

Chronic Pain – This Is How It Feels

Exploring Chronic Pain Services and Management
– A Patient and HCP Perspective

October 2019



This survey has been a collaboration between ARMA and Grünenthal Ltd (UK). Adelphi Research conducted the survey with sole funding from Grünenthal Ltd (UK).

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Foreword

There are an estimated 28 million people in the United Kingdom (UK) who experience chronic pain, with around 10–14% of people experiencing moderate to severely disabling pain. Not all of this pain is musculoskeletal, but osteoarthritis and back pain account for over half of chronic pain.

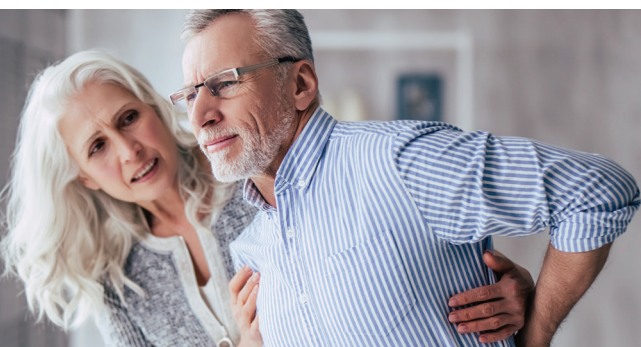
Pain is something which unites the variety of conditions which fall under the term musculoskeletal and for many patients it is the pain, not the condition, which they identify as most disabling. As the umbrella body of patient and professional musculoskeletal organisations, pain runs through everything ARMA does. In March 2019, we held a roundtable on mental health and musculoskeletal health. The importance of pain came across strongly and the recommendations included that integrated physical and mental health support should be available in a range of settings including pain services. Pain is something which is important to our members and the patients they represent.

This is not a new issue. The Chief Medical Officer’s Report in 2008 included a chapter on pain and in 2011 a pain summit was held. Both made recommendations, some of which have been implemented. But too little progress has been made; the results of this study demonstrate that we still have a long way to go. It shows that patients too often feel they are not getting the support they need. Equally, General Practitioners (GPs) often feel at a loss on how to best support people in the absence of adequate specialist services. When so many of your patients have chronic pain, it can be hard to know where to turn.

There is an urgent need to address this. The solution does not lie with any one organisation. Pain is complex, systemic, biopsychosocial; the solutions must be the same. This report shows where some of the issues lie and identifies themes which must be addressed if we are to make progress. This is an important issue for us all. I hope that ARMA, an organisation which exists to enable collaboration, can play our part in working with others to find solutions to the problems this report highlights.



Sue Brown
CEO, Arthritis and Musculoskeletal Alliance (ARMA)



Executive Summary

This report describes the results of a collaborative research survey initiative which was developed to explore healthcare support services for managing chronic pain in the UK, from both patient and healthcare professional (HCP) perspectives. The research has highlighted a number of key insights which have been developed into associated themes for chronic pain service implementations moving forward.

The survey found that the management of chronic pain in the UK appears to be deficient and inconsistent:

- Living with chronic pain affects all aspects of a patient's life – it places a huge burden on patients, exacerbated by a lack of clear answers about how best to manage daily life
- Patients often face delays and setbacks when trying to gain access to appropriate treatments and healthcare support services
- GPs also face hurdles at almost every stage of treating and managing chronic pain and are aware that there are inconsistencies that vary from location to location across the country
- Access to specialist pain services is difficult and is inconsistent across the UK
- Overall satisfaction with support for chronic pain is fairly poor and patients have mixed experiences of services

Patients and HCPs alike readily suggest improvements to provide enhanced support, equity of treatment and management approaches:

- HCPs would like to see more joined up care for patients with chronic pain – using a multidisciplinary team (MDT) approach
- The optimum treatment model would treat pain as a condition in its own right, with the same significance as with other long-term conditions, and aims to work in partnership with patients
- Almost all patients, and most HCPs, felt that an annual pain review would be beneficial

Key Themes

The research has highlighted a number of key insights and themes for how respondents felt that chronic pain services can be improved and made more equitable in the future.

1. Ensure patient involvement/buy-in

HCPs, and particularly specialists, say that patient involvement is very important and that treatment is more likely to be successful when HCPs and patients work in partnership. HCPs talk of engaging patients in discussions and decisions about their treatment, setting expectations and encouraging a 'mind shift' when required.

2. More equitable access to specialist services

Currently, there is huge variation by area and individual patient with regards to what services are offered. This 'lottery' is seen as unfair by both HCPs and patients with chronic pain. Thus, a key issue is ensuring a more equitable access to pain specialists, but improvements regarding awareness and referral processes are also required.

3. MDT approach to coordinate care

Effective management strategies are diverse and require multidisciplinary involvement. HCPs strongly advocate a multidisciplinary approach including pain specialists, physiotherapists, psychologists, specialist nurses and pharmacists. There are areas where this MDT approach is followed but HCPs say it is 'not the norm'. An MDT should be seen as essential to 'join-up' care.

4. Advocacy for pain to be afforded the same priority as if it were an actual condition

Patients report that discussions around chronic pain are often deprioritised despite being the primary concern for the majority of patients. Acknowledgement of pain as a serious issue is validating for patients. Having a community of support and an evidence base for strategies gives them hope.

5. Regular review for chronic pain

There was wide endorsement for the idea of an annual chronic pain review. It was seen as being beneficial for a range of purposes including medication review, time for patients to discuss and optimise their treatment strategies and updates on mental health.

6. Quicker referrals

Long wait times for specialist service referrals are common, especially for physiotherapy and pain clinics. Long wait times were thought to contribute to deterioration in QoL, and HCPs say that patients who are referred earlier are easier to treat and have better outcomes. Specialists were particularly concerned about this, as they felt that delays in seeing patients made issues harder to solve.

7. Improvement in provision of information for patients and GPs

Awareness of the services available for chronic pain was low amongst patients. It is confusing to understand how the different services fit together; e.g. primary care, specialist services for the underlying condition and services for chronic pain. Therefore, greater education and better informational provision would be welcomed to enable more informed and productive discussions with HCPs.

Background

Scope of the Survey

This survey was a collaboration between the Arthritis and Musculoskeletal Alliance (ARMA), the pharmaceutical company Grünenthal Ltd (UK) and Adelphi Research which aimed to explore the current UK chronic pain management and healthcare support services from the perspectives of patients living with chronic pain and HCPs involved in treating patients with chronic pain.

ARMA worked with Grünenthal and Adelphi Research to develop screening criteria for participant entry into the study, discussion guides and to shape the questions to be asked during participant interviews.

ARMA intends to use the information from this survey to inform our work for improved access to treatments, services and support for patients with musculoskeletal conditions and chronic pain. Our current priority area of mental health has identified a lack of support to manage chronic pain as one of the key issues for the mental well-being of musculoskeletal (MSK) patients. We will also be sharing this report widely and encouraging everyone to take action as addressing chronic pain requires a whole system approach.

Adelphi Research conducted the survey with sole funding from Grünenthal Ltd (UK). Grünenthal Ltd (UK) did not provide any direct financial support to ARMA for this activity. Grünenthal Ltd (UK) have reviewed the content of this report for factual accuracy (internal Grünenthal document reference number M-N/A-UK-09-19-0006). Grünenthal Ltd (UK) did not have access to any patient identifiable information during this collaboration.

Research Objectives

The objective of the research was to understand the patient journey for people living with chronic pain by conducting a series of interviews with patients and HCPs to understand the issues within chronic pain and also the potential impact caused by any inequity of access to chronic pain healthcare support services.

The research was designed to address the following specific research questions:

How are pain services currently set up?

- What referral pathways are in place?
- Are specialist pain services available to patients?
- How do HCPs feel about treating patients with chronic pain and the services available to them?
- When, if at all, do HCPs ask patients about the impact of chronic pain on their day-to-day activities and mental health?

What are patients' experiences of living with chronic pain and with accessing pain services?

- What is their history with chronic pain?
- What impact does their condition have on day-to-day activities?
- Which services have they been referred to (e.g. physiotherapy, pain clinics, MSK clinics, pain management courses, mental health support and complementary therapies such as acupuncture)?
- What is their level of satisfaction with specialised pain services? How could services be improved?
- What involvement do patients have in decisions?
- Would they see value in an annual pain review?

What level of variance exists across the country? How equitable is access to services and medications?

- What does good versus bad provision of services look like?
- To what extent are patients receiving the same opportunities for care across the country?
- To what extent are patients and GPs aware of the services available to them?
- To what extent are proactive, holistic reviews offered? How regularly? And to what extent would these be valuable?

Sample and Methodology

Length of interview

The research findings are based on a bespoke survey conducted via qualitative 60-minute telephone interviews with patients with chronic pain and HCPs during April and May 2019.

Research considerations

The research was qualitative in nature and should therefore be considered indicative, rather than representative, of the wider population. Further research and validation of the results would be recommended.



A sample of 23 patients took part based on the following inclusion criteria:

- Had received a diagnosis of chronic pain and had lived with chronic pain for > 3 months
- Had chronic pain that was musculoskeletal in nature but from any cause; e.g. arthritis, sciatica, osteoporosis
- At least 50% to have received additional support beyond primary care to manage chronic pain
- To include a full geographical spread across the UK

A sample of 20 HCPs took part based on the following inclusion criteria:

- Relevant occupation; i.e. GP (N=9), specialist pain nurse (N=4), pain specialist (N=3) physiotherapist (N=2), occupational therapist (N=1), specialist psychologist (N=1)
- Had responsibility for treating/managing patients with chronic pain
- Spent a minimum of 25% of their time managing patients with chronic pain and managed > 25 patients with chronic pain per month
- To include a full geographical spread across the UK

Who We Spoke To

The patient population

We spoke to 23 patients who had experienced pain for > 3 months.

Sex



Ages



Chronic pain characteristics

Main cause of pain:

- 10 with back pain
- 4 with rheumatoid arthritis
- 4 with psoriatic arthritis
- 3 with ankylosing spondylitis
- 3 with osteoarthritis
- 3 with fibromyalgia
- 3 with osteoporosis
- 2 with joint pain
- 9 had more than one of the above conditions

Duration of pain:

- 19 for > 5 years
- 2 for between 2 and 5 years
- 2 for between 1 and 2 years

Patients often had complicated medical backgrounds which had varying implications for their health, consequences regarding access to certain services and their ability to communicate with HCPs during appointments; e.g.

- 3 had experienced accidents leading to or exacerbating long-term back problems
- 2 had diagnosed chronic obstructive pulmonary disease (COPD)
- Other comorbidities included: addiction, mental health issues, previous stroke, human immunodeficiency virus (HIV), Hepatitis C, sickle cell anaemia, haemophilia, autism and weight management problems

The HCP population

We spoke to 9 GPs, 4 specialist pain nurses, 3 pain specialists, 2 physiotherapists, 1 occupational therapist and 1 specialist psychologist, all of whom were involved in treating patients with chronic pain.

Key Findings

Chronic Pain: Definitions

Patients

Patients defined chronic pain in more emotional terms and often found it difficult to find the words to describe it. Unlike other types of pain they said that chronic pain did not ease or go away over time and they said it is this aspect which was hardest to come to terms with.

"I don't define the pain as chronic, I think of it as something that happens all the time, every day, every minute of the day"

Patient, Middlesex

"Chronic pain is difficult to understand; the pain pathways aren't telling you what the matter is"

Patient, Swansea

HCPs

HCPs defined chronic pain as pain which has continued longer than expected and is hard to treat, regardless of the underlying condition and sometimes where an underlying condition is not necessarily evident. HCPs said that they would nevertheless be treating and managing any underlying condition at the same time. Many HCPs said that patients would have to be experiencing pain for longer than three months in order to be considered to be suffering with chronic pain, but they also said in practice that patients had usually been experiencing pain for much longer than that.

"Persistent pain that has lasted at least 3 months and beyond the time of expected healing"

Specialist Nurse, London

"It's pain that patients feel they can't manage or endure and need help with"

Specialist Nurse, South England

"When talking to patients it's pain which seems not to have a good reason"

Pain Specialist, London

"Pain that is there all the time and starts to affect a patient's daily life"

GP, Dorset

Chronic Pain: Importance

There was a disconnect between the HCPs and patients on the importance of treating the pain versus the underlying condition.

Patients

For patients, even though many had received a medical diagnosis of an underlying condition by a medical practitioner, their main day-to-day concerns revolved around living with and managing their pain rather than the underlying condition. Thus, for patients, dealing with the pain was of the highest importance.

"I don't always have the vocabulary to describe it"

Patient, Slough

"The pain is more concerning than the condition, pain has the most effect on a day-to-day basis"

Patient, London

HCPs

This was in contrast to many HCPs, and especially GPs, who typically saw pain as a consequence of something else rather than a primary concern.

"It's less important to get to quickly — it's more important to come up with the underlying diagnosis"


GP, Fife

"Pain is a by-product of something else"

GP, Fylde

Impact of Chronic Pain on Patients


HCPs and patients confirmed that chronic pain is a debilitating condition which has a huge impact on QoL, as shown in the following research findings.¹



"I am not in a relationship and not looking for one because you know you can't do things"
Patient, London

Relationships and social effects:

- Relationships breaking down due to strain
- Partners are a huge source of support, but patients worry about impact on them
- Parents concerned about effect on children
- Social isolation is common



"All family problems get magnified at night when you can't sleep through the pain"
Patient, London

Sleep difficulties:

- Sleep difficulties further contribute to other problems
- Stiffness and pain on waking up — hard to face the day
- Many have tried different solutions; e.g. special mattresses, but would appreciate more advice



"Losing my career was the hardest thing. I feel I have had part of my identity taken away"
Patient, Swansea

Effects on work:

- Many are unable to continue working
- Financial impact is considerable
- Must pace themselves to get tasks done



Physical effects:

- Unable to move due to intense pain
- Distorted movement creates other injuries
- Have good days and bad days
- Travel can be a challenge with implications for attending appointments
- Having to use a wheelchair in the future is a worry for many



Understanding of condition:

- Confusion about pain — what is my body trying to tell me?
- Hard to find the words to describe to others
- Don't want pain to define them
- Experience or fear of not being believed



Fatigue:

- Fatigue compounded by poor sleep
- 'Mental accounting' — storing up energy to spend on things which are important to them
- Many want to be more active but find it hard
- Causes 'downward spiral'; e.g. loss of fitness



Emotional wellbeing:

- Majority agreed with the statement *"The impact of my chronic pain regularly has a negative impact on my mood"* (4.2 average level of agreement on a scale of 1–5)
- Suicidal thoughts expressed by several
- Low mood — find it hard to look forward to the future and lack hope
- Accepting the pain may not go away is difficult



Activities of daily living (ADL):

- Majority agreed with the statement *"The impact of my chronic pain regularly has a negative impact on my ability to carry out activities of daily living"* (4.2 average level of agreement on a scale of 1–5)
- Self-care is time-consuming and laborious
- Getting up in the morning is often a low point
- Poor self-image
- Feeling like they're 'a burden' if they need help



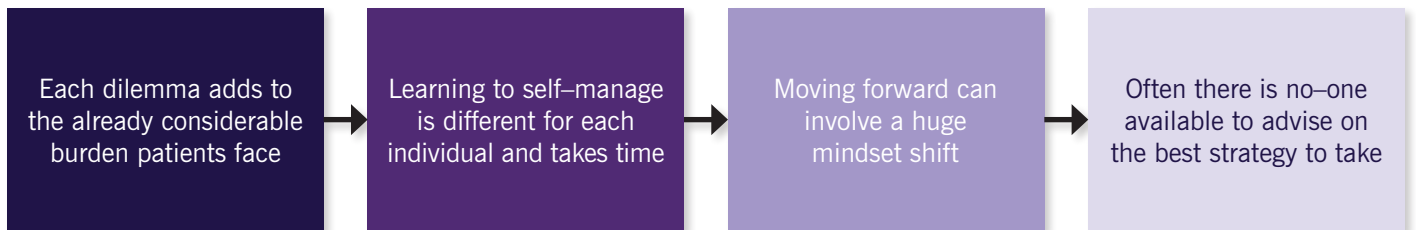
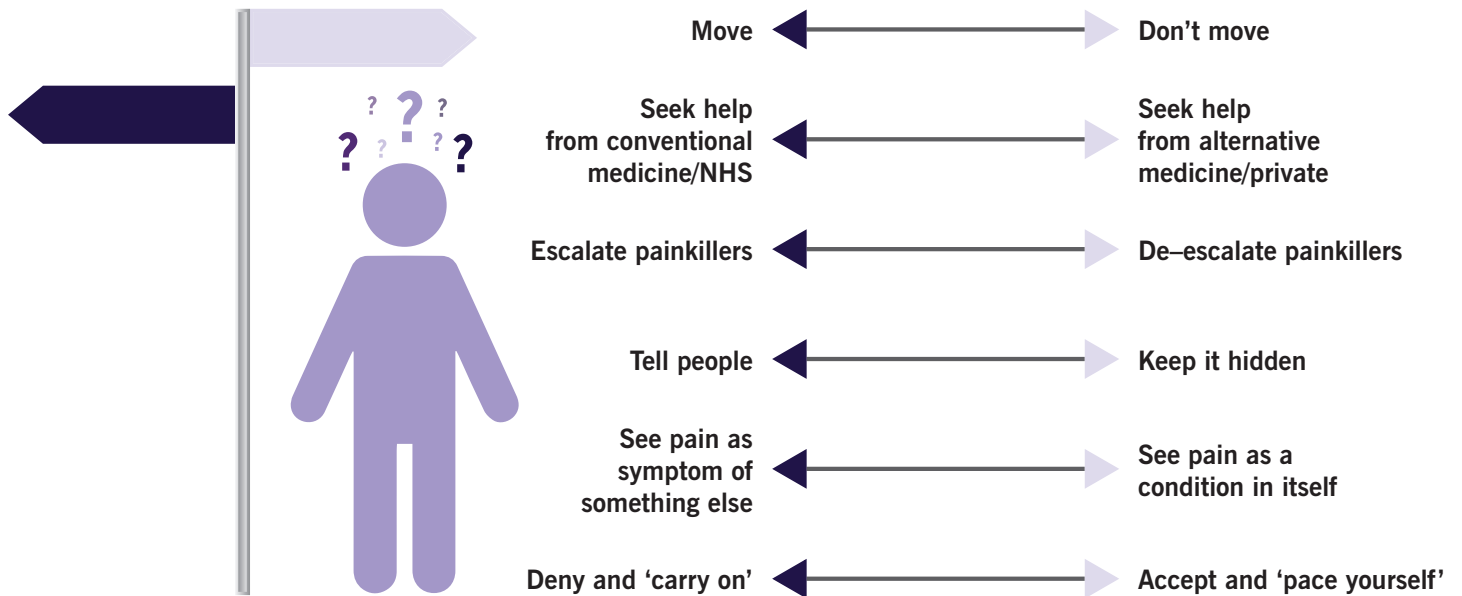
Confidence in Treatment:

- Constant dilemmas about optimal strategy
- Confidence in managing pain is mostly fairly low
- Anxiety that people will think *"it is all in my head"*

¹ Areas which patients talked about in terms of having an impact on their lives aligned well with categories in the Musculoskeletal Health Questionnaire (MSK-HQ), Oxford University 2014, a validated patient reported outcome measure for use with patients with joint, back, neck, bone and muscle symptoms.

Self-management: Daily Dilemmas

The impact on QoL seems to be exacerbated by a lack of clear guidance on how best to manage the pain in daily life, also adding to the mental burden on patients.



Patient Perspectives on Current Management Approaches

Who do patients see?

During the interviews, patients were asked:

“Apart from seeing your GP for your pain, have you ever had the opportunity to see, been offered or sought out anything else to help you manage your pain (e.g. additional types of pain management services like a hospital pain clinic with a pain specialist, a referral to a musculoskeletal pain clinic, physiotherapy, sports massage, acupuncture, cognitive behavioural therapy (CBT), relaxation classes, pain coping courses, etc.)?”

The responses indicated that patients with chronic pain are a very diverse group with a wide range of experiences when it comes to healthcare services:

- 13 patients had seen a physiotherapist though often these sessions had been fairly brief and were now finished
- Less than 50% of patients (11 in total) had seen a pain specialist or been to a pain clinic. Furthermore, three of these patients had attended a pain management course and one was seeing a specialist pain pharmacist
- Seven patients were waiting for appointments following a referral at the time of the interview; two for physiotherapy, two for a pain management course, and the others for secondary care specialists (musculoskeletal team, haematologist, neurologist). These patients reported long waits; one had been waiting for a year and a half
- Three patients had seen their GP only, and a further two had seen their GP and a specialist for the underlying condition (i.e. not focused on pain; usually a rheumatologist but also an orthopaedist, haematologist and neurologist). These patients had poor awareness of specialist pain services

How satisfied are patients?

Most patients were not very satisfied with the support they had received from healthcare services. There was a high level of agreement with the statement *“I’ve been left feeling frustrated by the lack of support available to me for my chronic pain.”* (3.7 average level of agreement on a scale of 1–5 where 1 is do not agree and 5 is strongly agree).

“Healthcare professionals are scared to confront it”

Patient, Slough

Reasons for dissatisfaction centred on the following:

- Not being offered support specifically for chronic pain
- Pain being undervalued/seen as symptom of something else
- The patient experiencing long waits and delays
- The patient being passed between specialties
- The HCP having no time
- The HCP not asking about mental well-being and health
- A lack of regular reviews

Levels of satisfaction at different points in the patient journey appeared to vary according to specific HCPs. For example, patients stated that some HCPs took the time to have a detailed discussion about their chronic pain, the various options available whilst also asking for opinions from patients. These HCPs could be GPs or specialists.

When describing interactions with these types of HCPs, patients said that they:

- Felt they were taken seriously
- Received some good tips and strategies; e.g. pacing
- Felt more in control and supported
- Felt their medication was managed more proactively

On the other hand, other HCPs came across as much more dismissive and less inclined to ask about chronic pain or involve patients in decisions. Many patients describe encountering both types of HCPs on their journey.

Primary care and referrals

Although there were some exceptions, in general most patients felt their GPs did not manage chronic pain particularly well.

Key problems were as follows:

- Patients felt that GPs don’t always appreciate the severity, duration or impact pain can have
- They suggested the pain element gets tagged to other issues; i.e. it is not recognised in its own right
- Patients reported not being believed; either discredited completely or with suggestions being made that the pain is “just in my head”

“The GP still doesn’t do the regular tests; he thinks it’s not required. It’s like a lottery”

Patient, London

Patients were made to feel rushed or like a burden:

- Patients reported difficulties obtaining GP appointments, making it hard to discuss issues
- Patients reported feeling they were only allowed to discuss one condition per visit
- Patients were rarely asked general questions about their state of health, mind or QoL in relation to pain
- Some patients mentioned that GPs seemed too busy to spend time discussing issues in any detail
- A small number of patients claimed they were referred on simply to get rid of them, while others were made to feel undeserving of a referral

“It would be better if you could have a 15-minute conversation with a doctor to understand the treatment options and pathways rather than a 2-minute — all over — you are done. And they move on to the next patient. When you go back in, half the time they don’t even look at your history”

Patient, Fife

Patients felt they were not given the information or support they need:

- It was common practice to see a different GP for every appointment, meaning the patient would have to start from scratch with their story each time
- Patients reported that discussions with HCPs tended to be very condition-focused; with mental health support often not even discussed
- Expectation setting, beyond the condition being unlikely to improve, was quite rare
- Patients are often not given any ‘proactive’ guidance, such as how to manage pain
- Many felt they were offered painkillers with no discussion around the impact of long-term use

Physiotherapy

A little over half of the patients had seen a physiotherapist (13 patients in total). Awareness of physiotherapy as an option for chronic pain was high and several patients had proactively sought help in this way. Advice about how to move in a way which helps rather than exacerbates chronic pain is something some patients appreciate and find hard to address by themselves. Referrals into physiotherapy were mostly initiated by the GP but in some cases the physiotherapy was offered as part of specialist MSK or pain services or following surgery.

There were some criticisms from patients about physiotherapy:

- Long waits to access the service
- Very short in duration e.g. can be as little as one session
- Sessions don’t seem tailored to specific problems or chronic pain
- Stringent rules about attendance e.g. if appointment is cancelled, the referral has to be made again with the associated wait. This can be a key barrier for those who find travel difficult
- Students present which can be off-putting for some

Many patients expressed the belief that the only way to attend enough sessions to impact on chronic pain was to access it privately.

“She offered some hope, she was of the opinion that if I did my exercises it would really help me to move forward and heal”

Patient talking about physiotherapy, Leicester

Pain specialists

A little under half of our sample had experience of seeing pain specialists or attending pain clinics. Those who had not been to pain clinics said that they would like to be referred into this service. Of those, a few had previously been unaware that specialists in pain existed and expressed surprise about this.

“The pharmacist will ring if I can’t go in because of the pain. She has a flexible approach and understands chronic pain. She doesn’t just talk about the pain and medication — she asks about all aspects of life... she’s very aware of my social and home situation”

Patient, Gorseinon

Those who had attended pain clinics reported mixed experiences. On the one hand, some found it validating to be seen by a specialist in what they were most concerned about, i.e. pain. They appreciated being able to have more detailed advice from specialists about the different options available in terms of treatment. In some, but not all areas, pain clinics were closely linked to services such as physiotherapy and psychology and patients liked being given the option to access these services. They also liked signposting or linkages to other therapies including some they had not realised were available on the NHS e.g. acupuncture, hydrotherapy and mindfulness.

Patients who were less positive about pain clinics expressed they:

- Hoped for better and stronger painkillers
- Felt they knew the advice already
- Found it too difficult to accept that the pain might not go away
- Did not 'click' with HCPs or felt rushed

"Pain management is helpful. Although it cannot cure the pain, it helps you know how to manage it"

Patient talking about pain clinic, London

Five patients had been to see a specialist musculoskeletal team, which was mostly in relation to an underlying condition; however, chronic pain was often included as part of the consultation. These patients reported similar experiences to those patients who had accessed a pain clinic in that they appreciated the specialist advice and further information about a variety of treatment options such as physiotherapy.

One patient was seeing a specialist pain pharmacist and was finding this very helpful.

"I know I can reach out to them if it is really bad and urgent. They won't give an appointment, but they will call back"

Patient talking about pain clinic, Edinburgh

Pain management courses

Out of the 23 patient respondents, only three had taken part in a pain management course. Their experiences were positive suggesting their use may be of some benefit. The patients felt that the multidisciplinary approach used on these types of courses worked well and they found hearing from different specialties, such as physiotherapists and psychologists beneficial.

"There was a psychologist, physiotherapist and a pain management doctor from the hospital and five patients... good group of people... all supporting each other. Multidisciplinary approach: brilliant. You're not a number"

Patient, London

Another respondent was on the waiting list for a pain management course and was cautiously optimistic about it.

"I've now been offered a course on how to best live with the pain. It's not the ideal situation, but a step forward"

Patient, Lancaster

Two other respondents had been offered pain management courses but had not taken them up due to personal inconvenience owing to transport issues or clashes with other commitments; they were also concerned that the course focused too much on psychological elements and would not be able to address the pain itself.

Of interest, awareness of pain management courses amongst the other respondents was low. Several said they would be interested in attending a course of this kind.



Private care

Some patients felt the need to seek help within the private sector. In total, seven patient respondents had sought help privately from a range of different services. Some examples include: a private rheumatologist for a second opinion (although this patient was subsequently referred back into the NHS); private physiotherapists to take advantage of shorter waiting times, more sessions, more convenient times and locations, or more tailored exercises; and also to gain access to services which patients perceive are not normally available on the NHS, such as chiropractors, hypnotherapy, Reiki, acupuncture, transcutaneous electrical nerve stimulation (TENS) machines, massage, reflexology and CBT. Several other respondents mentioned that they would like to access private services for their chronic pain but could not afford to do so.

Patient involvement in treatment decisions

Patients expressed contrasting views about involvement in treatment decisions. Most patients said that they did have some degree of involvement in decision-making, usually at the point of initiation of a new treatment. The HCP would describe the benefits and any side effects of a treatment and took the time to listen to patients about whether they wanted to take the medication or not. However, other patients said that they did not feel involved at all in treatment decisions and said that no-one had ever talked through the different treatment options with them.

"I felt — this is the diagnosis, this is the medication, go away and deal with it and just order repeat prescriptions and don't bother us"

Patient, Leicester

Opinions about ideal levels of involvement in decision-making varied considerably by individual patients with some patients wanting much more involvement than others. One patient did not want to be involved in decision-making at all as she was happy to entirely take the advice from a doctor, whereas others felt that involvement from patients was discouraged and ideally wanted a much broader discussion with HCPs, in particular about what had helped other patients with chronic pain.

"Yes. I have been closely involved. They offer it and if I want to try it, I can. If I don't, I don't"

Patient, Devon

Patients who had been suffering with chronic pain for a long period (e.g. over five years) said that they had often become more proactive and involved in treatment decisions over time. A number mentioned that involvement with charities helped them feel more informed about their condition as well as more connected to other people with similar problems. Online support in the form of health focused social media forums was also mentioned as an important source of information and support.

"I joined the local arthritis group and you meet with people with a similar condition — it helps you emotionally as well when you realise there are others going through a similar condition. You also get some tips on handling your condition"

Patient, London

Mental health support

In contrast to the negative impact on mental well-being that was expressed by patients, only five indicated that they were receiving specialist mental health support or had in the past although in a couple of cases this was for issues which pre-dated the chronic pain. This finding highlights the current lack of mental health support for patients dealing with chronic pain conditions. In addition, patients would appreciate being asked about the impact on mental health arising from their chronic pain. Currently this does not happen very consistently.

"I would like to be able to talk to somebody such as a psychologist and discuss the implications. You just get told this is one thing that will never be cured. You need to live with and adapt to it. And if you don't have anyone to talk to or support you, it can be really damaging"

Patient, Fife

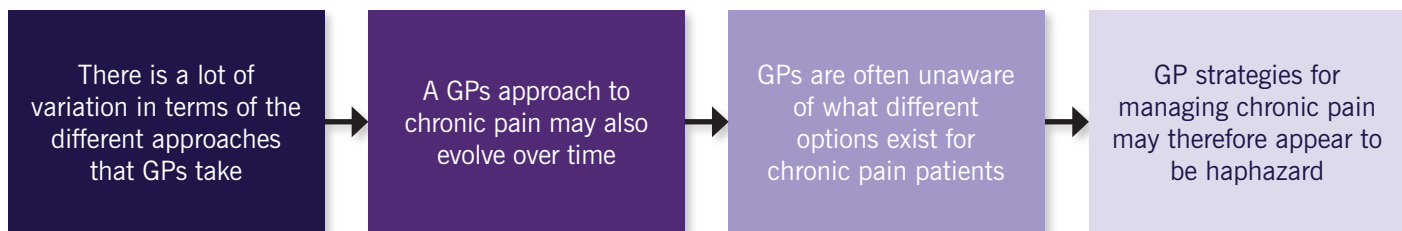
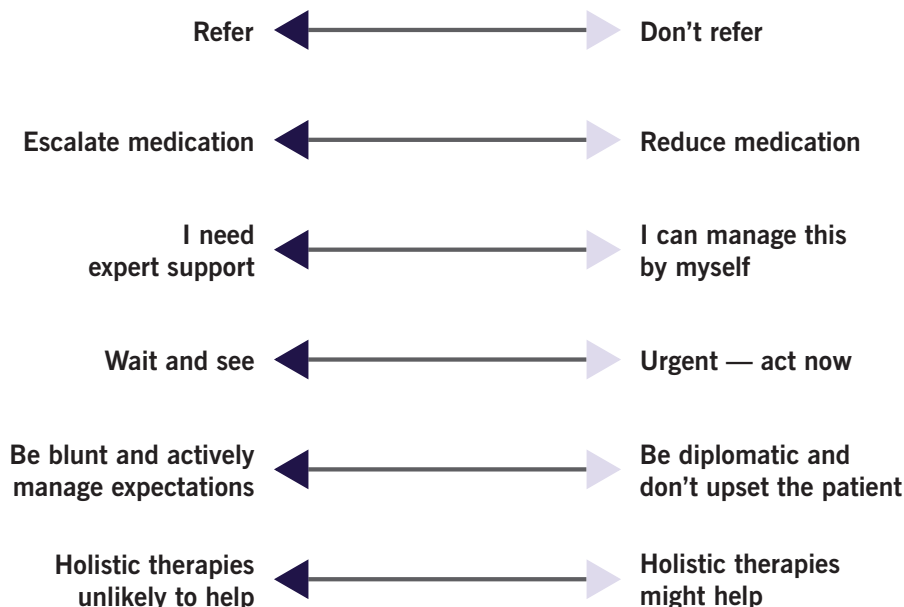
In summary, the overall picture taken from patients is that they would like to have more time with HCPs, they would like to be asked more explicitly about their mental health and well-being and they would like to be referred for additional support services earlier on.

"The pain psychologist had a good impact. There is so much to deal with emotionally. You need more than just exercises to do. You need to mentally deal with the pain"

Patient, Swansea

GP Perspectives on Current Management Approaches

GPs reported finding patients with chronic pain challenging to manage, primarily because they felt there are no clear solutions. GPs described being torn between a number of key dilemmas regarding their patients; e.g.



Those GPs who were more aware of the different options that exist for their patients reported feeling limited, and a sense of frustration about the specialist pain services they felt they were able to offer their patients. For example, a lack of, or minimal, access to pain clinics, pain management, mental health services and ‘holistic’ therapies such as acupuncture. In addition to this, there is also the concern of long waiting times. GP strategies for managing chronic pain may therefore appear to be haphazard and vary enormously by individual GP and patient. Some GPs seemed unaware of the different options that exist for their patients.

GPs do not feel adequately supported in managing patients with chronic pain.

“A big part of our consulting is pain, pain for various reasons. Almost everyone that walks in has some sort of pain”
GP, South Wales

“It can be very difficult, challenging, tricky. Every patient is different, how they look at their pain, how they look at their condition, their relationship with the GP, their relationship with their bodies, every patient is different”
GP, South Wales

Many of the GPs we spoke to described their frustrations when dealing with chronic pain, such as the wide variety of patient presentations and comorbidities as well as patient expectations to assess and manage pain with limited options and little or no support.

Some common themes were evident:

Chronic pain is often difficult to diagnose:

- It is considered ‘a diagnosis of exclusion’ — it is multifactorial in that there are numerous reasons, comorbidities, patient perceptions and experiences to consider
- Several acknowledge the discussions and diagnosis are very subjective with little in the way of tools or tests

The importance of psychological impact varies among HCPs:

- Some discuss as a high priority; i.e. part of overall consideration, others less so; i.e. more a case of ‘if needed’
- Some encourage patients to be involved in discussions and decisions in order to support their psychological well-being; i.e. give them a feeling of being in control

Ongoing frustrations are widespread:

- Medication is their only true resource; i.e. following the pain ladder — essentially, one medication after another until options are exhausted
- The addition of painkillers is a key worry, but not easily avoidable
- Generally, experiences are not very rewarding; e.g. pain rarely improves significantly, leading to dissatisfied patients
- A real feeling of ‘nowhere to go’; GPs often felt very much on their own, with no support or consultation with other HCPs
- Can be difficult to set patient expectations

“I think if they’ve got ownership and control over the management decisions then from some psychological point of view it gives them more insight and control as to what exactly is happening to them”

GP, Dorset

“From the offset it is about expectation setting, to say that as much as we are trying to control the symptoms, it might not be something that we’ll necessarily achieve to completely negate — although we will work with them to do as much as we can to regain that quality of life”

GP, Cannock

“GPs will often prescribe drugs that don’t help before referring to us”

Occupational Therapist, Swansea

“What you find is patients with chronic pain also have other comorbidities, like in particular there is a link between pain and mental health and so I think if we can improve that aspect of care, the mental condition, I think it would have a positive impact on the other aspects as well”

GP, Cannock

Referrals

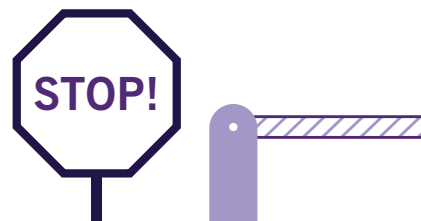
A key issue was that referrals to pain clinics are inconsistent and vary enormously from location to location, GP and patient.

From the interviews, we identified various triggers and barriers to referral.



Triggers for referral included:

- Patient proactively asking for a referral
- GP feels they have run out of ideas or options
- GP or patient wants to escalate pain medication to something not accessible in primary care; e.g. injections
- Specialist services for pain are available in the local area
- GP aware of specialist services and has permission and funding to refer to them
- Patient's history meets criteria; e.g. patient has complied with medication, attended physiotherapy etc.



Barriers to referral included:

- Sheer volume of patients; i.e. most patients have a degree of pain; no objective measure for which patients have 'chronic pain'
- Nothing or very little in the way of local specialist pain services
- GP not aware of specialist services or is not confident funding is available for referral
- Perception that a referral may escalate medication which the GP or patient wants to avoid
- Perception that specialist services can't achieve anything more than a GP can
- Patient not proactive or unwilling to travel

"Referral — sometimes it can just come down to 'I am really sick of seeing this patient, I don't know what to do with them, I just need someone else to input in this'"

GP, Hambleton

"To which department they are referred to depends on the training and bias of the GPs. Patients can randomly go either to the pain clinic, the orthopaedic department, the neurosurgeons or to the rheumatologist and it all depends on the individual GPs. They are not ever following any strict guidelines or care pathways"

Pain Specialist, Coventry

"Sheer volume is a barrier. For a GP, how do you decide to refer when 1 in 4 of your patients is telling you about their pain?"

Specialist Nurse, London

Where there are barriers to referral the HCP may take a 'wait and see' approach. Alternatively, they may make a referral but for the underlying condition or comorbidity. Within our sample this was usually a rheumatologist. The level of interest in chronic pain from these specialists as perceived by patients and pain specialists varied considerably. For some it was not a focus, whereas others were actively trying to manage chronic pain alongside the underlying disease. Some patients had been referred into pain specialist services via their rheumatologist.

Specialist Perspectives On Current Management Approaches

We spoke to a range of specialists managing patients for their chronic pain including: pain specialists, specialist pain nurses, physiotherapists, occupational therapists and psychologists. HCPs running specialist services for chronic pain patients typically feel they are unable to offer enough patients the care they need. The most commonly cited frustration was receiving patients too late, but they were also dissatisfied with the level of coordination between services and the lack of multidisciplinary approach to managing patients with chronic pain.

“If you look at the degree of interaction between the different specialties that are involved it is not as fluid as it ideally should be”

Pain Specialist, Surrey

“What I would like to see is at first consultations for the patient to be able to access psychology and physiotherapy as well as us, so we would have a shared care approach where we combined together at first consultation to come up with a management plan”

Pain Specialist, Surrey

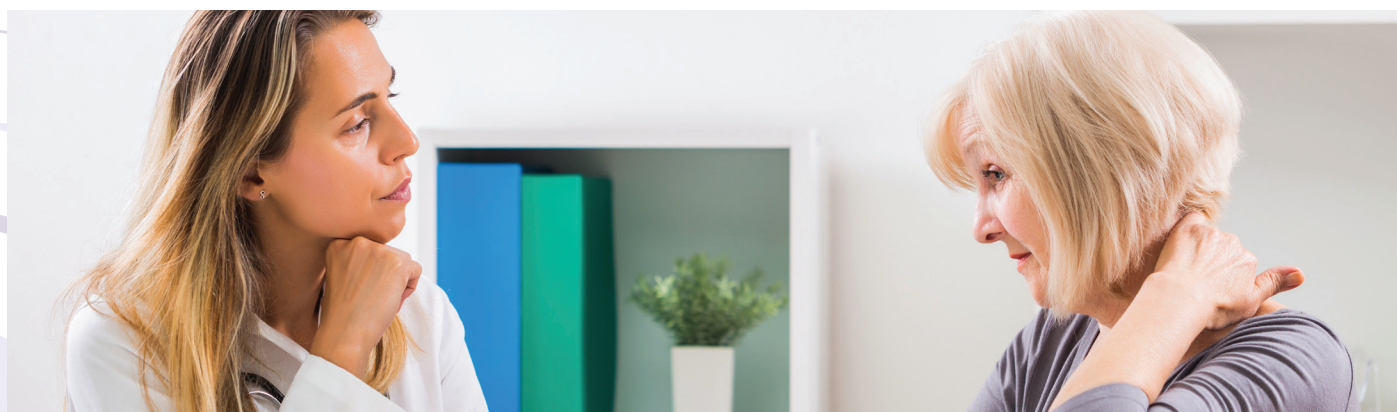
“The earlier you can manage, you actually prevent chronicity and disability. Sadly, these patients, by the time they come to the pain clinic they will already have had a strained family life, they will already have lost their job and when you are trying to mop up the mess, when you are trying to bring back their fitness level, then it is extremely challenging and frustrating”

Pain Specialist, Coventry

HCPs said that services which take a fully multidisciplinary approach achieve good outcomes for patients and patient satisfaction is high. The integration of psychological support services was felt to be particularly beneficial. However, in practice, HCPs said that this level of service and integration with psychological support is rarely achieved due to a lack of integration and funding.

“I think it would provide more timely treatment, it would mean the patients had earlier access to psychology if we had that and also the physios are very skilled at picking up underlying issues that cause it especially with MSK pain, so it would prevent chronicity potentially if we were able to catch them earlier”

Pain Specialist, Surrey



Inequity of Access to Specialist Support

Both HCPs and patients called for more equitable access to specialist pain services as the current system is acknowledged as confusing and unfair.

"In bigger cities they have plans for people with spinal injuries, an outpatient clinic and work with physio and OT [occupational therapy]. I never had anything like that"

Patient, Swansea

"We are in Northern Ireland, so we wouldn't be offered any of those things [specialist pain services]"

Patient, Northern Ireland

Both HCPs and patients perceived unjustified inequities within the healthcare system. For example, the availability of different services that are or are not available within the NHS to support pain management seems inconsistent between geographical areas and even different patients. This inequity applies to waiting lists and availability of specific services such as psychological support. In addition, there was confusion from patients about what is and isn't available on the NHS, with most assuming that complementary therapies such as acupuncture or mindfulness always have to be accessed privately.

"We have an MDT approach and can offer a quite comprehensive package of care compared to other trusts"

Pain Specialist, Surrey

"Pain services in the community dependent on geographical location"

Pain Specialist, Coventry

There is also a perception from some HCPs and patients that good pain services are only available in teaching hospitals or in larger urban areas; e.g. large cities. However, there is no clear evidence that this is the case and the presence of well-functioning MDTs for pain management seems to depend mostly on local champions and funding.

"It would be good if there was more clarity for patients as to what the NHS offers and what needs to be accessed privately"

Pain Specialist, Coventry

"Less than 20% of patients have access to psychologist support on the NHS in my area"

Clinical Psychologist, London

"The pain consultant, it's a very understaffed service. They don't have time to sit with everybody"

Patient, Northern Ireland

Response to the Idea of an Annual Review for Chronic Pain

HCPs and patients were asked about the concept of regular pain reviews. This was not the norm for those interviewed. The research found that the vast majority of both patients and HCPs could see the benefit of having an (at least) annual pain review to support current treatment approaches.

HCPs

Of the 20 HCPs interviewed, the majority endorsed the idea of an annual pain review.

They felt such sessions would allow:

- Regular review of medications, which would allow HCPs to ensure their patients were on the most effective individualised treatment and monitor any side effects
- Dedicated time to assess the patient's mental health and well-being, as well as the chronic pain, thus enabling them to signpost to specialist support if necessary
- Patient input into their management strategy, empowering patients to cope with their pain

"Patients feel empowered when their doctor is looking after their diabetes for example, because it's being monitored, so if patients were being monitored for their pain, the same thing would happen"

GP, London

One pain specialist rejected the idea, the reason being that he wanted patients to be self-managing. One nurse felt it was already happening in her area and perceived a degree of overlap with medication reviews. The rest of the sample were positive but there was some debate about feasibility owing to costs to healthcare services, individual time and workload pressures. There were also some who were uncertain about where annual reviews for chronic pain would take place. Most assumed primary care would be the most likely location, but this also raised doubts about the willingness of some GPs to take on additional responsibilities.

"It would be valuable for GPs to do an annual review. Gives a good base line to how the patient is. It would be feasible — would work. I think patients would engage with this"

GP, Dorset

Patients

Almost all patients (20 out of 23 interviewed) saw the value in having an annual pain review and some were even keen on more frequent reviews; e.g. twice a year or quarterly. Only one patient felt it was not necessary because it was happening anyway. The remaining two patients were concerned about an annual review replacing 'on demand' appointments.

"Regular review would be of value — quarterly would be good — if it has to do with seasons, that can be picked up — maybe the level of pain increases in winter"

Patient, Manchester

One thing that patients desire from the health service is more time to discuss their chronic pain, so any medium like this which gives them the opportunity to talk through their symptoms, treatment options and general mental well-being, would be more than welcomed by patients. Some also see it as an opportunity to explore specialist chronic pain support services, in order to make access to such services more straightforward. Another benefit of an annual review would be to review their medications with regards to effectiveness and side effects. Repeatedly patients felt that their often complicated medication regimens were not reviewed frequently enough.

"The ability to have something where I can see someone who can discuss all the relevant options, that would be great"

Patient, London

"Everything's on repeat prescription. When trying to get an appointment to discuss medication and alternatives, I can never get appointments. I would love to get asked about how I'm getting on"

Patient, Leicester

On the other hand, a few patients expressed reservations, owing to the fact that chronic pain can be unpredictable. They argued that a regularly scheduled review might fall at a time when it is less needed, and patients were concerned this might hinder their ability to receive medical support on an ad-hoc basis, when their chronic pain was at its worst and when they required it most.

"I don't think it could be a scheduled review as pain doesn't have a schedule"

Patient, London

Both patients and HCPs feel that they would benefit from a more collaborative approach.

Of particular interest, both HCPs and patients feel that they would benefit from a more collaborative approach, something that a regular pain review could allow. This may also have the knock-on effect of improving patient empowerment, which would motivate the patient to take management of their chronic pain into their own hands between reviews and possibly positively impact their attitude towards their condition.



The Ideal Future for Services

We explored how HCPs would like to see chronic pain managed in the future. The optimum treatment model described in the interviews would afford pain in its own right the **same significance as any other medical condition** and would aim to **work in partnership with patients**.

"Chronic pain is a multisystem condition, it is not just one system so one solution doesn't fit all"

GP, Dorset

"In my mind it is a separate entity altogether and these patients are completely different and you start recognising the pattern with these patients and you have to look at other avenues rather than just look at one targeted therapy and say this is your tablet and if you take it you will be fine, that's not the way it works and what you need is a well-coordinated MDT approach for these patients"

Pain Specialist, Sunderland

HCPs suggested they would ideally like future services to be based on the following principles:

- Different specialties work together; i.e. using an MDT
- Pain is recognised as an entity in itself
- Patients are willing to undertake a mindset shift; e.g. to try something different
- HCP has more time to spend with the patient
- HCP asks about patient mental well-being
- Pain is addressed as a distinct issue early on and reviewed regularly

"People that receive an MDT package of care involving different treatment options, they are the ones that are most satisfied"

Clinical Psychologist, London

"If they had a rounded programme that could offer all those different disciplines and it was easy to refer within a team and they weren't waiting months"

Occupational Therapist, Swansea

Key Themes

The research has highlighted a number of key insights and themes for how respondents felt that chronic pain services can be improved and made more equitable in the future.

1. Ensure patient involvement/buy-in

HCPs, and particularly specialists, say that patient involvement is very important and that treatment is more likely to be successful when HCPs and patients work in partnership. HCPs talk of engaging patients in discussions and decisions about their treatment, setting expectations and encouraging a 'mind shift' when required.

2. More equitable access to specialist services

Currently, there is huge variation by area and individual patient with regards to what services are offered. This 'lottery' is seen as unfair by both HCPs and patients with chronic pain. Thus, a key issue is ensuring a more equitable access to pain specialists, but improvements regarding awareness and referral processes are also required.

3. MDT approach to coordinate care

Effective management strategies are diverse and require multidisciplinary involvement. HCPs strongly advocate a multidisciplinary approach including pain specialists, physiotherapists, psychologists, specialist nurses and pharmacists. There are areas where this MDT approach is followed but HCPs say it is 'not the norm'. An MDT should be seen as essential to 'join-up' care.

4. Advocacy for pain to be afforded the same priority as if it were an actual condition

Patients report that discussions around chronic pain are often deprioritised despite being the primary concern for the majority of patients. Acknowledgement of pain as a serious issue is validating for patients. Having a community of support and an evidence base for strategies gives them hope.

5. Regular review for chronic pain

There was wide endorsement for the idea of an annual chronic pain review. It was seen as being beneficial for a range of purposes including medication review, time for patients to discuss and optimise their treatment strategies and updates on mental health.

6. Quicker referrals

Long wait times for specialist service referrals are common, especially for physiotherapy and pain clinics. Long wait times were thought to contribute to deterioration in QoL, and HCPs say that patients who are referred earlier are easier to treat and have better outcomes. Specialists were particularly concerned about this, as they felt that delays in seeing patients made issues harder to solve.

7. Improvement in provision of information for patients and GPs

Awareness of the services available for chronic pain was low amongst patients. It is confusing to understand how the different services fit together; e.g. primary care, specialist services for the underlying condition and services for chronic pain. Therefore, greater education and better informational provision would be welcomed to enable more informed and productive discussions with HCPs.

Glossary of Terms

Activities of daily living (ADL)

A term used in healthcare to refer to an individual's daily self-care activities; e.g. personal hygiene, dressing, feeding, ambulating; and used as a measurement of a person's functional status.

Healthcare professional (HCP)

Someone who works in healthcare. In the context of this report, HCPs include physicians, nurses, physiotherapists and other Allied Health Professionals, mental health and occupational health workers.

Multidisciplinary team (MDT)

Healthcare and a variety of other professionals working together as a team; e.g. physicians, nurses, pain specialists, psychiatrists, psychologists, physiotherapists, occupational therapists, holistic therapists.

Referral

The recommendation and transfer of care for a patient from one physician/professional or clinic to another by request.

Quality of life (QoL)

An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment².

² World Health Organization definition.

About Us

The Arthritis and Musculoskeletal Alliance (ARMA)

ARMA is an umbrella body representing the breadth of musculoskeletal conditions and professions.

Our vision for MSK health:

- The MSK health of the population is promoted throughout life
- Everyone with MSK conditions receives appropriate, high quality interventions to promote their health and well-being in a timely manner. We have 30 member organisations, ranging from specialised support groups for rare diseases to major research charities and national professional bodies. For further information please visit: arma.uk.net

Grünenthal Ltd (UK)

Grünenthal UK is an entrepreneurial, science-based pharmaceutical company specialised in pain. We are a fully integrated research and development company with a long track record of bringing innovative pain treatments and state-of-the-art technologies to patients. For further information please visit: www.grunenthal.co.uk

Adelphi Research

Adelphi Research is a healthcare market research agency based in Bollington, Cheshire. We are part of the Adelphi Group of companies who specialise in local and global market research, health outcomes research, real world evidence and healthcare communications. We are commissioned by pharmaceutical companies, patient advocacy groups, charities and NHS organisations to help navigate challenges and support key decisions across a range of health-related topics. For further information please visit: www.adelphiresearch.com

