Living with Back Pain

Understanding Shared Decision-Making

March 2022

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Content

Executive Summary

Supporting patients in the decisions they make about their healthcare is essential for achieving best health outcomes and effective use of NHS resources. Personalised care helps to bring together health and social models of care. This approach enables people to have choice and control of their health, which in turn increases confidence and resilience and helps people to live well with their health condition. However, personalised care, requires healthcare professionals to work collaboratively across organisational boundaries to aid flexibility and effective care for individuals. The key area that underpins personalised care is the right communication and information, at the right time to aid understanding.

This report inter-weaves researched evidence, with the experiences of Sussex residents, as explored by Healthwatch in Sussex in a widely promoted online survey, and follow-up in-depth conversations with people living with musculoskeletal (MSK) pain. Whilst it is recognised that this is too small a sample size to be regarded as statistically viable, when combined with system and national data, it provides an indication of where effort is needed to ensure that the commissioning of MSK services has a holistic, integrated approach. An approach that focuses on the whole person in terms of physical, social, social-economic, biomedical, psychological, and emotional needs. This will bring the ambition and benefits of personalised care closer to being realised across Sussex for people living with persistent pain and not be seen as an add on.

We heard about a number of areas that could improve a person's pain journey the main ones being clear and concise pathway, and communication, including the provision of timely and appropriate information. There seems to be no pro-active approach to these areas with regards to:

- referrals

- understanding the MSK pathways
- information flow between specialties
- what the next steps are
- who people will be seeing, where, and timescales.

This means that services are not consistent, coherent, or connected, leaving many people who live with pain, having their lives on hold. Those involved in this study confirmed that this was the case pre-pandemic as well as during.

Disappointingly, people stated they still experience poor communication from healthcare professionals, with many sighting feeling not listened to, or unheard, not treated with dignity and respect, with some female patients not being believed, not being aware of the person's experience, feelings and perceptions, culture, and social circumstances. This is one of the core values underpinning integrated care.

https://www.usa.edu/blog/communication-in-nursing/

Another area of experiential concern was the lack of patient-involved regular and timely medication reviews. Several of the conversations reflected people being prescribed a medication, which was not reviewed for extended periods of time or if a review had taken place, they were unaware or not involved in this, resulting in peoples' confidence and compliance being put at risk.

Finally, people spoke of a need for the confirmation of a clear and concise pathway that was easy for people living with persistent pain and those who support to navigate. It was clear that this would help to build trust, along with good communication from the healthcare professional -as communicator and listener - improve the quality of the outcomes in consultation with the person, based on a collective ownership and shared responsibility.

In conclusion, this lived experience engagement has highlighted that the values of the Integrated Care System and MSK provision need to be aligned and joined up, to better support people living with persistent pain.

> 'My Rheumatoid Arthritis is quite well controlled but still always present, the level of pain/discomfort varies from day to day and hour to hour. Fatigue remains an issue, preventing me from living my life to the full. Osteoarthritis in my neck is becoming a problem affecting daily activity.'

Recommendations

This work must support the commissioning and development of a clear and concise pathway for MSK provision that goes beyond the clinical needs of people to one where the person, information and good communication is at its centre. This will provide better support to those living with persistent pain.

The system needs to consider how the pathway can avoid unnecessary re-routing (sending people down inappropriate side roads) or asking them to get off one pathway to get onto another pathway in order to access onward and ongoing support. This just causes longer delays, much frustration and does not support people living with persistent pain.

Preparing people

- **Co-production** - using the voices of people living with persistent pain to inform the development of care pathways and treatment programmes is vital for those living with persistent pain and for the sustainability of services. This approach can bring fresh solutions to the table, as well as highlighting areas for improvement. This will help to actively promote self-care and supportive self-management strategies to reduce over dependency on services and increase resilience for the person.
- **Primary care** – we recognise the challenges in accessing GP-led services (which we have shared insight on and one that continues to attract media interest) but also the need for early diagnosis.

  Therefore, when reviewing and recommissioning the MSK support this is an area that should be considered carefully, to ensure there are simple, well-advertised routes into accessing information, diagnostic support and onward care and treatment. For example, this may be through hubs and or links to community diagnostic hubs.
- **Personalised care** – helps to bring together health and social models of care together. By developing best practice, and what patient-centred and accessible community care could look like from the viewpoint of those living with persistent pain. This needs to include the **language used and timely back-up information** to explain strategies, medications, and treatment options.

  For example:

Communication between healthcare professionals and patients – who need to be listened to and heard, by using accessible language, rather than medicalised jargon. 'Be curious and ask, 'how can we make you more comfortable.'

An urgent referral will mean different things to different people. It is not a term that necessarily helps to manage peoples' expectations, nor does it provide a real timeframe for exploring support whilst waiting.

- **Pharmacological treatment options –** the evidence suggests this is an area that needs careful reviewing to ensure appropriate and safe use of medication. Therefore, timely and inclusive reviews, to help reduce addiction or over reliance to pain medications, which can lead to wider risks to peoples' health and wellbeing.

Supportive systems and well-trained staff

The national ambition to deliver personalised care and national guidance for pain management requires a move from transactional care to a more supportive system. This will mean exploring things like:

- **Pain Management Programmes (PMPs) -** development and implementation of a community specific PMP, one that is co-delivered in equal partnership by a healthcare professional and someone living with persistent pain or by support groups.
- **Additional Roles Reimbursement Scheme (ARRS) –** create a specific Social Prescribing role for Persistent Pain and MSK.
- **Physio support –** easy access to top up support such as drop-in sessions to support patients and increase access to support such as hydro-pools.
- **Emotional and mental health –** appropriate support for mental wellbeing of people living with pain and MSK as part of a holistic, integrated approach. 'Wheels of depression and pain – the physical has received support but not for the emotional and mental health side.'
- **Personalised care training for staff -** ensure staff are trained to actively support personalised care and that this is tracked through evaluation

and outcomes. The training needs to include having honest conversations with patients – which might be difficult – to discuss what help and support is available to support their individual needs and to make healthier choices and shared responsibility.

- **Accessible information –** ensure that the NHS England accessible information and communications policy is followed to ensure that patients receive good communication the enables individualised dialogue to enhance the patient experience. https://www.england.nhs.uk/wp-content/uploads/2016/11/nhse-access-info-comms-policy.pdf

Digital solutions

- **Integrated care** – people and those that support need to have more accessible IT systems for patients notes/records that can be accessed by all service providers. The need to explore opportunities to improve accessibility to treatment and bring care closer to home.

  For example:

  Making MSK information available in Sussex via My Care Records. Clear communication for apps, information, videos, etc.

Exploring Back Pain

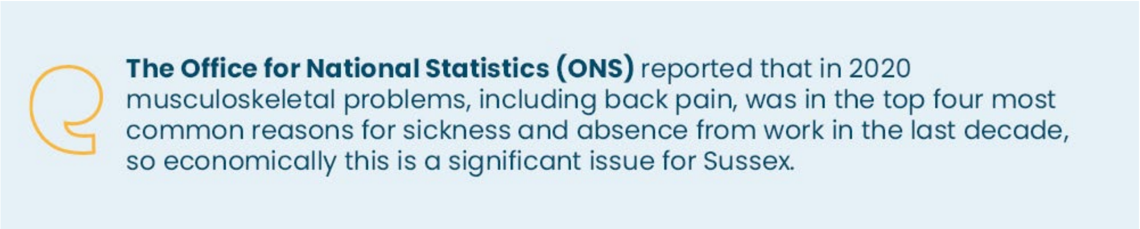
"More than 8 in 10 of us will have lower back pain at some point during our lives. [1] Sussex MSK Partnership

Many people experience back pain throughout their lives, whether an occasional twinge or longer-term discomfort. Versus Arthritis[2] estimates that over 20 million people in the UK (around a third of the population) live with MSK conditions, such as arthritis and back pain.

The cause of back pain can be difficult to diagnose, and in many cases, resolves on its own without medical intervention. However, for some people, back pain can cause enormous disruption to their day to day lives and activities.

> 'After a period of time the pain became intermittent and would come on for no apparent reason – getting out of the car, when walking, when sitting etc. But would settle for short periods of time.' (Interviewee.)

Treatment for back pain can vary, and may include pain medication, physiotherapy for mechanical issues, psychotherapy for related mental health factors or even surgery in severe cases.[3]



The Office for National Statistics (ONS) reported that in 2020 musculoskeletal problems, including back pain, was in the top four most common reasons for sickness and absence from work in the last decade, so economically this is a significant issue for Sussex.

[4]

Musculoskeletal issues accounted for 15.4% of sickness and absence in 2020.

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[1] www.SussexMSKPartnership

[2] https://www.versusarthritis.org/about-arthritis/data-and-statistics/the-state-of-musculoskeletal-health

[3] https://bepartofresearch.nihr.ac.uk/articles/Back-pain/

[4] https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/labourproductivity/articles/sicknessabsenceinthelabourmarket/2020

Introduction to Topic

The number of people living with chronic conditions, including back pain, is rising and many are intense users of health services.

In fact, over 300 million contacts take place annually between patients and NHS professionals to help make positive changes in lifestyle.[5] This accounts for 70% of the total health and social care spend in England.[6]

Care for chronic conditions 'account for **55% of GP appointments** and **68% of outpatient and accident and emergency appointments.'**

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In part this is due to the paternalistic role of healthcare professionals, which is costly, time consuming and does not enable people to self-care, especially when one considers that 'between 70-80% […] could.'[7]

People living with physical conditions such as back pain commonly experience mental health conditions, estimated to be about 30%. However, health service in England is not organised to fully support dual diagnoses, due to lack of integration and co-ordination across health systems, which means people do fall between the cracks.[8] The same is true for many people who live with co-morbidities living in deprived areas, as they have limited access to services which maintains the cycle of inequality. This has been highlighted since the pandemic. Although people living with chronic conditions and co-morbidities are intense users of health services, they are likely to only spend '1% of their time in contact with healthcare and the other 99% […] they look after themselves.'[9]

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[5] www.kingsfund.org.uk
[6] www.gov.uk
[7] www.kingsfund.org.uk
[8] www.healthcare@parliment.uk
[9] www.england.nhs.uk

> ‘I received some physio and traction but was told to: *‘just live with the pain as it is not a major injury.’* Sometimes the pain is bearable, sometimes unbearable, and always there. The pain has got worse over the past 5 years. I have to consider what movements I make and some days it is really disabling and sometimes better than others.’ (Interviewee.)

Self-Care

Many people want to take an active part in the management of their health and wellbeing. As suggested by Perkins et al. (2012, p.2) ‘becoming an expert in your own self-care: building a new sense of self and purpose in life: discovering your own resourcefulness and possibilities.’[10] However, this can be challenging without appropriate support. Self-care is not an alternative to medical care but aimed at helping people to ‘become an active partner with healthcare professionals.’[11]

Self-care is how a person looks after their health needs -medical, social, emotional – considered in a holistic way. Enabling people to consider making changes such as: eating healthy, doing some form of exercise, relaxation, making a social life or work life. Living with a chronic condition such as back pain means that some adjustments are needed but it does not mean giving up on all of the important things. The importance of encouraging people to see themselves as more than their condition and becoming an active partner in their healthcare journey is well evidenced.

> ‘I saw my GP around 15-20 years ago, when in my early forties and he prescribed a book -The Alexander Technique – and I use many of the tools in this book.’ (Interviewee.)

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[10] Perkins et al. (2012)

[11] Lorig, (1993)

The Care Act (2014), breaks 'prevention' into three general approaches:

1. Primary prevention: promotes healthy lifestyles to help prevent or avoid deterioration
2. Secondary: supports those with increased risk of developing needs
3. Tertiary: aims to minimise the effect of disability for those with chronic conditions and complex needs.[12]

This shows that prevention overlaps due to multiple conditions, stage of condition, as well as a variety of individual needs that benefit from a more individualised solution.

Self-care is a person's ability to manage the symptoms, treatments, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition such as back pain.[13]

Self-care is integral to the governments approach of Personalisation, enabling people to be at the heart of decision making about what matters to them.[14] The social determinants of health – the conditions in which people are born, grow, live, work and age – influence our resistance to illness and disease, as well as our ability to self-care. There is a risk that without easily accessible support and advice the advantages of self-care will only be felt by higher socioeconomic groups.[15]

> 'I know I am a complicated patient, and it does not help being told 'we can do nothing for you.' I do not know why, and they do not know what I am going through. So, I go to see the HIV Team and they write a letter to the GP.' (Interviewee.)

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[12] www.gov.uk/government/publications

[13] Barlow et al. (2002) https://pubmed.ncbi.nlm.nih.gov/12401421/

[14] www.rcn.org

[15] www.bma.org

Self-Care Continuum

The Self-Care Continuum[16] illustrates the sliding scale of self-care in the UK, starting with the individual responsibility. People make daily choices about their lifestyle, such as brushing their teeth, eating healthily, or choosing to do exercise.

Moving along the scale, people can often take care of themselves when they have common symptoms such as sore throats, coughs etc. for example by using over-the-counter medicines. The same is true for some back pain where people often self-manage without intervention from a health professional.

> 'A lot of people like me have difficulty accessing physio but need their support and advice. A drop in for physio would be great as you could check in every 6-12 months to confirm you are doing the exercises right. That would be helpful.' (Interviewee.)

At the opposite end of the continuum is major trauma where responsibility for care is entirely in the hands of the healthcare professionals, until the start of recovery when self-care can begin again. The NHS can support people to self-care at any point on the continuum.

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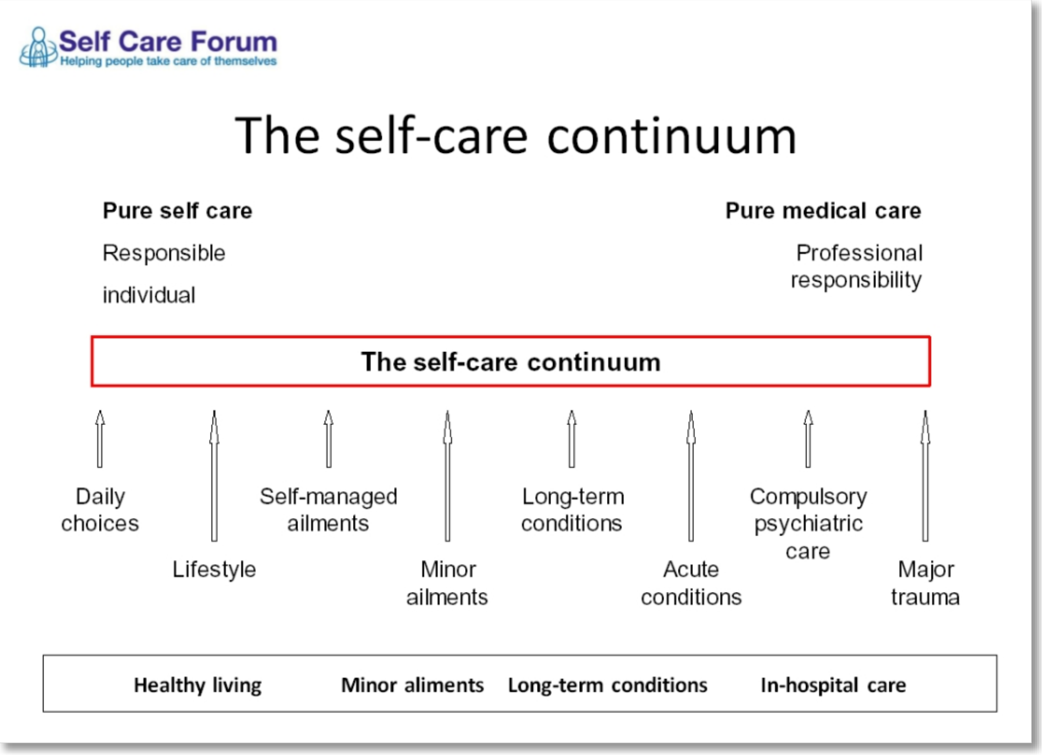
[16] www.selfcare.org



Self Care Forum
Helping people take care of themselves

The self-care continuum

Pure self care
Responsible individual

Pure medical care
Professional responsibility

The self-care continuum

Daily choices
Lifestyle
Self-managed ailments
Minor ailments
Long-term conditions
Acute conditions
Compulsory psychiatric care
Major trauma

Healthy living **Minor aliments** **Long-term conditions** **In-hospital care**

https://www.selfcareforum.org/about-us/what-do-we-mean-by-self-care-and-why-is-good-for-people/continuum-6/

Psychological adjustment

Self-care helps to empower and activate a person to cope better with the many challenges that living with a chronic condition such as back pain brings. However, the earlier a person acquires the skills and tools to self-care/manage the earlier the benefits for the health system. Benefits for the health system include cost savings, from people having the right advice, increased skills, less crisis management, being a partner in care and living a more full and productive life.

> ‘I use various Breathing techniques and have done so for many years. In fact, when I gave birth to my daughter the nurses could not believe that I was managing the pain using breathing.’ (Interviewee.)

Psychological adjustment is a unique relationship between a person and their world. For someone, living with a chronic condition such as back pain, the symptoms of the condition can be physically overwhelming, stopping participation in meaningful activities of daily living. As noted by Cox (2009) 'becoming the focus of their thoughts and feelings which can lead to depression, isolation and disability.'[17]

From the insight collected by Healthwatch we know people have difficulty

- **accessing safe information about their condition and available treatment options,**
- **the cost of treatment options,**
- **some feel silenced by clinicians who treat episodically and may not acknowledge their distress and use language that is too medicalised.**

This leads to loss of confidence, motivation, and self-worth.

Psychological adjustment refers to a 'healthy rebalancing by patients to their new circumstances'[18] Therefore the whole person is part of the solution, as these adjustments are not static, they are multi-dimensional and dynamic. Cognitive theories mediate between psychological and physical responses for example: two people living with back pain will have a different experience.

Psychological adjustment is individualised, a holistic process in order to find meaning by focusing on the positive to aid adjustment, this develops over a period of time and is influenced by a person past experience, age, gender, and those who support. The aim is to build many new tasks into daily habits – one step at a time.[19]

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[17] Cox (2009) as cited by Creedon (2011, p17)

[18] De Ridder et al. (2008, p.246)

[19] Realising the Value (2016)

For change to occur the person needs to be ready, willing, and able to make the desired change.

> ‘I guess people’s experience is individualised and the approach needs to be individualised. As all parts of the health and care system need to have an appreciation of the individual issues people face.’ (Interviewee.)

Personalised Care

Personalised care means people have choice and control over the way their care is planned and delivered. It is based on 'what matters' to them and their individual strengths and needs.

Personalised Care aims to benefit up to 2.5 million people by 2024, giving them the same choice and control over their mental and physical health that they have come to expect in every other aspect of their life. It has been noted that a one-size-fits-all health and care system simply cannot meet the increasing complexity of people’s needs and expectations.

Personalised care helps a range of people, from those with long term illness such as back pain and complex needs through to people managing mental health issues or struggling with social issues which affect their health and wellbeing. It helps them make decisions about managing their health, so they can live the life they want to live based on what matters to them, working alongside clinical information from the professionals who support them.

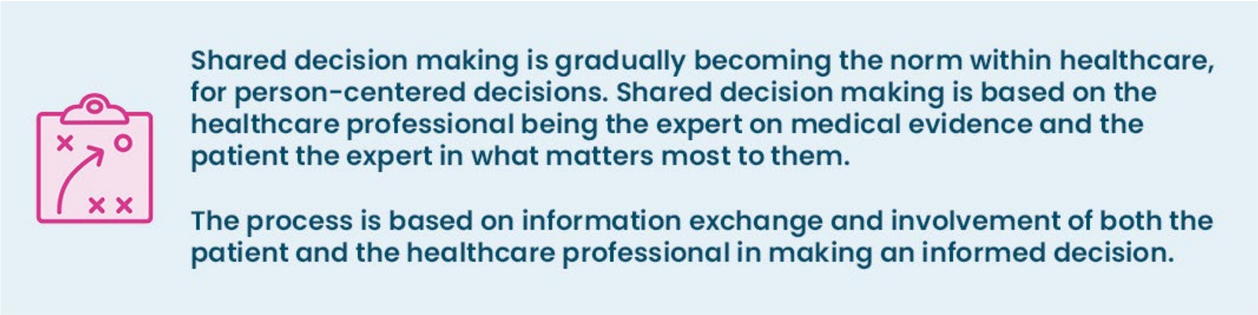
Shared Decision Making

Shared decision making is a process in which healthcare professionals and patients work together to decide interventions based on clinical evidence and the patient's informed preferences. It involves the provision of evidence-based information about options, benefits, risks, and uncertainties, together with decision support counselling and a system for recording and implementing patients' informed preferences. [20]

There is evidence that patients want to take part in decision making. A recent systematic review of peer reviewed journal articles found that, in 63% of articles most patients expressed a wish to actively participate in decisions around their treatment.

The wish to participate appears to have increased over time as studies published before two thousand, around 50% of articles found that most patients wished to be active partners in their treatment decisions, whereas from 2000, the percentage rose to 71%.

However, patients' preferences for involvement in decision making are variable and affected by factors such as, age, sex, and education.[21]



Shared decision making is gradually becoming the norm within healthcare, for person-centered decisions. Shared decision making is based on the healthcare professional being the expert on medical evidence and the patient the expert in what matters most to them.

The process is based on information exchange and involvement of both the patient and the healthcare professional in making an informed decision.

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There are many models for shared decision making, different setting, generic, and different elements: making a decision, patients' preferences,

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[20] BMJ Decision aids in the context of shared decision making (2021) BMJ 2021;373:n1430

[21] BMJ Decision aids in the context of shared decision making (2021) BMJ2021.373n1430

[22] Bomhof-Rooordick et al. (2019), BMJ Open

tailored information, create choice awareness to better understand what is important to the patient.

The main components suggest patients are encouraged to ask three questions:

1. What are my care options?
2. What are the pros and cons of each option?
3. How do I get the support to help me make a decision that is right for me?

Shared decision making has been shown to improve people's comprehension, reduce decisional conflict, and better align peoples' expectations with the outcome.

Image from Centre for Ageing Better

What do people need to do to make shared decision making a reality?

What motivates people to self-care has been defined as a person's 'ability to manage the symptoms, treatment, physical and psychosocial'[23]

Confidence and motivation

Realising the Value (2016, p14)[24] suggests that 'motivation means being moved to do something.' Self-care is an opportunity to build confidence and expertise communicating with care providers. So often 'complex content, style, and language […] can limit confidence, and motivation.[25]

It is important to add that people need confidence and motivation to carry out a behaviour change to reach the desired outcome.

Empowerment/self-determination

A key driver for behaviour change is empowerment, to feel able to 'engage in their own care and to partner with professionals.'[26] Self-determination encompasses empowerment, confidence, and participation.[27]

Helping people help themselves (Kings Fund) report showed there is a correlation between 'how people think and feel about their condition and the impact on their health behaviours and outcomes.'[28] (p.3) This report also noted that there is a 'direct link between education, self-care behaviours and psychological outcomes, stress, coping and quality of life.' (p.5)

The Richmond Group Vital Signs conditions such as back pain (p

The Chronic Care Model vision is for 'interaction between a prepared, proactive practice team and an informed, empowered patient and family.'[1]

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[23] Department of health (2011)
[24] Realising the Value, (2016)
[25] Galdas et al. (2014)
[26] Yukawa et al. (2010)
[27] Colagiuri and Eigenmann (2009)
[28] Kings Fund (2011)

not equal partners in their care.' [29] The report noted (p.12) that it is important to support people to 'cope better and become more knowledgeable and independent.' Yet currently, few people attend any form of structured education for back pain conditions.

The National Context

Shared decision making, the shared responsibility relationship between a clinician and a person living with a condition such as back pain helps to make informed decisions about their treatment, tests and support options drawing on clinical evidence and the person's preferences is referred to in a number of publications.

- The Care Act[30]: 'look at an individual's life holistically' (DH, 2014, p.16).
- The NHS Five Year Forward View[31]: 'increased prevention' (NHS, 2014, p. 6).
- The NHS Implementing the Five Year Forward View for Mental Health[32] states parity of esteem 'integrated with physical health' (NHS, 2016, p. 16).
- King's Fund, Transforming Our Care System[33] suggests 'helping patients chose healthy behaviours' (2011, p.2).
- Kings Fund, bringing together physical and mental health: a new frontier for integrated care[34] (2016) suggests 'explore[ing] what a person's wider needs might be' (p.14), and the importance of communication as the 'psychological impact of physical illness [be] less harmful if professionals had communicated [...] more effectively' (p. 15).
- Kings Fund, Long-term conditions, and mental health: the cost of co-morbidities[35] (2012) suggests; 'improved support for the emotional,

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[29] The Richmond Group Vital Signs (2015)
[30] www.gov.uk/government/pubications
[31] https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf
[32] https://www.england.nhs.uk/wp-content/uploads/2016/07/fyfv-mh.pdf
[33] www.kingsfund.org.uk
[34] https://www.kingsfund.org.uk/publications/physical-and-mental-health
[35] https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/long-term-conditions-mental-health-cost-comorbidities-naylor-feb12.pdf

behavioral and mental health' (p.1). That those with multiple conditions have worse 'quality of life [indicators, especially when having] two or more physical conditions' (p. 7).

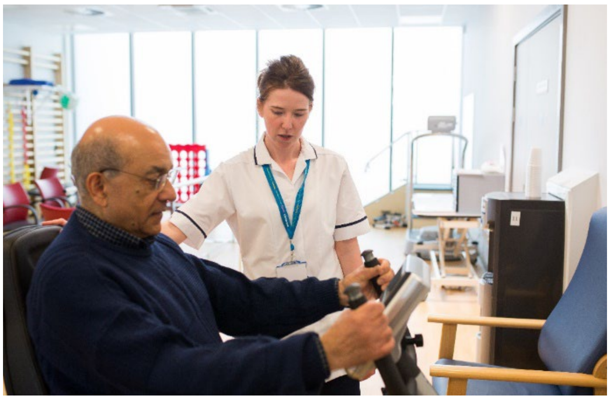
- Realising the Value, at the heart of health: realising the value of people and communities [36](2016) suggests; 'increases in people's self-efficacy and confidence to manage their own health and care' (p.5).

Integrated Approach

An Integrated Care Approach aims to support people's health and wellbeing – physical and mental – in a more joined up way. The interprofessional nature of today's care, needs different specialities that work together to create a clear and concise pathway. This means that traditional silo working moves to a more collaborative integrated approach to care, which is holistic and seamless for people.

This approach works closely with the local community and voluntary sector to address needs.

The Sussex Health and Care Strategic Delivery Plan is available from www.sussexhealthandcare.uk/about-us/sussex-health-and-care-plan/ .



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[36] www.realisingthevalue.org.uk

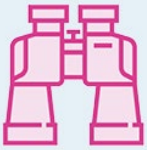
Learning from our Living with Back Pain Project

Our research included a quick evidence review, for back pain, we found that it is a common and disabling disorder, representing a great burden to the person, those who support and society. It often results in reduced quality of life, time lost from work, and increased medical interventions.

Pain completely dominates a person's life by infiltrating every aspect of their life, personal and professional – home life, relationships, social life and work, study, and professional progression. On a more personal level feelings, emotions, thoughts, and behaviours which is why dealing with persistent pain can be so overwhelming.

> 'Pain is like the bogey man who enters a person's life uninvited and affects every area of it and won't go away, we find ourselves living with pain whether we like it or not and truly we don't like it. It makes us feel inadequate, unhappy, and unable to live the life we want.' (Interviewee.)

The aim was to learn from Sussex residents the impact of living with long-term physical pain.



To achieve this, we co-produced a focused way of looking at what matters to the individual to better understand if the right provision is currently available to give choice, control for pain management, and ensure that the right care is commissioned and delivered for the future.

Our work had two main elements, a survey and telephone conversations with people living with back pain.

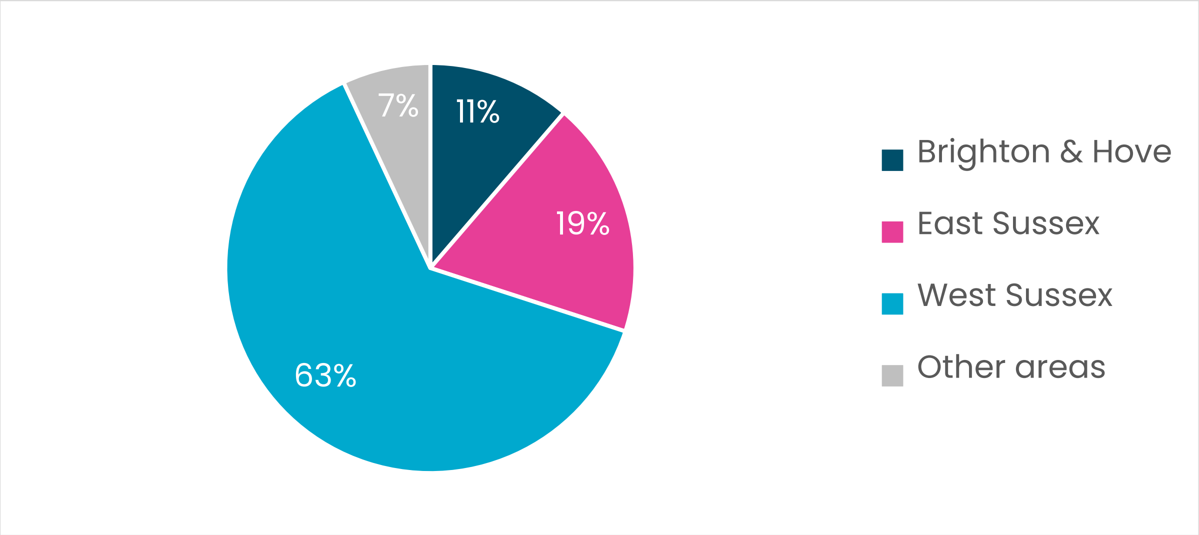
The survey was co-produced and tested by volunteers during October 2021, suggested amendments made. It was live from 12 November 2021 to 31 January 2022. 230 people completed the survey.

The survey was widely communicated to the voluntary and community groups and via social media.

We would like to 'thank' all who completed the survey, and shared their stories, to support this work.

Participants for the second element, the telephone conversations were sourced through survey respondents answering 'yes' to taking part in a follow up telephone interview. Seventeen people living with back pain participated. The aim of the telephone conversations is to ensure that the lived experience is included.

Survey information



81% (n182/224) of responders had received a diagnosis for their pain and condition.

Half (51%, n97/191) reported living with one condition and half were living with more than one condition, comorbidities (49%, n94/191).

The main reported conditions being:

Osteoarthritis (n39)

Ehlers Danlos Syndrome (n38)

Arthritis (n31)

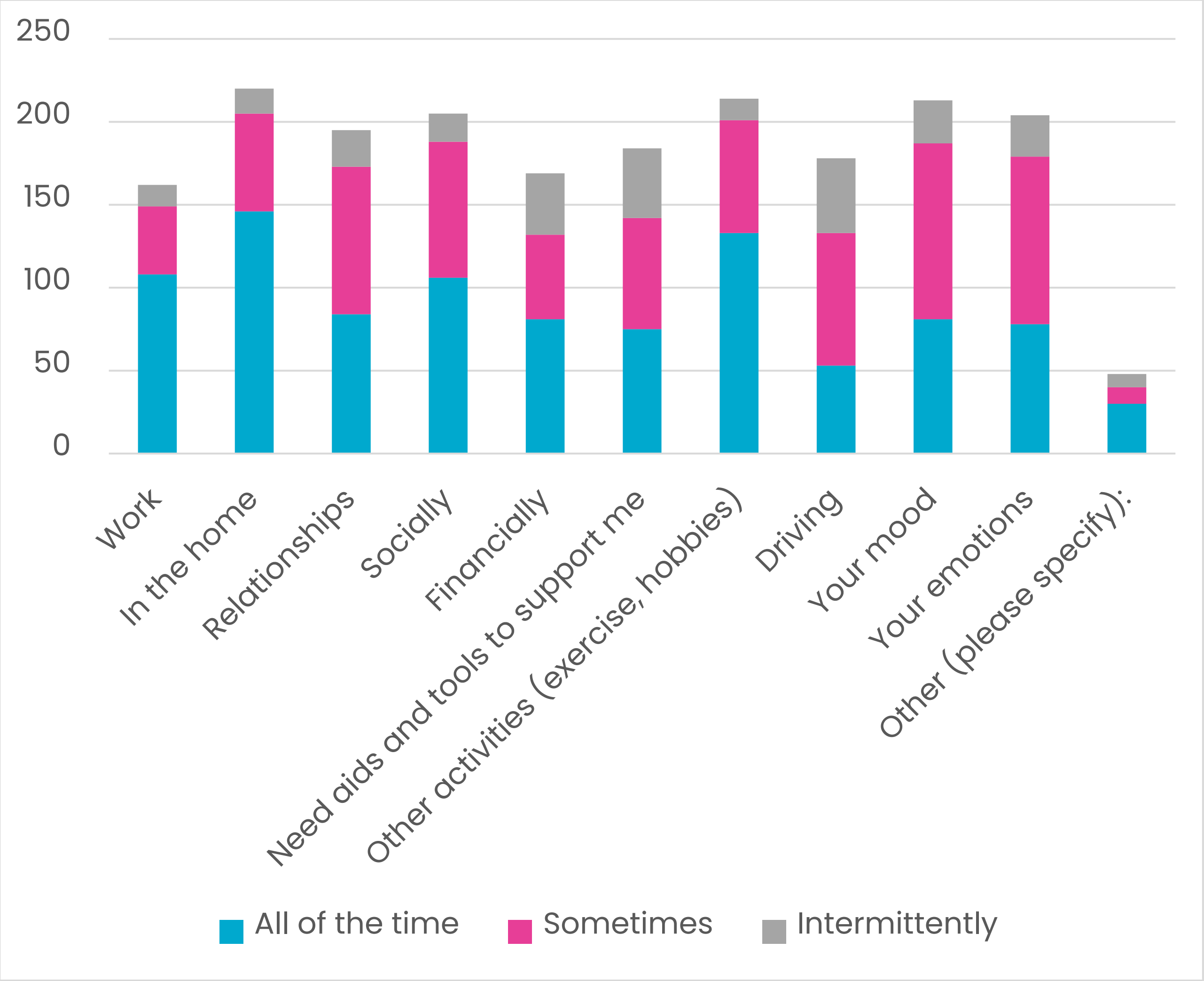
Fibromyalgia (n24)

Degenerative and slipped discs (n15)

Hypermobile Ehlers Danlos (n14)

Accident (n6)

In answer to the question as to how pain and condition affects day-to-day living there is a wide spread of responses.



Additional responses from responders help to put these responses into context.

- Mental health suffers when pain is extreme.
- Fatigue/tiredness/quality of rest.
- Depressed, unmotivated, quick tempered, zero interest in sex life, comfort eating.
- Pain is ongoing, I go to sleep and wake up in pain and most nights I am awake because of the pain.
- Self-confidence.
- The most frustrating is not having answers as to the cause.

More detailed responses include:

- I am always in some degree of pain, some days are better than others, but I am almost always affected by this (6 out of 7 days a week) - tend to be more unwell in the colder months especially.
- Pain is something I have lived with for 4 years. I have had multiple surgeries and been told 'this should sort the issue, reduce the pain.' I am still in constant pain all of the time. Pain is ongoing, I go to sleep and wake up in pain and most nights I am awake because of the pain.

How pain and condition affect close family and those who support the following comments were made.

- Husband restricts his walking to walk with me.
- I become irritable.
- I don't think they believe how bad it can be, or care.
- I don't visit them so often.
- I rely on family and friends to help in practical ways when my pain means I cannot function properly.

- They can struggle to engage with me as I can become very shut off when in pain and feel guilty about cancelling plans. They have to support, with daily household tasks. I can be snappy and emotional.
- They feel helpless.
- Grumpy due to constant pain.
- I rarely get to see them and making plans is hard as my condition can fluctuate. I always suffer more after driving and social interaction, its physically and mentally challenging. Invisible illness is hard to explain to others and they look at you and say, *'well you look ok.'* The feeling of isolation is like *'lock down'*. It was not much different for me, except the choice was removed for good days. I know my family don't understand the full extent of my pain.

> 'I am unable to regularly contribute to home costs, and things cost more. I use the bathroom more, my food is more expensive, I am unable to help with cleaning the home, so we pay a cleaner to help us stay on top of it. I can't change my bedsheets; I barley use my car I had to sell it recently and now share with my mum. I struggle to sleep and can have a flare at any time and need to lay down in the dark and quiet. When we are out of the house, I need help locating food and ordering, finding bathrooms and seating for breaks. They do a lot of the thinking for me as I can panic and be unable to focus.'

Comments on the effect on those caring for someone living with pain.

- A lot of extra help required from partner, who in addition to working full time, has to carry out many tasks around the house that I would normally have done i.e., prepping food, vacuuming, cleaning. Simple things like opening bottles, removing foil from milk bottles, even cutting my food when hands are bad.
- Husband cares for son and it causes a great amount of stress for him and affects our relationship.

- My partner is now my carer so has a lot more responsibility however does not receive money to care for me.
- I feel dreadful needing help dressing/undressing. My poor husband!

Nearly all responders (94%, n205/217) confirmed that they have had to retell their story more than once when engaging with services.

- I visited the GP who said it looks like osteoarthritis. On another visit he told me to self-refer to physiotherapy. I self-referred and saw a lovely physiotherapist who gave me some exercises to do at the gym and at home and was seen about four times. He seemed happy with my progress and decided there was no need to continue seeing him.

  The pandemic hit and my exercise went downhill rapidly. I don't feel I'm any further forward and most probably I'm in a worse situation than previously.
- No one has ever heard of the condition or if they have, feel they know more than the patient who has had it all their life.
- A diagnosis of Endometriosis took eight years and I had to explain my circumstances many times to GPs, consultants, and nurses.
- It almost feels as if the doctor hasn't even properly read my notes before the appointment. I understand my consultants won't remember me, but I do expect them to read my notes before, so it doesn't feel like I'm constantly repeating myself. I've even had a doctor ask about one symptom when my actual symptom was the complete opposite (one I mention every time as it's my most prominent symptom). It makes me feel like no progress is being made.
- Nightmare! My wife and I had to do all the research and attended many appointments with specialists both locally and at Guys Hospital in London. After months of driving back and forth we paid nearly £1000 out of our own money and after three appointments, obtained a diagnosis from Private hospital. The next three years I was given numerous

different pills and potions and tried numerous painkillers and none of the attempts ever helped with the pain.

- I was referred (upon my request) to a private specialist in Harley Street who confirmed the diagnosis and gave me a pain killing injection into each buttock but once again, it never even touched the pain. This has turned my whole life upside down and I have no hope that this condition will ever be treated in the future. I can’t bear the thought of having to live the rest of my life in this constant pain.
- The most common fob off we get as a patient body is that we are ‘just a bit bendy’ or that our condition is caused by anxiety- my joints are DISLOCATING! I usually end up having to show people which is not good for my joints. Patients should be believed - not have to prove themselves!
- I have a life-long impairment but the way it affects me is unique to me - so although doctors and nurses will be familiar with my diagnosis, they don't always understand how it affects me personally, I have to explain - frequently.

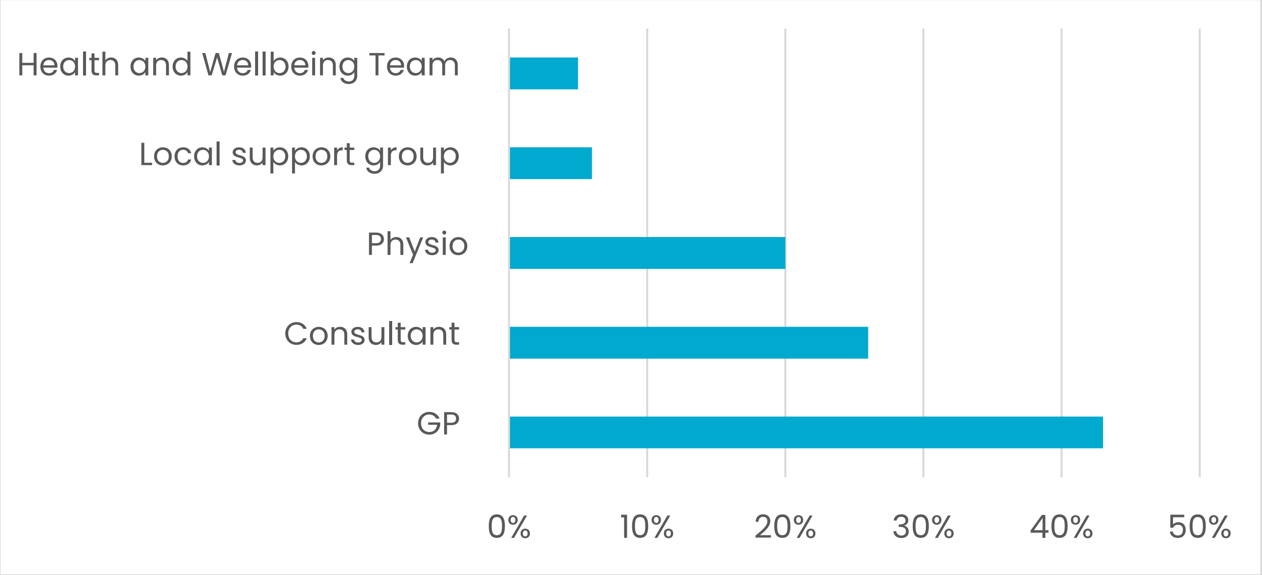
> ‘As I'm young I've felt that my *pain and comments about stiff, achy, and cracking joints have been ignored.* I have been told countless times that some people have joints that crack a lot. I have been told to do exercises that led to increased pain and when I explain that frequent exercise causes pain, joint stiffness and fatigue which only stops once I have had a period of rest. I was told to continue exercising even though it hurt for days. I’ve had countless blood tests due to fatigue all of which have shown that there was no known reason for my tiredness.
>
> The pain in my left hip has been on and off for years it hurt for a few days and then went away. In August 2020, the pain started but never stopped even after prolonged periods of rest. I was seen by Sussex MSK physio who examined me and gave me exercises which made the pain worse. By this point my lower back was causing me a great deal of pain and tensed to the point I couldn't walk more than a couple of hundred

meters without having to stop, as the exercises exacerbated my lower back. I explained all my symptoms to the physio who only focused on my hip. I enquired what might be causing the pain and was told that *'a confirmed diagnosis of a condition wouldn't change the physio plan I had been given'.*

I was referred to the rheumatology nurse who spoke with me over the phone, she informed: '*that Ehlers Danlos Syndrome (EDS) is very rare, so I probably didn't have it.'* The specialist nurse did not even go through the hEDS check list and instead supported a Hypermobility Spectrum Disorder diagnosis which I had been given over 20 years before when I had cartilage removed from both knees. The pain in my hip continued and I insisted on an x-ray which showed severe osteoarthritis in my left hip and needed a total hip replacement. I was then given different and less frequent physio exercises as a result.

I have had no further support from the Sussex MSK Rheumatology team about how best to manage my symptoms, nor a face-to-face appointment with the rheumatology nurse. Again, raised that I suspected I may have EDS, and yes, it is rare but so is such a severe case of osteoarthritis at 44-year-old - just because it's rare doesn't mean I don't have it! Rather than see the Sussex MSK nurse, they have referred me to the rheumatology department at Surrey and Sussex Healthcare NHS Trust.'

In answer to the **current support receive to manage their pain and health condition**, respondents (n220 replied to this multiple question) stated it is provided by:



The following comments help provide context.

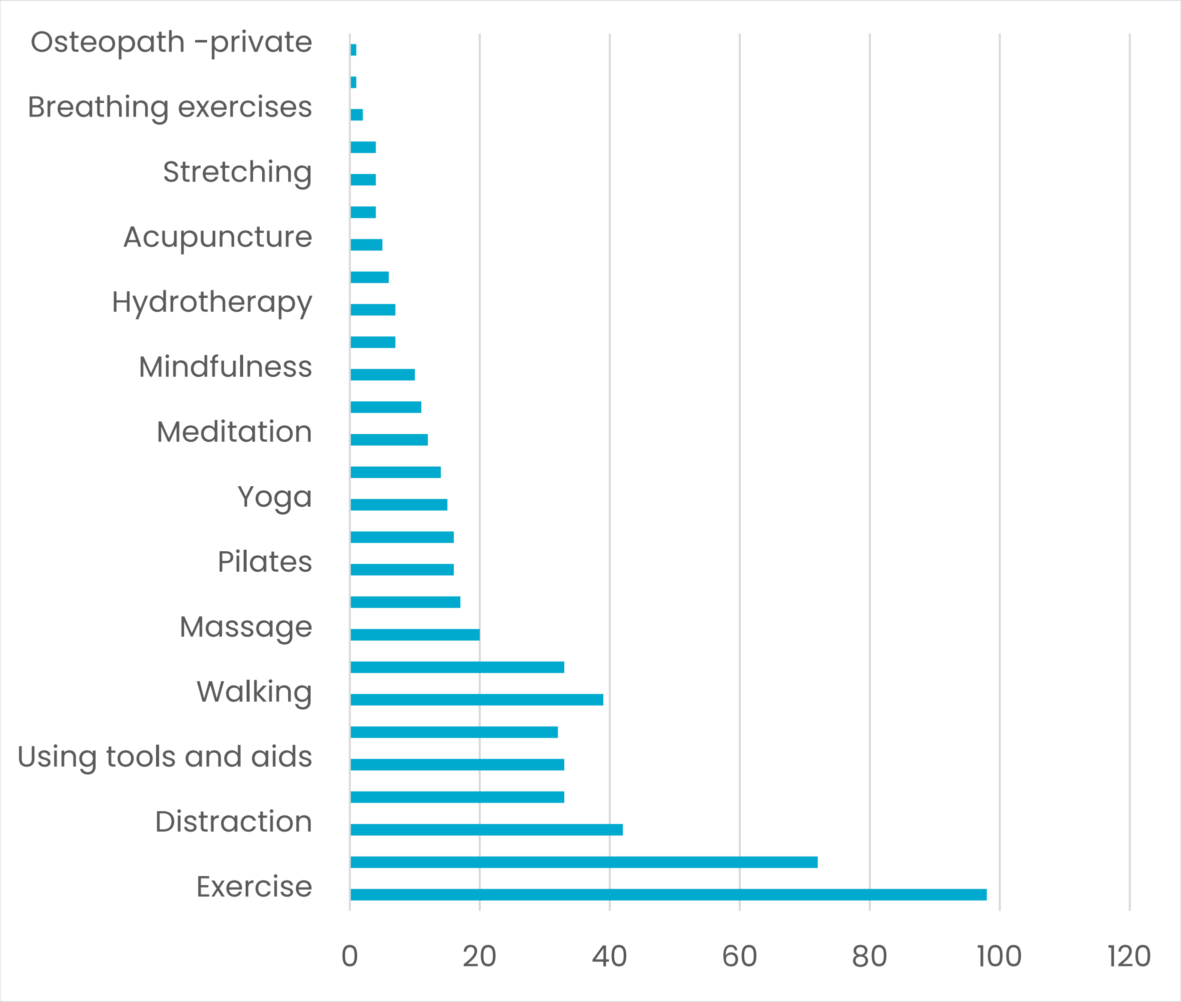
> ‘Every time I go to a new appointment they start with a blank page! They never know my medical history – it’s long/very complex and hard to relay everything each time! By the time I’ve explained everything they just look at me bewildered and say I’m too complex! There needs to be a way of medics sharing a summary across all hospitals/trusts/GP’s etc., every time repeating, and they also repeat the same treatment, which is a waste of their money, for example: they keep referring me to the pain clinic and physio.
>
> I do the meditation and stay active as the pain clinic suggested and I do the exercises that the physio asked me to do. Both the physio and pain clinic say there is nothing else we can do but the GP keep referring me to them. I am sure that they could offer vouchers towards therapy sessions, swimming, and others but the NHS have become greedy just wants the taxpayer’s money without giving the services that we need and deserve!’

- Currently not being treated as floating between Clinical Commissioning Group, GP, and University College London Hospital are not accepting referrals yet, so no suitable service has been identified.
- There is no one doctor who is actively understanding my day-to-day issues. No doctor actively trying to understand all my issues as a collective of many different body systems impacted. It is so very discouraging, invalidating, despairing, angering, depressing, frightening.
- Each time I speak to a new GP or consultant I explain what hEDS is, as I'd rather explain it to them from my perspective than they presume; a) know anything at all about it and b) don't presume that my experience is the same as their knowledge. At my doctor's practice I don't often speak to the same GP each time and as my pain is variable it makes sense to try and explain as best I can each time. I'm not sure how clearly, I manage to explain it though.

> 'I don't feel the GP service has the capacity to consider options of support. I have been asked why I am there at appointments. I have explained about musculoskeletal problems but there was very limited exploration of the problem. Two occasions I asked to be referred to physio, which I was and the other time I asked to be referred to orthopaedics for back pain. I was asked about pain relief and when explained I was taking Ibuprofen and paracetamol at all regular intervals, I was prescribed Omeprazole (one occasion)/ Lansoprazole on another.
>
> There was going to be a long wait for an NHS referral, so I requested a private referral to Orthopaedics. Was sent for an MRI which showed some degenerative changes, it did not provide any clarity to the source of pain. The consultant asked what I wanted to do, but it seemed that as I did not need surgery nor going to be paying a high surgery bill, he had no real interest in exploring. After much probing for support, he offered to give an injection that he said, 'probably

> wouldn't help but it might so to let him know if I wanted it.' I have lost all confidence to seek help. No one has the capacity to explore my individual difficulties.'

217 respondents shared the wide range of self-care strategies they use to support themselves with their pain and/or health condition.

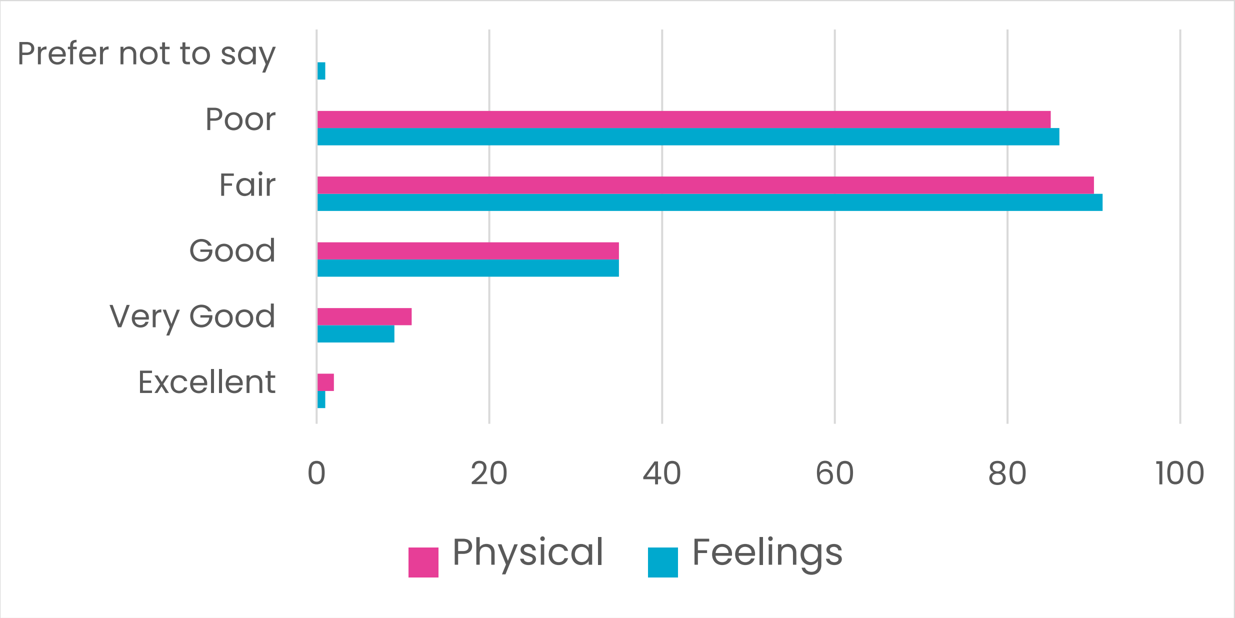


The following comments help provide context.

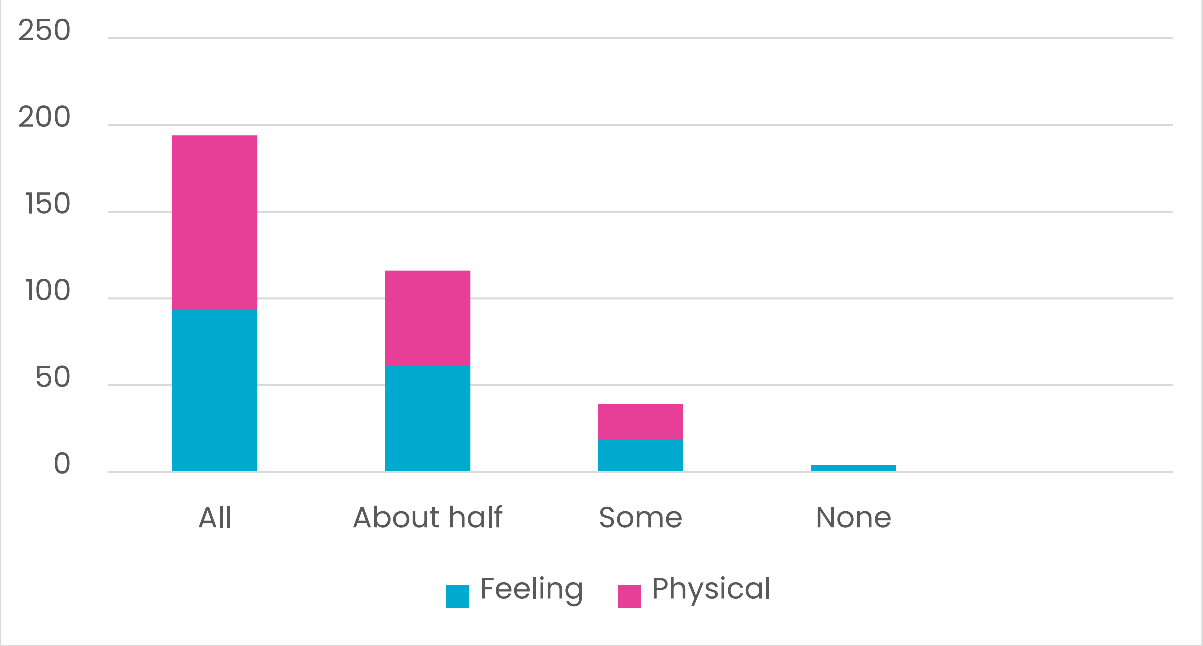
- Self-medicate whenever I can and use over the counter.
- Distraction is the only thing that works. Nothing else helps.
- Exercise and medication, mindfulness, distraction, I should be doing stretches but need reminding and support for this, pacing myself.
- Manage my routine and schedule to allow for rest periods and 'quiet' days balanced with busy days.

> ‘At the moment I am struggling with self-care. These things are critical, but I don't have access to hydrotherapy pool (or a way to get to the pool). I cannot do the exercise needed to get my whole body moving and improving. Without this foundation to help improve weakness and fatigue there is very little energy to ‘push’ myself.
>
> Self-care is much of what I have done over the years very successfully while I had funds to pay for things privately. Then having learned body management and other tools (meditation, improved nutrition, etc.) and enough physical improvements (strength, and energy) to be able to continue these positive steps forward on my own.
>
> Currently, I am in high fear/anxiety mode and mostly resorting to negative coping strategies - often distraction and freeze shut down. On days I feel better can-do laundry, change bed linens, cook a meal, occasionally get outside for a walk with my kids or go to the nearby grocery store for a few bits and bobs. Priority must be to get my body moving regularly and very gently.
>
> It is a massive mountain to climb. I am knowledgeable, still trying to stay hopeful but the NHS has really let’s down those of us with EDS and all the complexities of this multi-system disorder.’

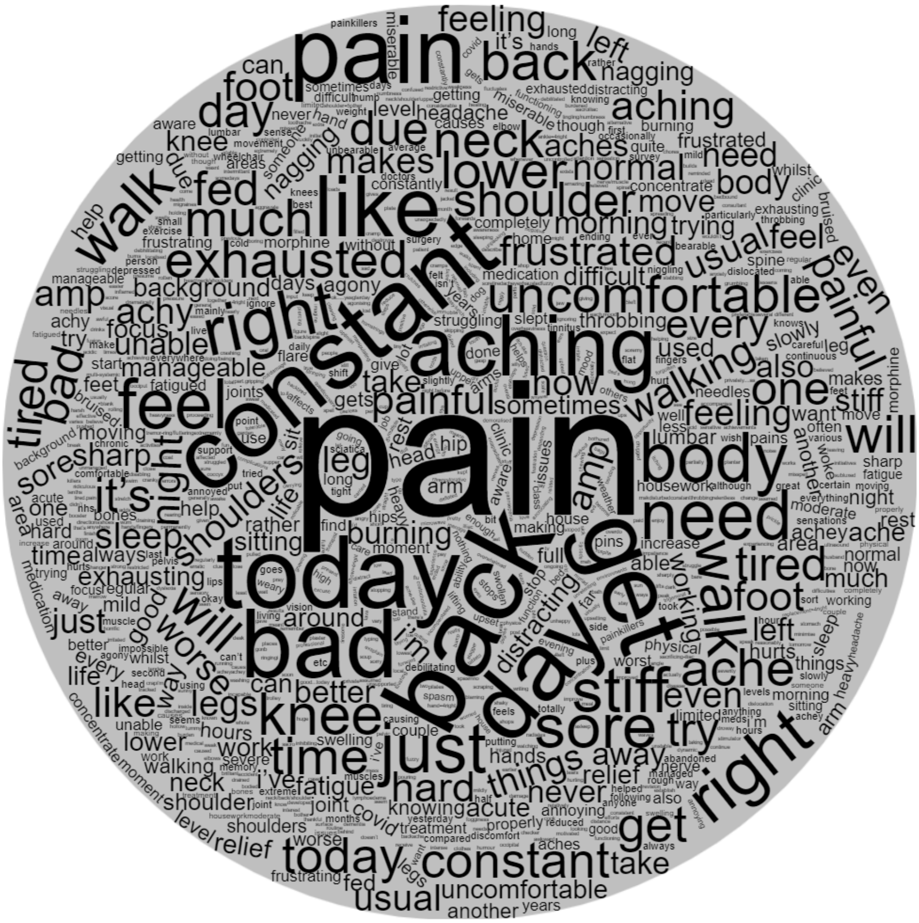
Almost all of the responders (97%, n223) self-rated how they were currently feeling and their physical health.



80% feelings and 78% physical health was reported as being linked to pain or condition.



The word or words used by respondents (n217) to describe how they feel pain wise today, is shown in the following word shower.



The following responses provide context.

- Can vary from hour to hour, not just day to day. I usually feel rough for the first couple of hours, after which it varies depending on what I do, that day.
- Achy, inflamed, constant, exhausting.
- Very painful, especially my back.
- Tired, overwhelmed, angry, upset, confused.
- Acute pain in knee and hip caused by dislocated hip earlier this evening. Ache-like pain in one part. Gripping pain in my stomach. Itch-like prickle in another area.
- Better today because the sun is out! Lifts mood and, to a certain degree, lessens pain. Also slept better last night.
- Exhausted and totally demoralized with life.

Just over half (n115/221) reported having had a conversation with their healthcare professional about the benefits, harms, and consequences of potential treatment. The following comments explain their experience.

> 'I feel like my GP respects me and my knowledge about my condition and ability to conduct my own research, and where the research comes from (anecdotal or proper, peer reviewed science, or a single scientific study). But consultants are often a lot less likely to accept you know about your own condition. I feel there is still a lot of prejudice and post code lottery going on that does not allow for the best care of patients.'

- GP explained that surgery might be an option, at some stage, but regarded as a 'last resort', because success rates are not high and could make things worse. Not a risk I would take, all the while I can manage and cope with the pain.

- GP spoke about dangers of opioids but prescribed them after a discussion about how they were used.
- Helped me understand that there isn’t a potential treatment that will improve things, but I can help myself.
- I always ask about side effects and combinations of the numerous prescription drugs I take. I feel that GP doesn't always know the answers, and I have previously asked for changes because of side effects.

> ‘Helpful, but dismissive, for example *‘you just need to carry on with what you're doing and learn to live with it.’*

- I have done this, but they had already made the decision of what treatments I was going to have. They gave me the information but not the choice.
- Arthritis. Yes, very clear advice. I was given a form to fill in which proved the pros and cons. Currently, pain management is working. if I'm offered a choice, I will not choose surgery until the loss of mobility becomes acute.
- Felt very textbook, following a protocol, didn't feel tailored to me as an individual.
- Generally, when I speak to a clinician, I just want something to reduce the pain, however, I do also want to know how the medication works and any contra-indications.
- GP and pain clinic were constructive in discussing referral to most appropriate clinic. But this was not helpful as this clinic is closed to referrals outside of London, for the last 2 years due to COVID. This is the only clinic in the south to treat my condition.

> ‘Having just had yet another operation on my spine, I found the list of potential problems quite daunting and even wondered why on earth anyone would still have this operation with such a doom-laden list.

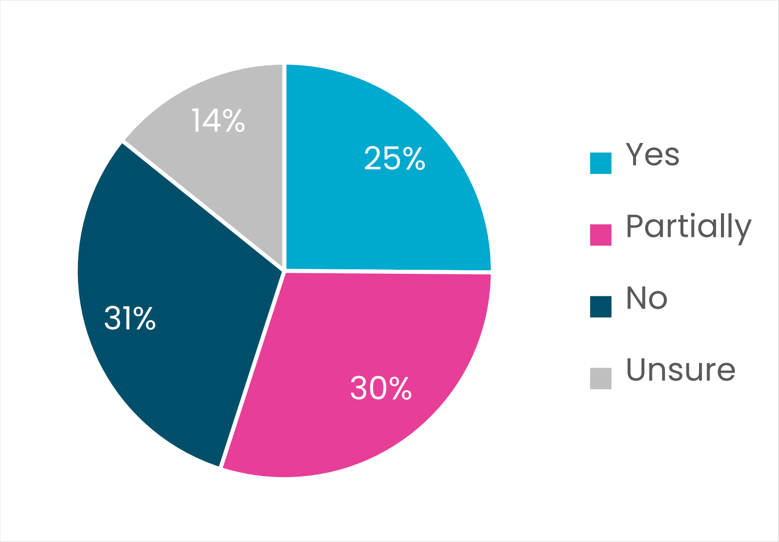
> However, I do realise that in these days of suing suits the NHS has to cover themselves.'

Just under a quarter (22%, n49/220) reported having had a conversation with their healthcare professional to understand their values, beliefs, and preferences. (What is important to you?)

The following comments were received.

- A superficial conversation with GP - I said I'd carry on with my 2 paracetamol, at night, continue with private Pilates and physio sessions. No further discussion planned.
- A final follow-up with the Nuffield consultant who organised MRI on behalf of the NHS (because of time delay.) He talked to me and reassured me I did not have spinal stenosis (every health professional I've seen has thrown that one at me - causing much anxiety!) He applauded my aim of rejecting drugs and continuing Pilates and Physio and certainly did not make me feel like a nuisance for not taking painkillers! I thought NICE recommended in April 2021 that painkillers for chronic pain were not a good thing!! HELP!

202 respondents answered the question, during 'your conversation with your healthcare professional, did you feel your ideas, concerns were listened to.'



The following comments help provide context.

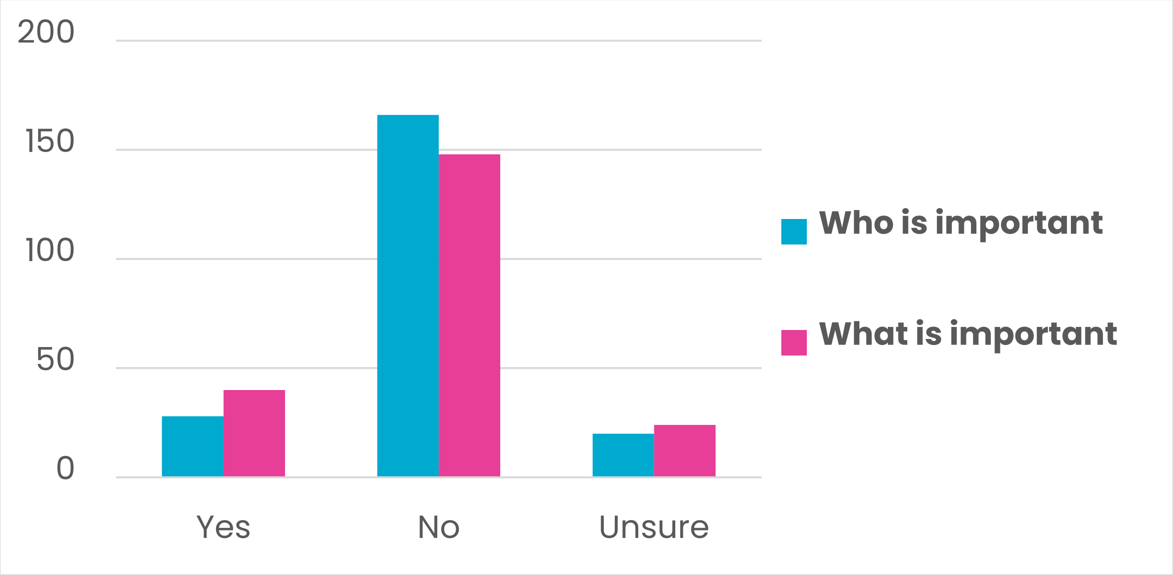
> ‘I am comfortable being assertive expressing my medical needs because of having experienced so much medical trauma in the past where my needs were not listened to, or I assumed that my best interest was also the hospital/doctor's best interest and that proved not to be the case.’

- I feel my consultant understands me, but my GP seems not to be in the loop!
- I felt heard and understood and part of my treatment team.
- I have to be very positive to get attention - also it gets very difficult to get continuity of care from my GP practice.
- I see so many. Some aware good and some need referring to PALS!
- I was listened to but feel that I have to self-manage my condition.
- I went to a private consultant rheumatologist.

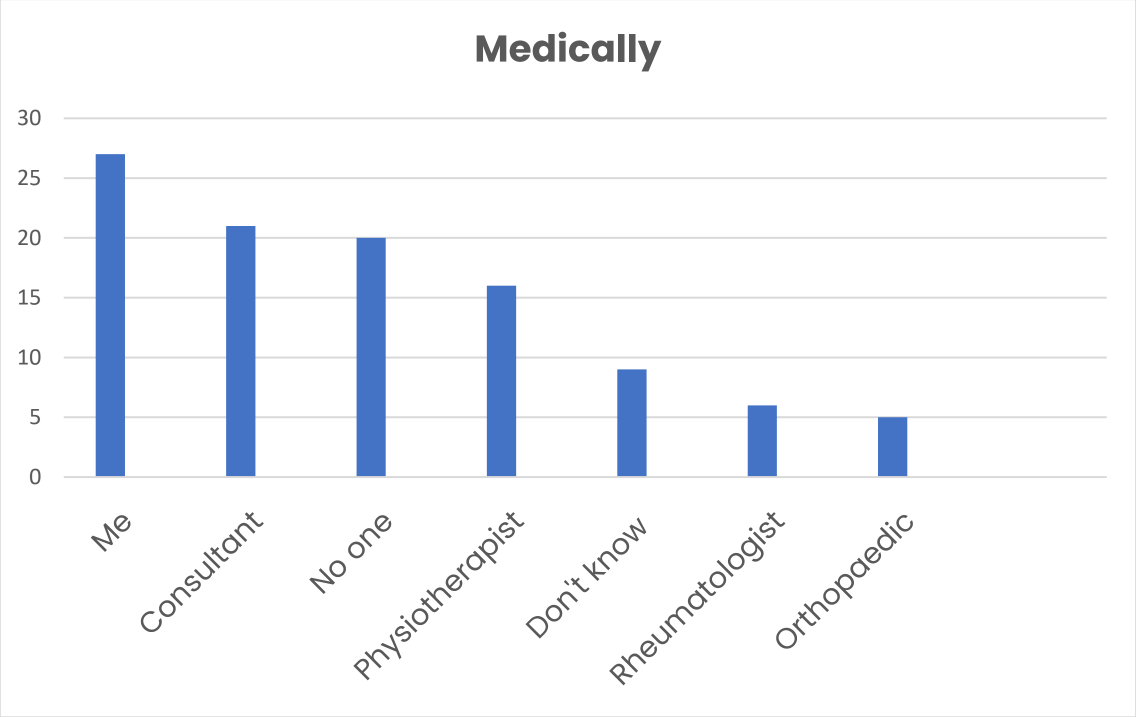
- In the absence of an appropriate specialist to treat my genetic condition. I have discussed research from EDS UK with my GP, and we have agreed referrals based on this. I am having to treat myself with my GP’s support and medical knowledge!
- Doctors are too busy to give full attention to you. They are always reading their computers or explaining medications.
- GPs do the best they can in 10-minute appointments. It is not possible to see the same GP on every consultation. Of course, they listen and respond appropriately. I supplement my understanding with information available in NHS leaflets and websites.
- More recently, during the pandemic my GPs have talked with me for up to 30 minutes on the telephone, which has proved extremely valuable.

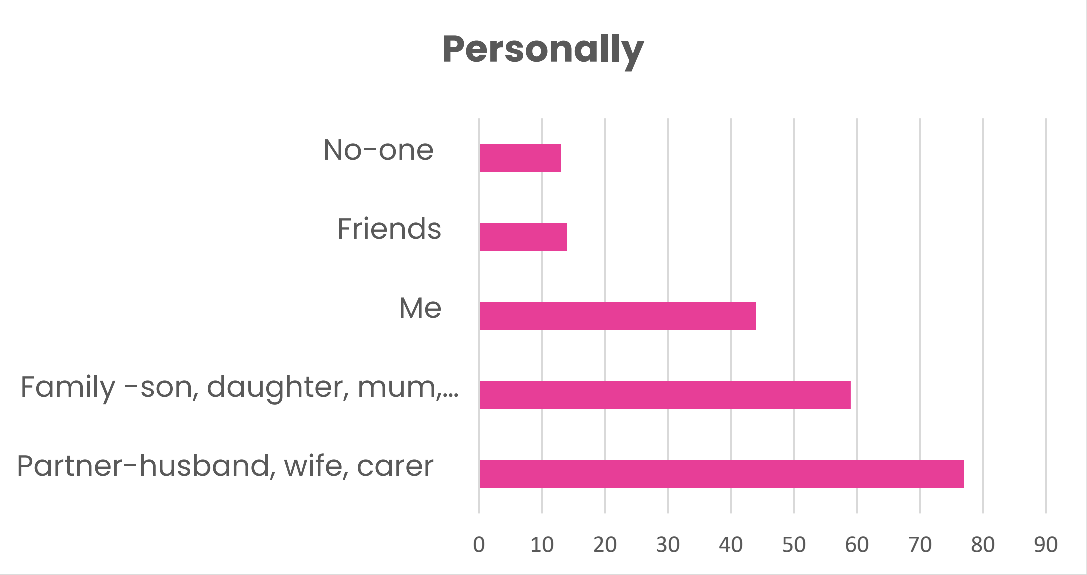
> ‘I KNOW I won't get any help or advice from my GP surgery as experienced when I last contacted them about breathlessness. I also know that I will never know what causes, or could help, with nerve pain. I was diagnosed with Essential Dystonic Tremor (not severe), and no one knows what causes this, so it's a waste of everybody's time.’

Respondents confirmed that they have had no discussion with the NHS on who is important (n166/214) and what is important (n148/212) to them.



Just under 200 people answered the question around who were most important– medically (n191) and personally (n199) - regarding pain and condition.





The things respondents said they needed/not needed in their life to make them happy and to be able to live with pain, were:

Must have (n201):

- Access to medication and regular reviews.
- A diagnosis from doctor.
- A listening, empathetic consultant.
- Access to nature, healthy and enjoyable diet, warmth, and companionship.
- Adapted living space, access to the outdoors, and people.
- Aids, support with finances, understanding, awareness, knowledge of my condition.
- Control of severe symptoms.
- Deep heat, fun things to do.
- Easy access to GP and Consultant.
- Family and friends.

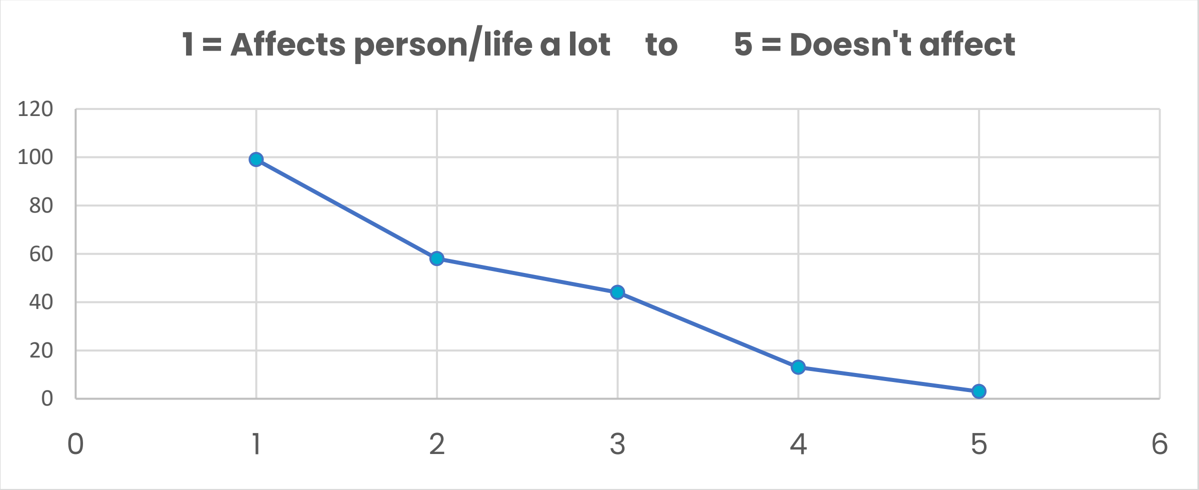
Not have (n175):

- Cold, noise (which I'm quite sensitive to), loneliness.
- Could do without stress as increases pain level.
- Dismissive or condescending clinical interactions.
- Doctors have lost their passion that now unfortunately affects us as patients.
- Judgment, assumptions.
- Enough finances to get essentials.

> ‘A real chronic pain unit in the Conquest run under experts who deal with pain. Difficult to get a GP telephone appointment and then end up in A&E. They are busy enough and I feel bad asking for help! So, you ask yourself where else is left? Yup that's why we need that clinic, it helps to save money, so please understand this unit saves

lives, it's that simple. When you are begging God for a release from the pain and thinking of doing something stupid to get rid of the pain that's why you need help that is a telephone call away. Please understand I beg you how much we need this lifeline!'

217 respondents **self-rated their pain**:



207 respondents described what **a good day looks like living with pain**, for example.

'Being able to do 2 school runs (with adapted Motability car); being able to watch my son do sport (with assistance); being able to have a shower (with help).'

- A good day is being able to get out of bed by myself, do my own personal care, work and be able to focus on my customers rather than the pain. A day without a panic attack is a good day. A day with only a couple of dislocations is a good day.
- Able to go out and engage with others, can mobilise but will have a rest.
- Able to move, work and socialise.
- Being able to get out of bed more easily. (n2) Having time for a hot bath first thing in the morning, being able to do jobs in the house more easily. Being able to get dressed without it being an undignified struggle.

- I can get up, get dressed and move around, though I will be unable to stand for longer than about 5 minutes, or walk for more than about 10 minutes without resting. I will use support to get up from seats, toilets, and on stairways. I will need help to pick things up from the floor, or high shelves.
- A day when I have the energy to spend time with loved ones. when I feel in control of my pain. a day when I'm not frightened of pain getting worse. Of not being anxious about undiagnosed health issues, or not being anxious that I can ask, access, obtain support and help from healthcare professionals.
- A good day is being able to get out of bed by myself, do my own personal care, work and be able to focus on my customers rather than the pain. A day without a panic attack is a good day. A day with only a couple of dislocations is a good day.

207 respondents described what **a bad day looks like living with pain**, for example.

- I struggle to get up and dressed, I cannot go out of the house, and I have to rest with my legs up to gain any pain relief.
- Cannot function due to extreme pain. Can barely walk so have to sit on the sofa all day. Can barely think straight due to brain fog so can't get any work done. Can't even get dressed. Often can't eat and drink very little. Sleep through a lot of the day. Not in the head space to talk to anyone.
- Continuous pins and needles, neck back and hip pain bad because yesterday I pushed hard to get things done for my young kids.
- Curling up in bed in pain crying and unable to function.
- Extreme pain levels, not being able to stand upright. Being stuck in the house as too painful to walk. Also, unable to get comfortable in chair, unable to carry out even small tasks like washing up.
- High pain levels all day

- Reaching for pain killers immediately I get out of bed. Bath doesn't help it much. Choose not to get dressed properly as it's too difficult. Don't want to cook as I can't hold things. Go to bed ASAP after supper.
- I am anxious and angry; I have taken lots of pain killers. I have changed my plans for the day, and I can't move very well.

A third of respondents (36%, n78) felt confident having a conversation and sharing decisions about their care/treatment with their healthcare professional. However, 39% (n84/217) felt less confident and 25% (n55/217) felt no confidence having a conversation with their clinician.

182 responders stated what they needed to feel more confident to engage with their healthcare professional, for example.

- A better response from the people I see.
- Help when I need it, instead I was told to wait until I lose control of my bladder and bowels, I can seek help then.
- Covid has made it almost impossible to see my doctor.
- For them to understand and not feel that I'm having to lead them.
- I would like my GP to have / be aware of the same conversation.
- I would need to have reason to think that it's worth having another conversation about this. I don't wish to waste any clinicians time, or mine, come to that.
- If the doctors at my surgery listened and reported on what we say rather than their own interpretation.
- If they did what they say they will do.
- If they cared.
- Longer, more relaxed conversations - consultations always feel rushed and time pressured.
- More drugs.

- A clinician who wants to listen.

Three quarters of respondents (79%, n172/218) stated that it was important to have a conversation and share decisions about their care/treatment with their healthcare professional.

42% of responders (n68/162) rated on the not-important half (scored between 1-3) and shared what would support them to have a conversation to share decisions about care and treatment with their clinician. For example.

- A more responsive and interested GP.
- A face to face not just being pointed to some useless website that tells me first I must accept my pain. I accepted years ago how this is going to help.

> 'Please just listen to me and hear my story. Don't dismiss me because my signs and symptoms don't fit in to a neat little box. When any tests are fine, let me know the results and impact on your formulation, hypotheses, and treatment options. Give me an appointment or a time in which to expect and appointment, and a point of contact please.'

- A medical degree - at the end of the day I am not aware of all clinical options.
- A meeting with the Consultant.
- A longer appointment time which would allow adequate time to discuss the various options and to be able to form an informed decision.
- Actual contact, even a video consult would be something. I have been being my GP to help with an associated condition for over two years.
- I believe it's important but if 90% of the time it leads to no treatment then the importance is lost. It needs real treatment for longer than 6

weeks (physio for example) when you have conditions which cause all joints major problems.

- I think it is an important conversation to have, but a lot of GPs just don't care about having conversations or looking at your wellness as a whole. Many GP's just look at each symptom as being totally unrelated to every other symptom happening to your body and provide a different medication for each, rather than looking at your overall collection of symptoms, to see if there is a bigger condition which needs to be considered and treated.
- I'd like some advice, but I'd also like my opinions and self-treatment to be valued.

Lived Experience Telephone Conversations

We conducted seventeen telephone conversations during February and early March 2022, with people who had completed the survey and agreed to a follow up conversation.

The main theme from these conversations was Communication.

- Healthcare professionals' general communication skills with patients many felt not listened to or unheard, or not taken seriously by their GP, not being treated with dignity and respect.
- Timely access for referrals such as physio, osteopath, imaging etc. Information explained about the referral the pathway, who they will be referred to, for what and timeframe.
- Some patients were provided with information and advice that was not explained, which meant it was not used.
- Having a clear and joined up MSK pathway that does not have to go back to the GP to start all over again.

Timely access for referrals consultants, physio, osteopath, imaging etc.

I have now waited two years and do not know if I am in the system or not.

My GP has never sent me to see anyone else about my back pain.

About 1.5 years ago I was referred to physio and have chased up, but as yet I have not seen anyone because of 'COVID precautions.

I have had five rounds of physio over the years. But they never help you to manage on a day-to-day basis. I have also paid privately for osteopath, chiropractor, and a homeopath. *All work for a period of time but do not sustain.* The chiropractor gave me some exercises (seated ones) and I do these every day.

A lot of people like me have difficulty accessing physio, but we need their support and advice. It is impossible to get an appointment. I self-referred in 2021 and was informed there is a 26 week wait *and then feel guilty*, as I do manage things well, that *I am taking a space someone else might need.*

A drop in for physio would be great as you could check in every 6-12 months to confirm you are doing the exercises right, that would be helpful.

I was then referred to an excellent Rheumatology Consultant.

The Rheumatology consultant was appalling. About 6 months ago I received a telephone call from the team, and she was very thorough and gave me a face-to-face appointment, but this was cancelled. I am still waiting for the appointment.

Lost medical notes

The Ear, Nose and Throat consultant was a horrendous experience: *they wanted to take an ultra-sound on the salivary ducts and was asked where my maternity notes were! I was 60 years and had a hysterectomy when 27.*

NHS services people referred to for back pain.

Referred to the **osteopath** and given simple exercises to do. I then saw **physiotherapy** a couple of months after, and they suggested warm water classes in the hydrotherapy pool. I had 6 sessions, and these were very helpful.

The main issue is the back pain, and arthritis in knees. The **Rheumatoid Consultant** does not want to do anything because of my back and sent me to Bexhill **Physio**. They were good with the exercises for the knee. The physio stated, *you need exercises for the back, and I will contact the **MSK Team** to see what exercises they recommend.* I then received a telephone call from the physiotherapist informing, *the MSK Team cannot do anything until my knee is dealt with.* I cannot walk properly and do not know who or how to sort out the knee and back issue so that I have the right exercises.

After 12 months referred to the **Pain Clinic**. I had high expectations of the pain clinic as believed they would provide some supportive self-management tools. The reality was very, very different.

After an examination the consultant informed, he would prescribe Amitriptyline. He was very surprised when I refused these, and I explained. *If he had looked at my notes I had just gone through 'cold turkey' to get off Tramadol and he was suggesting I take a tricyclic addictive drug!* I ask if there were any self-care/management strategies I could use? He stated, *these would not be helpful for me and did not elaborate as to why!*

NHS appointments have not come through I had a *referral 12 months ago and still not heard anything*. I appreciate that there are lots of people in similar situations. I have not been sleeping properly, the sleep issue began just before the lockdowns and has got worse.

Role of carer

My husband is my carer, and he has had an operation on his spine, and this has left him with a dropped foot. He has pain in his feet and arthritis. *You have to have a sense of humour.*

I cannot do things and my husband who is my carers does. For example: *I cannot do up my bra myself.*

To be taken seriously by healthcare professionals

My GP put his hand on my leg and told me: you have lost your husband and are stressed.

I feel ignored by the NHS as my GP never referred me to anyone to look at my spine and mobility.

The GP did not take me seriously at first because of my age (24) so it would have been nice to have been taken seriously.

The GP could have referred me to a certain path pre-COVID but not during. The first thing they did was an X-Ray *'I had nothing broken so do not know why.'*

Luck! As I found a brilliant surgeon and GP; both essential for someone with long-term pain. It is essential to be able to see the same GP, I had to change GP surgery as was unable to see the same person. I did not feel able to discuss the pain issues as was seeing different GP's: where do you start 40 years ago? And EDS it is essential to see the same GP. 'As soon as you walk into the surgery, they know you.'

Diagnoses

My GP recorded in my notes that I had fibromyalgia. This diagnoses of Fibromyalgia **has** stopped me getting the right treatment. My life is on hold. I am just waiting, and my pain has got worse. Because of the diagnoses of Fibromyalgia, I have been told by the GP surgery that they cannot just pull me out of the system to get the support I need.

I recall the GP apologising to me *'as he could not do anything about the pain.'*

I saw the rheumatologist about 4 years ago as part of an assessment for potential MS, he examined me and really hurt me and informed me that there was nothing that can be done as it is not surgical. The Consultants letter informed that *if she loses weight and is still in pain, I will see her again. So, I guess that if I do not lose weight no-one will see me.*

I began having lots of weird and wonderful pains and dislocations. I recall asking my consultant; '*Why is this happening?*' and his response was '*You are just unlucky.*'

A new consultant, who was very proactive for Ehlers Danlos Syndrome (EDS), who first diagnosed me and was good at answering the questions I had and what could be done. At least I did not have to now wait until *'I fell apart.'*

One GP a few years ago – as the medical notes were being put onto the system, saw the X-Ray, and said to me *this is not in your notes, so you do not have a problem.*

I have had pain issues throughout childhood and *non-one connected the two individual conditions.* Things got worse when I hit puberty and was told *your pain is normal period pain.* This made me feel *weak and affected my confidence. At this time, I was diagnosed with depression and mental health.*

My current GP is great, the opposite to my previous one who just told me *you are too young for this*. He would not *put my medications as a repeat prescription, so I had to take time off work to go to the surgery to sort things out, every month.* This GP had new ideas and could not understand how the medications help me function. My *new GP has been incredibly supportive.*

Information, advice, and support

The GP gave me a printout of exercises I should be doing but no-one has ever showed or explained how to do these exercises. I am afraid to make things worse by not doing the right things.

My GP referred me for low impact exercise at the local gym. But this will cost £30 each month and is not free. This is a lot of money so I will not be able to access this. I know there are a lot of 'free exercises' around but they are high impact and I need low impact.

I have never been given any information for my back care or osteoarthritis. A diagram from the osteopath but never provided any information or where to go or what support there is.

They do not see the whole person. So do not know where to go or what things to do to support. My GP referred me to Slimming World and if this worked, they would be out of business. An app is ok, but you need to check to see you are doing and not to ignore a health crisis.

It would be good to have some supervision when exercising to ensure you are doing the right things. For example: when in hospital post operative you are given sheets of exercised by physio, and whilst in hospital they show you and support you. But once you are home you forget, and do not bother. Your head is in a different place, it feels different, and you are not so motivated.

I know what I need, *it is support and motivation*; if someone was to ring me up to see how things are going this would motivate me, *I need a social element and to be with other people*.

The Rheumatologist was very vague and gave me some information and website details to look into. He also told me to pace myself. No-one explained what they meant by pacing as they did not give a lot of advice. I just looked into it and learn by myself.

The hospital has given me exercises to do – they gave me information sheets and also showed me how to do the exercises – some of the exercises are ok but most aggravate the pain. *'I try to do the ones I can but the other just make the pain worse.'*

The HIV Team is very good and very supportive. They understand my problems and me and try other things. They sometimes speak to other healthcare professionals to check what might be helpful.

One episode left me with general nerve pain, but no-one advised me to *'not drive'*, and continued to drive for a week.

Referral pathway

Have a clear, easy to follow pathway that does not involve having to go back to base (GP) and start again for each referral.

If you are in the system, then the system should be able to move you along and not have to go back to the start (GP) and incur long waits.

I was informed that a referral has been made to the pain management clinic but am unsure if any letter or referral has been sent from the GP, as it has been two years now and I have not heard anything. Every time I see anyone you have to start again from scratch, and they do not listen to you.

I have never been referred to the pain clinic. I have had physiotherapy as a self-referrer. Unfortunately, they do not know what to do with me, they ask *what do you think!* and then say, *yes do that, no need to see us*. I have a complex history and you learn to know what you can and cannot do.

Pain Clinics

The GP could have referred me to the Pain Clinic. When I asked, he said; *we have not got one anymore in East Sussex.* However, in 2021 I received a letter from In Health Pain Management in Eastbourne.

One lady chatted with me and informed, *'I need to speak to someone and will come back to you next week as all of our appointments are by telephone during the pandemic.'*

I then had a lady teaching me over the phone meditation for half an hour. The pain is still there when I finished the eight sessions. She told me that *it sounds like you are one the right track and do that every month or fortnight,* **I did find it helpful when she supported me but tried it afterwards and it did not work.**

They also showed me about Mindfulness and meditation and mind/body for pain. They also gave me the Pain Toolkit.

The healthcare professionals could have explained the pathway better and who would see me next or what would happen. Also, to explain things more clearly.

I joined a Pain Management course in Shoreham and Haywards Heath (a referral from the Pain Clinic). There was this lady (facilitator) who was trying to be empathetic and said things like *'when I go on holiday, I rest for the first three days as I know I will be in pain.'* And other stupid things. I also found that when I was listening to the other people in the group explaining their pain draws your focus to your pain. I did not find this group positive.

The Pain Management Consultant and clinics *gave me advice in the early days such as pacing but I was not ready for that. I can see that might be helpful, but I am not ready yet for that – pacing. It is funny but I am now using pacing for somethings.* I am now more conscious when gardening and so some sitting, and some standing or go back to it later.' *I got the advice about pacing some forty years ago but shelved this and can now see what they were saying. Now it is right for me then it was not.*

Consultant sent a letter 18 months after the appointment with the wrong name, date of birth and information. *I just felt so disempowered.*

At Brighton Pain Clinic I joined the fibromyalgia and Pain Clinics and again told there is nothing we can do for you and opiates do not work for chronic pain conditions. They just ignored the lived experience of someone with multiple conditions. I have heard this from other people as well. Some GPs and healthcare professionals do not listen to people with lived experience as they prefer to rely on research, NICE guidance, and numbers.

Medication

The GP left a prescription for Tramadol, Valium and Co-codamol with the pharmacy. Eight months later I was still on the medications and had to go 'cold turkey' to get off them. Not a pleasant experience.

I contacted PALs. I had a telephone conversation in November, and PALs put me in contact with a locum and he prescribed the steroid Prednisolone. This helped immensely but I was given no information about the drug.

Two months later I was told by a different consultant that I had been taking the steroid for too long and he prescribed hydroxychloroquine. His entire discussion was about *'do you want to try this'?*

When I had an allergic reaction to hydroxychloroquine, he told me (via a nurse) *to stop taking it*. The nurse said she would get back to me, which she did and asked, *what is your weight? and to watch your weight.* I have been waiting ten months for a follow up appointment, and *not been provided with any advice.* I contacted PALs about the Rheumatology appointment and received one. *The consultant was very angry and talked over me while I was explaining where the pain was and found him very patronising.* He gave a follow up appointment for four months' time, but this has not been received.

If records were shared, then maybe someone would have noticed how long I have been on steroids! Medication I am told if they work very quickly there is a dramatic effect. But I do not see the link. The best treatment is not to have so many medications.

My GP provides codeine in 5mg tablets as I monitor what I take between 5 and 30 mg depending on the level of pain and because the effect is like drinking a bottle of wine if too much. However, my surgeon does not like this and is writing to my GP. I have to admit *I feel disempowered,* - self-managing medication for over 25 years - by this but will wait and see what happens.

About 12 months ago and have been waiting to see someone about my joints as the pain is worse upon waking up and walking. I was prescribed pain control but was unable to take these and I informed the Consultant on multiple occasions, but he kept prescribing them.

The GP was supposed to monitor me whilst using the patches. I never received a call, or a check-up and *just requested repeat prescriptions. I did not know that they were supposed to monitor and did not want to disturb the GP, so did not go back.* The patches got stronger and by the Eastertime the doses were getting higher and higher as was being increased weekly. I was not sure where I was going. My daughter visited and took me to A&E. The doctor at

A&E said *I had overdosed and to stop using the patches and go back to my GP.*

I am on a lot of *medication and have only had one review*, which was in the past year. Yet I have been on the medications for a long time. The hospital suggested a new medication and the GP prescribes it. The medications do help and make a difference.

I need medications to function. *Some days I can function without pain medications and others I need morphine for a few days to get things under control.* But it is difficult to get the *morphine drugs without being labelled as an addict*, which I am not. In some areas of the United Kingdom, you can obtain Pethidine, which would work better, but in Brighton this is not so. It seems to be a *postcode lottery.*

I was on antibiotics for 18 months.

Continuity of services

There is no continuity of services as each service is independent and not joined up.

The GP element is tricky as you make an appointment for pain or mobility, and they automatically default to the consultant and do not want to get involved or to advise. Maybe they do not know enough, but my GP should be able to support me better with the pain.

I was referred by the GP to the orthopaedics in 2017 – 2018, 2019-2020 cancelled due to COVID appointment January 2022.

I had physiotherapy and hydrotherapy – *I found the Hydrotherapy very helpful* – I could only have a set number of sessions but one of the physiotherapist opened the Hydrotherapy pool in the evening there was a charge, and I did this for a while. Then the person left, and the programme folded.

I too have worked throughout COVID and appreciate the impact. But communication, follow up and flow of information between specialities is of importance. As is listening and being heard.

Personalised

Over the years I have been under the orthopaedics; as most GP's doctors' priorities are not the same as mine; they tend not to see you as a person – *we will do this operation and you will have increased movement in an area*, but my priority is *will this improve the level of pain.* There is a conflict of priorities which *makes you feel not listened to or unheard. I am not a robot who just needs to move better, or fuller.*

To have been suffering from back pain for 30+ years and no-one has ever looked at me as a 'whole person' or asked my family history of rheumatoid arthritis. I have never been referred to the orthopaedic for my pain.

There was nothing personalised, it would have been helpful to have had a conversation with someone as to what I needed to do and what services could support me.

Peoples experience is individualised, and the approach needs to be individualised. As all parts of the health and care system need to have an appreciation of the individual issues people face.

For example: *When attending a smear test the healthcare professional needs to check my physical limitations as my hips do not bend and cannot drop my legs and am in chronic pain so maybe a different position might be needed.*

It is the same when going to the dentist as the chair can make the back pain worse and I need a break. So, they need to be open, to working with the patient and **'ask, and be curious.'** How can we make you more comfortable as this would produce better outcomes?

I recall a young physiotherapist who left for Germany, and he told us that the health system there work very closely together, the physiotherapist, MSK Team, and the consultants to help patients. *Things are more joined up and less siloed working.*

Our GP surgery has also been less supportive since COVID. *We cannot see you until you have had a PCR test and we have still not been seen. They do not phone you back as promised. Again, things are not joined up at all. The GP practice were excellent pre-COVID and are now awful.*

I do feel sorry for the NHS staff as they see patients and are unable to join up the system for them. So, in effect they are not able to support patients because of the system.

Shared Decision Making

The most productive conversation I have had with the Rheumatologist was about 6 months ago as he showed me some NHS websites and told me what I should do.

He explained the clinical side of things to lose weight. Then went through a number of NHS exercise sites: Couch to 5k, NHS weight loss, and NHS meals. These are only available online or via an app for mobile, which is fine for me, but wonder about the accessibility for people without access to technology. Could this be a barrier?

Today probably, the communication is better; as a child healthcare professionals spoke with my parents *this is what we are going to do,* *or this is what she needs. 10-20 years ago.* Nowadays it is more *we could do this and what do you think?* This could be because I have become more confident, stroppy, or GP's, consultants are better at explaining things.

At my most recent appointment I was asked *what are your goals?* (Royal Orthopaedic Hospital Stanmore). The young registrar asked me; *what do you want, your goals and outcomes from this appointment?* I told him to reduce my pain, increase my mobility and avoid having to use a wheelchair for as long as possible. This appointment felt so different to 30 years ago, when I was simply told; this is what we are going to do.

I have never had a Shared Decision-Making conversation with a healthcare professional. Everyone is different and they do things differently. I ask myself *will it be worth it as I may be laid up?* It is important for me to be in the driving seat and was not at this stage for a long time. If you *have an operation you rely on the physio for a period of time, but you have to take back control.*

When I talk to people in pain management area, they use a lot of *'should'*, not solutions like a, b, c, etc. as you can only find out what you can do by trying.

I have not had anyone to sit down with me to talk about how my health is affecting me and my family. I do not know where to go because of COVID the NHS has shut down.

Communication

The GP surgery, nor the hospital staff, do not listen to you and mis diagnose, they were like this before COVID and do not have the time to care properly. **There is no pathway as you have to keep going**

back to the GP to be referred. This is a cost to the system and to you personally.

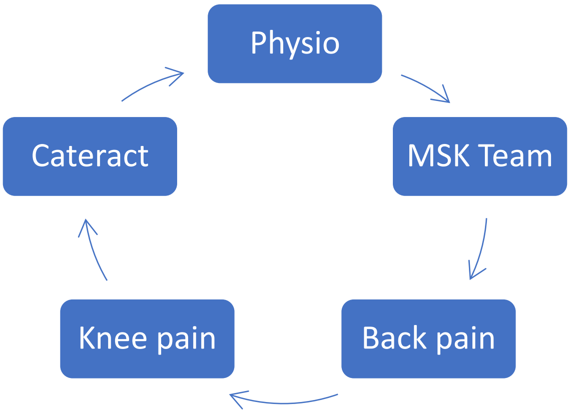
To have an honest conversation and set a plan. To understand how the referral process will work, as have not been referred to the dietitian to help with weight loss nor targeted physio for the back. One clinician stated he would refer me for physio, and I waited for 3-6 months and as I had not heard anything I asked at my next appointment only to be told ‘you have to do this yourself.’

Being able to talk to someone who was both *hearing and listening*. There is a difference between the two.

To get some physio to help with the pain and hydrotherapy. To be able to see properly with both eyes as this would help us to live independently.

But need a little extra support from the NHS physiotherapist and MSK Team. *When the MSK Team said no it felt like a slap in the face.*

Viscous cycle



There is a total lack of communication, if everything is ok you are told *‘everything is ok.’* I was told that they are recruiting for a Rheumatology Consultant, but they also need to recruit admin staff. *If I treated my customers like this, I would not have a job.*

I saw a female consultant and she informed that I was slightly overweight for my age bracket *but did not give any support* as they do not care.

I asked her *'can you recommend any exercise? 'Go for walks.'* I had already stated I went for walks; they talked over me and were patronising. They do not listen.

Communication, follow up appointments and less delays. For contrast I recently visited the Ear, Nose and Throat team and had an MRI within a week, and someone phoned me with the outcome.

Being heard and listened to, one female GP was really good at doing this and her *referral letter stated what was discussed, outcomes and follow up and was accurate.*

When my GP referred me to the consultant, I have not heard anything and in 18 months did not have a physical examination, all very bizarre.

- *I just want to be heard and listened to and not have healthcare professional making assumptions.*
- *Please discuss with me what my medications are for, what they do, why I am taking them.*

I saw a triage nurse at radiology, and she told me: *'you are too heavy and too obese to go into the MRI machine.'* I did not really want to go into the machine, so went home.

'I was then told do not worry about things we have another planned in our 'new suit' at the Conquest. But was too fat, too heavy and too obese for this one.'

I went to the new suit at the Conquest, and it was wonderful. The receptionist has a lovely smile from ear to ear and told me 'Not to look so worried.' The staff wore civilian clothes with aprons and masks. '*Two men in the MRI were brilliant*. They took me to the room and laid me down and asked me to put ear plugs in as the machine was noisy. They asked me if I would like to hear music and gave me headphones. They asked me if I wanted to go in feet or headfirst – as the scan was for my spine and hips, I went in feet first. All went well. In fact, *I almost fell asleep as was very relaxed.* I then received a letter about the MRI scan and was referred to the Orthopaedic people.

I am making adjustments and managing currently. Joined up services are not happening in East Sussex. As patients you go back and forwards to the Conquest hospital in Hastings and Eastbourne. I have an appointment in Hastings and try to get something moving but struggle with the communication – *I do not understand why the records cannot be shared.* There is also *transport issues* – sitting in a bus for one hour and when you get to the hospital you are told they do not have your records and then have a one-hour journey home is no fun.

Pain and mental health

My mental health and mood are linked to my pain. For example, I am trying to lose weight currently and keep a food, mood, and pain diary, rating each area out of ten. But pacing helps my pain and my mood.

The wheels of depression and pain – the physical have received support but not for the emotional and mental health side. I sometime go into a depressive state *'why me'* but I am better at dealing with this side of things. I did do some CBT and *'one thing I still use at these times is an elastic band on my arm and ping it and say no.'*

As the pain has got worse it has affected my emotions massively as do not know what was happening or how things would progress.

To get an appointment. When you are in pain every day and are trying to get an appointment, it is very difficult. You have to try to get yourself strong for these days. But I tend to write a letter or send an email and the surgery responds back. This helps with the initial appointment and *to be able to explain the problems you are facing because of the pain.*

Effect of pain on day-to-day living.

The pain in my neck and back affects all areas of my life.

I am unable to use the shower and carry items and do not receive any help at all. It is all very frustrating and depressing. I nor my children have a good quality of life. Everyday there is lots of tears, frustration, as I cannot walk, or stand, so we do not go out as a family, we are not having a good quality of life.

I live with the possible problem but do know the types of activities that make the pain worse. If I do any gardening I have to stop after a short time. I am really careful with certain movements as these can cause the back to seize up. I can't cuddle my wife on the sofa as this would be an issue. But by being aware of what I can and cannot do helps. It has become a habit now.

Sometimes the pain is bearable, sometimes unbearable, and always there. The pain has got worse over the past 5 years. I have to consider what movements I make and some days it is really disabling and sometimes better than others.

The thought of life without pain would be weird to me as would not be used to it. I have learnt to manage it.

I have learnt what makes the pain worse and what to avoid; walking, movement, mobility, lifting things. I do things in moderation; I live in a first floor flat and if I have to go down the stairs then I do as much as possible on each trip, to avoid going up and down multiple times. But this is unconscious, I do not stop and think about this.

On busy days I ensure that my diary is clear for the next one. So, use pacing to support me. This is all right when you can manage the situation, but the curve ball things can be an issue.

The pain is variable day-to-day, but this has been thrown out by COVID-19. Before COVID-19 I was going out often, since the lockdowns have not been going out, so am *not getting so much exercise and have no stamina and cannot use the wheelchair and I am unable to support myself.*

Self-care strategies used

I lost three stone, and this has not helped with the pain. I do swimming but am not a good swimmer so do not enjoy this. I walk the dog each day.

I use some self-care strategies from the web and apps such as mindfulness, self-care, pacing myself – planning for activity with rest periods. Learning what is best for me.

I use **Pacing** and just learnt this. My mother used to plan a busy day and a quiet day, so I think pacing came from this. When on holiday we would go out and about and then have a day at the pool when on holidays.

My weight is a problem and always has been. I eat when I am happy and when I am low or stressed. It has become a cycle and if I am heavy the pain increases. When I need an operation, I tend to need to lose two stone before an operation. I have joined the West Sussex County Council (WSCC) Wellbeing scheme.

There are talks from a health coach each week and there is 40 minutes of exercise (sitting or standing). But the *yoga is on zoom, and this is during the day*, so if working it is *a problem, and a barrier*.

Mindfulness to ground myself, learn via brownies and relaxation. When in hospital as a teenager the nurses helped me with the breathing and other techniques. I have also done CBT for anxiety, and it works well for pain.

I would also add that having cats is good as stroking a cat feels good. I also like hearing the purring. I do not like silence so appreciate a ticking clock, cat purring, fridge buzzing, and have the radio on, as find this comforting.

I use a number of self-care strategies, as you have to. I use rest and exercise or activity, heat and ice, good nutrition, and condition, use a tens machine. Some were instinctive, some through work, the Pain Management courses, peer support and Facebook groups. *Really by just talking to people.* I have even tried a massage gun thing as this had worked well for my friend, but it did not work for me.

GP around *prescribed a book* – *The Alexander Technique* – and I use many of the tools in this book.

When the swelling begins, I have difficulty getting undressed so as soon as it begins, I change into my pyjamas. I am also unable to hold a toothbrush so also have a plan for this.

Ophthalmology and pain

We try not to rely on the NHS as there are people worse off than me. But this *constant pain I just want to sit a cry and do not know what to do*. I am waiting for a cataract operation. I went to the optician in October 2021 and could not see the board letters from my right eye and this *does not help with walking around. I do not feel safe on the pavement as unsure where the traffic is.*

What services are needed

Easy access for top up support such as physio.

Someone to support you with *adaptions*.

Access to *Hydrotherapy* as there is none in the Brighton area except expensive private ones which I cannot afford. (n3)

GP prescriptions for the GYM. It is such a shame as the *NHS were running a scheme, signed up but when I got there it was up a flight of stairs, and I am in a wheelchair. It needs to be accessible.*

To have gym programmes delivered by people who have knowledge of *what I am talking about*, such as physio and *adjusted for wheelchair users*, and other disabilities could use. *I do feel self-conscious when having to exercise with body builders etc.*

I do not want to take pain killers or antibiotics but need answers. There has got to be answers. It is an absolute drain, and you need good resilience. How some people just give in as they do not have good support system.

The NHS cannot put people into boxes as we are all different. People like labels, I do not want to a label but to know what is happening.

Not having to *travel for more than an hour to get there and having to manage the pain as I travel. (n3)*

Appendix A – About Responders

225 people responded to the question about age. The age of responders: 18-24 (n6), 25-34 (n23) 35-49 (n55), 50-55 (n24), 56-59 (n15),60-64 (n26), 65-69 (n23), 70-74 (n23), 75-79 (n18) and 80+ (n12).

225 responders reported they: worked full time (n59), part time (n32), seeking work full-time (n3), seeking part-time work (n2), unable to work (n58), choose not to work (n4), unemployed (n3), retired (n71) student (n6), and volunteer (13).

Gender (n216)
Male (n34)
Female (n173)
Non-binary (n7)
Prefer not to answer (n2)

Is your gender different to the sex that was assigned to you at birth? (n213)
Yes (n25)
No (n183)
Prefer not to answer (n5)

Ethnic background (n1217)
White British (n193)
White Irish (n4)
White other (n7)
Asian or Asian British
Indian (n0)
Pakistani (n0)
Bangladeshi (n0)
Any other Asian background (n1)
Mixed
White and black Caribbean (n1)
White and Black African (n1)
White and Asian (n0)
Any other Mixed background (n1)
Black or Black British
African (n2)
Other Ethnic group
Chinese (n1)
Any other Ethnic Group (n2)
Prefer not to say (n4)

Religion or beliefs (n214)

Buddhist (n5)
Christian (all denominations) (n92)
No religion (n96)
Prefer not to say (n5)

Muslim (n1)	Other (please specify) (n15)

<u>Sexual orientation (n216)</u> Asexual (n8) Bisexual (n15) Gay (n3) Heterosexual (n166)	Lesbian (n2) Pansexual (n4) Prefer not to say (n13) Other (please specify) (n5)

Considered disabled, as set out in the Equality Act 2010 (n214) Yes (116) No (86) Prefer not to say (12)
Carer, have a disability or a long-term health condition (n217) • Yes, I consider myself to be a carer (n49) • Yes, I consider myself to have a disability (n111) • Yes, I consider myself to have a long-term condition (n159) • None of the above (n35)

Appendix B – Footnote links

1	Sussex MSK Partnership	www.sussexmskpartnership.com
2	Versus Arthritis	https://www.versusarthritis.org/about-arthritis/data-and-statistics/the-state-of-musculoskeletal-health
3	Be Part of Research	https://bepartofresearch.Nihr.ac.uk/articles/back-pain/
4	Office of National Statistics	www.ons.gov.uk/employmentandlabourmarket/peopleinwork/labourproductivity/articles/sicknessabsenceinthelabourmarket/2020
5, 33	Kings Fund, (2015). Transforming our healthcare system. Ten priorities for commissioners.	www.kingsfund.org
6	Department of Health, (2010). Equality and excellence: liberating the NHS	www.gov.uk/government/publications
7,28	Kings Fund, (2011). Transforming our health care system.	www.kingsfund.org
8	House of Commons Health Committee, (2014). Managing the care if people with long-term conditions, Second report of sessions 2014-2015 Volume 1&2 (HC401)	www.healthcare@parliament.uk
9	NHS England, (2014). The NHS five year forward view.	www.england.nhs.uk.ourwork/future.nhs
10	Perkins, Repper, Rinaldi & Brown, (2012). Briefing: implementing Recovery through organisational change.	Recovery Collages, Center for mental health, London https://imroc.org/resources/1-recovery-colleges/

11	Lorig, (1993). Self-management of chronic illness: A model for the future generation.	https://www.jstor.org/stable/44877774
12, 30	Department of health, Care Act, (2014). Care and support statutory guidance issued under the Care Act 2014.	www.gov.uk/government/publications
13	Barlow, Weight, Sheasby, Turner & Hainsworth, (2002). Self-management approaches for people with chronic conditions: A review.	https://pubmed.ncbi.nlm.nih.gov/12401421/
14	Royal Collage of Nursing website	www.rcn.org
15	British Medical Association website	www.bma.org
16	Self-care website	www.selfcare.org
17	Creedon. R., (2011). The psychological effects of living with chronic oedema. Cox (2009) as cited by Creedon (2011, p17)	https://www.magonlinelibrary.com/doi/abs/10.12968/bjcn.2011.16.Sup4.S14
18	De Ridder, D., Greenen, R., Juijer, R., and van Middebdropp, H., (2008). Psychological adjustment to chronic disease. (2008, p.246)	The Lancet, vol. 372, pp. 246-255 www.thelancet.com
19, 24, 36	Realising the Value, (2016). At the heart of realising the value of people and communities.	www.realisingthevalue.org.uk
20, 21	BMJ Decision aids in the context of shared decision making (2021)	Bmj2021.373n1430
22	Bomhof-Rooordick, H., Gartner, R., Stiggelbout, AM. Pieterse, A., (2019). Key components of shared decision-making models: a systematic review	BMJ Open 2019, 10.1136/bmjopen-2019-031763. http:/bmjopen.bmj.com
23	Department of Health, (2011). Improving care for people with long-term conditions. Information sheet 5 what motivates people to self-care.	www.gov.uk/government/publications

25	Galdas, P., Darwin, Z., Kidd, L., Blickem, C., McPherson, K, Hunt, K., Bower, P., Gilbody, S., & Richardson, G. (2014). The accessibility and acceptability of self-management support interventions for men with long-term conditions: a systematic review and meta-synthesis of qualitive studies.	Bio Med Central www.biomedcentral.com
26	Yukawa, K., Yamazaki, Y., Yonekura, Y., Togari, T., Abbott, F., Homma, M., Park, M., & Kagawa, Y. (2010). Effectiveness of chronic disease self-management programme in Japan: preliminary report of a longitudinal study.	Nursing and Health Sciences, 12, pp. 456-463. Blackwell Publishing Asia Pty Ltd.
27	Colagiuri, R., &Eigenmann, C. (2009). A national consensus on outcomes and indicators for diabetes patient education.	Diabetes UK, Diabetic medicine, 26, pp. 442-446. Blackwell Publishing Limited.
28	Chronic Care Model	www.improvingchroniccare.org
29	The Richmond Group. Vital Signs. (2015)	www.richmondgroupofcharities.org.uk
31	NHS five year forward view (2014)	www.england.nhs.uk
32	NHS Implementing the five year forward view for mental health (2016)	www.england.nhs.uk
34	Bringing together physical and mental health: a new frontier for integrated care (2016)	www.kingsfund.org.uk
35	Long-term conditions and mental health. The cost of co-morbidities	www.kingsfund.org.uk

Talk to us

If you have questions about the content of this report, please either call 0300 012 0122 or email cheryl.berry@healthwatchwestsussex.co.uk

How this insight will be used?

We recognise that all health and care services are under pressure at this time and have had to adapt their ways of working. We will share this report with the local NHS, Local Government, and other providers to help them understand where things are working well and services are adapting to meet peoples' needs, and to help them identify any gaps. We see this as a continuation of discussions taking place and will continue to use this fresh insight and the solutions presented to challenge for a better future.

For help, advice, and information or to share your experience

We also help people find the information they need about health, care and community and voluntary health and care support services in West Sussex.

ADVICE AND INFORMATION

Here to help you on the next step of your health and social care journey

You can review how we performed and how we report on what we have done by visiting our website www.healthwatchwestsussex.co.uk

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Healthwatch West Sussex works with Help & Care to provide its statutory activities.

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