my diagnosis', I was so angry at every person who had dismissed me and made me believe it was all in my head. I felt like I had suffered unnecessarily.

It took 5 years to diagnose me with costochondritis. Over the last year I have been getting pain all over my body. They suspect it is fibromyalgia. I have been given high doses of codiene which doesn't work and now they think I may not have had Costo and it's been fibro all along. I've now been left with no official diagnosis or pain management.



Acknowledgements



Healthwatch Derby would like to thank our in-person and online respondents for their time, for sharing their very personal stories with us and for their general participation, support and interest in this project.

We would also like to thank all those who have shared and promoted this project to enable it to have reached such a wide audience.

Provider Responses



East Midlands
Academic Health Science Network
Igniting **Innovation**

The results in this report create an incredibly useful picture that highlights the complexity of chronic pain and the challenges associated with living with the condition. The stories shared by respondents living with chronic pain are particularly powerful and we hope the survey findings will improve everyone's understanding about chronic pain and drive improvements to services. As part of the National Medicines Safety Improvement Programme, we will use this report to support our current work with Derby and Derbyshire ICB to improve the lives of people living with chronic non-cancer pain by reducing the harm from opioids.

*Gill Gookey – Medicines Safety Lead Pharmacist
East Midlands Academic Health Science Network*



England

I found this report to be insightful and compelling. It is a very significant piece of work and contributes greatly to our understanding of the experiences of people living with persistent pain. Understanding just how important it is to be listened to, understood and believed comes through strongly in the report and this feels like something every health professional can freely offer. What struck me was that there was a great deal of dissatisfaction with people's experiences of the medication that is used for persistent pain and that positive experiences were associated with things that help to accept and live well despite the pain. Support to live well is clearly much more than medication, and in many ways just more holistic.

*Tony Jamieson FRPharmS – Patient Safety Specialist & Clinical Improvement Lead
Medicines Safety Improvement Programme, NHS England*

Provider Responses



Lister House / PCCO PCN have been incredibly proud to be a part of this report. Our Health & Wellbeing Coaches, Dawn and Nikki created a programme with aim of increasing our patients ability to self-manage their conditions and to live well with pain. They wanted to support our patients to improve their overall wellbeing, increase their confidence and knowledge to enable them to take control of their own life. The sessions focussed on what mattered most to the patients, we were able to create a safe space and took time for conversations, building relationships and listening. At the end of the programme we were delighted that some people wanted to set up a peer support group which will offer sustainable support for people with chronic pain within the community.

*Nel Flint – Head of PCN & Deputy Practice Manager
Lister House Surgery, PCCO PCN*



Derby and Derbyshire
Integrated Care Board



Thank you to Healthwatch and all the participants of this survey their candid responses to support this important topic of chronic pain. The report provides a valuable snapshot of the experiences and challenges, both positive and negative, that have impacted on people in many ways. Our aim is to provide open, transparent, and effective communication with individuals and/or their representatives to ensure they have been listened to and totally involved in decision making. The feedback received from this survey will be shared with our Derbyshire System partners to further inform the changes we make and support our continuing dialogue on these topics.

*Patient Experience Team
NHS Derby and Derbyshire Integrated Care Board / Joined Up Care Derbyshire*

Appendices

Appendix 1 – Alphabeticised list of all noted illnesses for Q1 (continued on next page).

Adductor muscles and tendon damage	1	Disc (degenerative disc disease)	4
Amygdala abnormality	1	Disc (prolapsed)	1
Ankle pain (bone island)	1	Disc (slipped/bulge)	5
Ankle pain (chronic)	3	Dupuytren's	1
Anxiety	2	Dystonia	2
Arthritis	2	Ehlers Danlos (EDS)	1
Avascular Necrosis	1	Electrosensitivity	2
Back Pain (chronic)	10	Endometriosis	3
Bilateral Pars defect	1	Feet pain (chronic, both)	2
Bile acid/salt malabsorption	3	Fibromyalgia	124
Bladder dysfunction	1	Functional Neurological Disorder (FND)	9
Bone pain from biologics	1	Functional Myoclonus	1
Bowel (slow bowel transit)	1	Gastroparesis	1
Bursitis	1	Golfer's Elbow	1
Carpal Tunnel Syndrome	2	Gout	1
Cauda Equina	2	Graves disease	1
Coeliac Disease	1	Haemochromatosis	1
Cervical Myelopathy	1	Hidradenitis	1
Charcotte Marie Tooth	1	Hip pain (chronic)	4
Chronic Fatigue (ME/CFS)	57	Hypermobility Syndrome	5
Crohn's Disease	4	Hyperthyroidism	2
Cirrhosis of the Liver (auto immune hepatitis)	1	Hypertrophic Cardiomyopathy (HOCM)	1
Cluster headaches	2	Hypothyroidism	28
Complex Regional Pain Syndrome (CRPS)	24	Idiopathic Intracranial Hypertension (IIH)	1
Connective Tissue Disorder (mixed)	1	Indolent Systemic Mastocytosis	1
Connective Tissue Disorder (undifferentiated)	1	Inflammatory disease	1
Costochondritis	2	Irritable Bowel Syndrome (IBS)	71
Degenerative Spine	1	Jaw pain (chronic)	1
Depression	2	Joint pain (chronic)	1
Diabetes	30	Joint pain (repetitive)	1

Appendices

Appendix 1 – Alphabeticised list of all noted illnesses for Q1 (continued).

Kidney stones	1	Post Polio Syndrome	2
Knee pain (chronic)	1	Postherpetic Neuralgia	2
Leg pain (chronic)	3	Psoriatic Arthritis	7
Long Covid	5	Pulmonary Embolism	1
Lower lumbar deterioration	1	Raynaud's Syndrome	1
Lupus	28	Rheumatoid Arthritis	36
Menopausal inflammation	1	Rotator cuff injury	1
Meralgia Paresthetica	1	Schleroderma	1
Migraines (chronic)	6	Sciatica	1
Multiple Sclerosis (MS)	13	Scoliosis	2
Muscle spasms	2	Shoulder pain (frozen)	1
Nerve pain (damage/trapped)	3	Sjogren's Syndrome	1
Neuropathy	2	Sphincter of Oddi dysfunction	1
No diagnosis	28	Spinal Arteriovenous Malformation	1
Osteoarthritis	82	Spinal stenosis	1
Osteomalacia	1	Spondilosis	1
Osteoporosis	1	Spondyloarthropathy	21
Other	122	Symphysis Pubis Dysfunction (SPD)	1
Palindromic Rheumatism	1	Teeth pain (chronic)	1
Patellofemoral Pain Syndrome	1	Temporomadibular Joint Disorder (TMJ)	1
Pelvic Pain (chronic)	1	Tendonitis	1
Pelvic Pain (congested pelvic disorder)	1	Tinnitus	1
Pelvic Pain (rotated and tilted)	1	Trigeminal Neuralgia	3
Peripheral neuropathy	2	Ulcer (leg)	1
Phantom/Unidentifiable Pain	2	Ulnar nerve compression	1
Piriformis Syndrome	2	Ulcerative Colitis	2
Plantar Fasciitis	3	Unhealed surgical wound	1
Polycystic Ovary Syndrome (PCOS)	3	Vasculitis	2
Polycythemia	2	Vertabrae and Disc (damage/worn)	2
Polymyalgia Rheumatica	1	Vertabrae (narrowing)	1
Polymyositis/Dermatomyositis	0	Vertabrae (T8 & T9 crumbled)	1
Post operation pain	1	Vulvadynia	1

Appendices

Appendix 2 – Alphabeticised list of tests/procedures/treatments given to establish diagnosis – Q7.

Acupuncture	3	Lumber puncture	9
Allergy test	1	Medical/genetic history	5
Alternative therapy	1	Medication	5
Arthroscopy	1	Mental health questionnaire	2
Barium meal scan	1	Mobility test	3
Biopsy	3	Move home	1
Blood pressure monitoring	3	MRI	132
Blood test	169	Needles in feet and legs	1
Bone marrow check	1	Nerve conduction	46
Bone scan	1	Neurological exam	4
Breathing test	2	None	12
Camera test	2	Occupational therapy	2
Catheter	1	Pain clinic	5
CBT/Counselling	3	Physical exam	15
Colonoscopy	8	Physiotherapy	17
CR Scan	1	Pressure on joint	1
CT Scan	35	Pressure points	9
Dietary	1	Referral	12
Dye in bladder	1	Reflex test	1
Dye in body	1	Rest	1
ECG	5	Scans	21
EEG	1	Schirmer test	2
Electronic wave test	1	Sigmoidoscopy	2
EMG	1	Surgery	5
Endoscopy	8	Swabs	1
Flaccid plate	1	Talking symptoms	3
Gastroscopy	3	Teeth modelling	1
Glucose test	1	Temperature scan	1
Grip test	1	Tests	5
Heart and lung test	1	Thyroid test	1
Heart scan	1	Transit Studies	1
HIDA Scan	1	Ulna nerve decompression	1
Hysterectomy	1	Ultrasound	56
Injections	6	Urology exam	3
Kidney function test	1	Visual exam	2
Laparoscopy	1	Website	1
Liver function test	1	X ray	120

Appendices

Appendix 3 – Alphabetised list of responses to “What helps you live well with Chronic Pain?” – Q10

		Holiday/beach	2
Acceptance	8	House - adaptations/conversions	6
Advocating for myself	5	House - hot tub	1
Alternative Therapy - Acupuncture	1	House - relocation	4
Alternative Therapy - Chiropractor	3	I do not live well	28
Alternative Therapy -		Information on what support is available	4
Counselling/CBT/Psychotherapy	5	Laughter	1
Alternative Therapy - general	1	Learnt by myself	11
Alternative Therapy - Hydrotherapy	3	Lifestyle adaptations	13
Alternative Therapy - Hypnotherapy	1	Medical procedure - Lymphatic drainage	1
Alternative Therapy - massage	3	Medical Procedure - Shunt	1
Alternative Therapy -		Medication - HRT	1
mindfulness/relaxation/meditation	8	Medication - management/reduction	5
Alternative Therapy - Naturopath	1	Medication - OTC/Prescribed	66
Alternative Therapy - Osteopath	2	Mobility/Support aids - Epsom Salts	2
Alternative Therapy - Pet therapy	1	Mobility/Support aids - general	13
Alternative Therapy - Physiotherapy	2	Mobility/Support aids - heat pads/hot water bottle	9
Alternative Therapy - Reflexology	1	Mobility/Support aids - knee pillow	1
Alternative Therapy - Reiki	1	Mobility/Support aids - knee/ankle/foot/toes	
Ask for help	3	brace/support	4
Carer/Social care	5	Mobility/Support aids - massage gun	1
Diary of symptoms/triggers/changes	3	Mobility/Support aids - supportive footwear	1
Distraction techniques	6	Mobility/Support aids - TENS machine	4
Do nothing/stay in bed	2	N/A / Still waiting	3
Employment - adaptations/hours	14	Nap	1
Employment - Occupational Therapy	2	Nutritional - castor oil	1
Employment - supportive employer	3	Nutritional - CBD oil/cream/capsules	3
Exercise - chair exercise/seated yoga	2	Nutritional - curcumin	1
Exercise - gentle/general/movement	23	Nutritional - diet adaptations	19
Exercise - Personal Trainer	1	Nutritional - essential oils	1
Exercise - Pilates	4	Nutritional - glucosamine	1
Exercise - Qigong	1	Nutritional - herbal tea	1
Exercise - stretching	4	Nutritional - herbs	1
Exercise - Swimming	7	Nutritional - Marijuana	1
Exercise - TaiChi	3	Nutritional - supplements general	4
Exercise - walking	3	Nutritional - turmeric	1
Exercise - weights	1	Nutritional - vitamin D	2
Exercise - Yoga	7	Nutritional - vitamin injection	1
Faith	1	Nutritional - vitamin K2	1
Financial support/PIP	2	Pacing	22
Get on with it/Cope	15	Positive mindset	15
Health professionals - advice	4	Reduce activity - daily	10
Health professionals - appointments	4	Reduce activity - daily stress	5
Health professionals - consistency	1	Reduce activity - driving	1
Health professionals - Diabetes Awareness Team	1	Reduce activity - phone usage	1
Health professionals - Living Well With Pain course	1	Reduce activity - sport/exercise	7
Health professionals - pain clinic	7	Reminders and alarms	1
Health professionals - Pain Management course	3	Research and understanding condition	8
Health professionals - support	14	Rest	10
Hobbies - art	1	Retirement	1
Hobbies - community work	1	Sleep quality	3
Hobbies - crafts	1	Stop justifying your actions to others	3
Hobbies - gardening	1	Support - friends/family/partner	52
Hobbies - general	4	Support - general	
Hobbies - music	1	understanding/public/community	16
Hobbies - outdoors/nature	3	Support group - in person	17
Hobbies - pets	2	Support group - online	5
Hobbies - photography	1	Take each day as it comes	3
		Warmth	1

Appendices

Appendix 4 – Alphabeticised list of responses to “What support would you like to be easily available?” – Q11.

Access to diagnostic testing/services	3	Medication	19
Accessible toilets at healthcare providers	1	Mental health support	19
Acknowledgment of condition	3	Mobility Aids	5
Alternative therapies - community/home based	1	Occupational Therapy	2
Alternative therapies - general	19	Pain course	4
Alternative therapies - hydrotherapy	14	Pain management general	6
Alternative therapies - massage	6	Physio - access	13
CBD Oil	1	Referral - exercise	4
Coping strategies	1	Referral - nutritionist	1
Diagnosis	7	Referral - Pain Clinic	17
Financial support/PIP/DLA	11	Referral - specialist/consultant	6
GP - "being taken seriously/heard"	42	Research into pain	3
GP - "not being fobbed off with medication"	6	Social services	1
GP - "Whole person approach"	7	Someone to talk to	12
GP - access	21	Specialists - access	14
GP - knowledge of conditions	14	Support around the home	6
GP - medication/review appointments	11	Support caring for partner	1
GP - named professional at surgery	1	Support from employer/workplace	5
Help/Support - general	17	Support group	16
Housing	3	Support with isolation	3
Information - about my condition	3	Support with weight loss	2
Information - for own support network	1	Support worker	1
Information - general	21	Transport	3
Information - what to expect	5	Understanding - general	26
Less waiting times	7	Unsure	11
		Warm exercise	2

Appendix 5 – themes of responses written as case studies – Q12.

Positive sentiments of experiences:

- I have learnt to cope with my condition (14 - 3.5%)
- I received good service/support (8 – 2%)
- I had a medical procedure that helped (7 – 1.7%)
- I was given medication that worked (6 – 1.5%)
- I paid for private treatment and had good service (5 – 1.3%)
- My friends and family are supportive (4 – 1%)
- A holistic approach to my treatment helped me get answers (3)
- I received a quick referral (3)
- I was supported/heard (3)
- Adaptations and aids helped (2)
- My life improved after leaving domestic violence (2)
- Pain clinic support group helped me feel heard (2)
- I will be paying for treatment that will work for me (1)
- I was offered information (1)
- My workplace was supportive (1)

Appendices

Appendix 5 – themes of responses written as case studies – Q12.

Negative sentiments of experiences:

- Poor quality of life (physically/practically) (57 – 14.4%)
- Poor quality of life (mentally) (48 – 12.2%)
- Health professional did not believe me/listen (33 – 8.4%)
- I have had no help/support (33 – 8.4%)
- My medication does not help/makes it worse/side-effects (25 – 6.3%)
- My referral/appointment/operation took too long (20 – 5.1%)
- My diagnosis took too long (13 – 3.3%)
- I was given medication and sent away (12 – 3%)
- There are no answers to help me (12 – 3%)
- Health professional made unsupportive comments (12 – 3%) – of these 6 were related to the patient’s weight and 6 were told to ‘deal/get on with it’
- My doctor won’t help/refer me (9)
- My operation was unsuccessful (9)
- My pain is getting worse (9)
- My employer is unsupportive (8)
- It is hard to access/get an appointment (7)
- The hospital/GP “made mistakes” (7)
- I am struggling financially as I can’t work or claim benefits (3)
- My family history was ignored (3)
- I am still waiting for help (2)
- I cannot clearly explain my problem to my doctor, and so I don’t get help (2)
- My doctor will not prescribe what I need (2)
- My family is unsupportive (2)
- There are no follow up/review/check ins on mental health (1)
- I have not seen my GP during the Covid pandemic (1)
- I received poor care (1)
- I would have liked to have been signposted (1)
- The pavement and road surfacing are to blame (1)

Appendix 6 – Background data

NHS Digital – Public Health England. “Chronic Pain in Adults 2017”

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/940858/Chronic_Pain_Report.pdf





Appendix 7 – Google keyword data

→ ↺ 🏠 🔒 tools.wordstream.com/fkt?website=chronic+pain	
Keywords	📈 Monthly search volume
chronic pain	8,100
chronic pain management	720



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