

### **CHRONIC PAIN**

### **POLICY POSITION**





































































### CONTENTS

SECTION AND HEADING	PAGE
Executive summary and recommendations	4-7
1.WHY PAIN IS IMPORTANT; CHRONIC PAIN, A DEFINITION	8-9
2. FACTS AND FIGURES	10
3. CHRONIC PAIN LINKS TO HEALTH INEQUALITIES AND DEPRIVATION	11-15
3.1 Systemic inequality	12
3.2 Chronic pain and ethnicity	12
3.3 Chronic pain, gender and age	13
3.4 Chronic pain, deprivation and geographical area	13
3.5 Chronic pain, income and jobs	13-14
3.6 Inequalities in life expectancy, healthy life expectancy and disability-free life expectancy	15
3.7 Summary	15
4. IMPACT OF PAIN	16-18
4.1 The individual	16
4.2 Economic impact	16
Case study - Beverley – impact and a future with constant pain	16-18
5. UNDERSTANDING PAIN	19-21
5.1 Pain is not recognised as important	19
5.2 Pain and the emotional impact	19-20
5.3 Chronic pain can be a condition in itself	21
5.4 Research and pain data	21
6. PREVENTING PAIN	22-26
6.1 Predictors and risk factors affecting development of chronic pain	22
Case study - STarTBack Tool	22
6.2 Exercise/physical activity	22-23
6.3 Obesity	23-24
6.4 Treating underlying conditions associated with pain	24
6.5 Pharmacological treatments for underlying conditions associated with pain	24
Case study - Ailsa has lived with severe inflammatory polyarthritis for 40 years and is now on he	er ninth
biologic/advanced therapy	24-26
6.6 Falls prevention	26
6.7 Education	26
7. SUPPORTING PEOPLE WITH CHRONIC PAIN	27-31
7.1 Disjointed services and delays	27-28
7.2 Biomedical model versus a personalised approach	28-29
7.3 Support options	29
7.4 Good conversations and shared decision-making	29-30
7.5 Community pain services	30
7.6 Commissioning and funding	30-31

31
31
32-36
32
32-33
33
33
33-34
34
34
34-35
35-36
36
37
38-44

### ARMA is an alliance of charities, health professions and research organisations for the musculoskeletal community. Our member organisations are:

Arthritis Action	National Ankylosing Spondylitis Society (NASS)
BackCare	National Rheumatoid Arthritis Society (NRAS)
British Association of Sport and Exercise Medicine	Physio First
(BASEM)	Physiotherapy Pain Association
The British Association of Sport Rehabilitators	Podiatry Rheumatic Care Association (PRCA)
(BASRaT)	Polymyalgia Rheumatica & Giant Cell Arteritis UK
British Chiropractic Association (BCA)	(PMRGCA UK)
British Dietetic Association	Primary Care Rheumatology Musculoskeletal
British Orthopaedic Association (BOA)	Medicine Society (PCRS)
British Society of Rehabilitation Medicine (BSRM)	Psoriasis Association
CCAA Kids with Arthritis	Rheumatology Pharmacists UK
Chartered Society of Physiotherapy (CSP)	Royal College of Chiropractors (RCC)
Ehlers-Danlos Support UK (EDS UK)	Royal College of Nursing (RCN) Rheumatology
Faculty of Sport & Exercise Medicine (FSEM)	Forum
Fibromyalgia Action UK (FMA UK)	Royal College of Podiatry
Hypermobility Syndromes Association (HMSA) UK	Royal Osteoporosis Society
Institute of Osteopathy (iO)	Scleroderma & Raynaud's UK (SRUK)
McTimoney Chiropractic Association (MCA)	The Society of Musculoskeletal Medicine (SOMM)
Musculoskeletal Association of Chartered	The Society of Sports Therapists (SST)
Physiotherapists (MACP)	UK Gout Society
	Versus Arthritis

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### **EXECUTIVE SUMMARY**

#### 1. WHY PAIN IS IMPORTANT

Chronic (persistent or long-lasting or recurrent) pain is life-changing; It can significantly impact individuals, their families, and carers. Chronic pain affects all parts of life. Pain often goes hand in hand with other symptoms - low mood, fatigue, and memory impairment. Chronic pain is linked to deprivation and health inequalities.

#### 2. FACTS AND FIGURES

The Public Health England, Chronic pain in adults 2017, Health Survey for England reported:

- 34% of adults in England reported chronic pain in 2017<sup>1</sup>, that's around 15.5 million people<sup>2</sup>.
- 81% of people with a musculoskeletal condition report being in chronic pain<sup>3</sup>.

#### 3. CHRONIC PAIN LINKS TO HEALTH INEQUALITIES AND DEPRIVATION

There is clear evidence that persons with chronic widespread pain experience excess mortality<sup>49,50</sup>. There are links between chronic pain and health inequalities. Some differences result from gender, age, geography, income, racism, also conscious and unconscious bias play a part. To make a difference, health inequalities need to be understood, discussed and we need to rapidly implement levers for change. Systems and services should allow equity in access, experience of using NHS services and equity of outcomes for all groups. Systems and services should be inclusive and culturally sensitive.

#### 4. IMPACT OF PAIN

The impact of chronic pain is huge, affecting daily living, reducing quality of life, hampered by lack of clear guidance and where to seek help. It affects:

- Family relationships, intimacy and sexual relationships, socially leading to social isolation, people worry about impact on children
- Sleep
- Finances and work/education
- Physically difficulty in travelling and moving; fatigue
- Emotional wellbeing mood, suicidal thoughts, poorer self-image.

#### 5. UNDERSTANDING PAIN

Specific reasons for people's dissatisfaction with support for chronic pain include:

• Pain being undervalued and seen as a symptom of something else, such as arthritis.

- Healthcare professionals do not always appreciate the severity, duration or impact pain can have<sup>4</sup>.
- People living with chronic pain not being offered specific, proactive or the right information and support for chronic pain; for example, what the pain is, what they can do about it, treatment options, long-term implications and the time to discuss this with the healthcare professional.<sup>5</sup>
- This can result in long term reliance on health services and people's inability to manage their own health. <sup>6</sup>

#### Pain and the emotional impact

There is currently a **lack of mental health support** for people dealing with chronic pain conditions. The provision of support on the psychological aspects of physical illness often do not meet people's needs.

People with chronic pain would like to have more time with health care professionals and would like to be asked more explicitly about their mental health and well-being, being referred to additional support services earlier on.

#### 6. PREVENTING PAIN

While most people are aware of the benefits of physical activity and want to be active, many people with pain and long-term conditions find physical activity hard to do. Pain, fear, fatigue and a lack of time are some of the barriers that prevent people from incorporating physical activity into their lives. How a person feels from day to day can change, and so staying active can be a real struggle.

#### Treating underlying conditions associated with pain

Many cases of chronic pain are related to an underlying condition such as rheumatoid arthritis, osteoarthritis or axial spondyloarthritis. Treating the underlying condition is therefore important.

For instance, for people with severe osteoarthritis, joint replacement surgery is usually very effective at reducing pain and restoring independence. A delay in surgery may result in people living with daily pain, plus barriers to mobility and independence, compromising their wellbeing and quality of life. Delays to treatment can lead to worse outcomes for people. The COVID-19 pandemic has resulted in significant lengthening in waiting times for joint replacement surgery from an already long waiting list. Reducing waiting times is therefore important as is actively supporting people on waiting lists to help with the pain.

Pharmacological treatments (e.g. biologics) that could help chronic pain are not always accessible to all people due to their cost against a background of a restricted health care budget.

#### 7. SUPPORTING PEOPLE WITH CHRONIC PAIN

People with chronic pain consult their GP around five times more frequently than those without, and chronic pain is a presenting condition in around 22% of primary care consultations. Other people with chronic pain might see a private practitioner, or self-care. GPs face hurdles at almost every stage of treating and managing chronic pain and there is huge variation by patient presentations and comorbidities.

Disjointed services and delays

People can feel they are passed between services or fall between services e.g. they may not be able to access a psychologist until they have been to the pain clinic, adding delay. Specialists in pain management are commonly frustrated by delays in accessing them, the level of coordination between services and a **lack of a multidisciplinary approach**. <sup>7</sup> A joined-up approach is needed.

#### **Support options**

Pain is individual, no single treatment works for everyone. It is therefore important to have a range of different treatment and therapy options and combinations that will best meet the needs of people with chronic pain. Choice of treatment will depend partly on what pain management works for the person and also partly on any underlying causes of the chronic pain. A person's specific needs, preferences and abilities should be taken into account. For chronic secondary pain, the relevant NICE guideline appropriate for the condition should be followed.

#### Good communication and shared decision making

The complexity of chronic pain and the significant distress and disability associated with it can influence clinical interactions. There is evidence of shortcomings in people's experience of consultations with healthcare professionals. People often expect a clear diagnosis and effective treatment, but these are rarely available. There needs to be honesty about the uncertainty of the prognosis. For chronic pain, there are often treatment options without a clear best choice.

#### **Community pain services**

Only a very small percentage of the population currently access specialist pain services, whereas the need for pain services in the population is much higher, with millions in chronic pain. Currently, people with chronic pain tend to be passed between the wrong services for their need until they eventually reach the right service for their need.

There are opportunities in primary care for everyone to be offered a holistic assessment of the symptoms, including a review of the impact on their physical and mental health. Easy to access community pain services with specialist input (where needed), mental health, peer support, support from social prescribing link workers and connecting people with chronic pain to local healthy lifestyles, would all help people with chronic pain get the right treatment earlier.

#### Peer support and patient organisations

There are many patient organisations offering a range of support from local groups, helplines, self-management programmes and online resources. Every patient should be signposted to the patient organisations relevant to their condition.

Everyone should have access to peer support, with a choice of virtual and in person groups. In the case of children and young people, parents and siblings may also benefit from peer support. Local systems need to support these groups as needed, which may include funding, access to meeting spaces or staff time. Everyone should be signposted to appropriate voluntary organisations and patient groups both national and local.

### RECOMMENDATIONS

- 1. Develop multidisciplinary, networked, personalised approaches to pain as standard.
- 2. Develop more community based approaches to pain. Everyone with chronic pain should be offered a holistic assessment of their symptoms in primary care reviewing the impact on their physical and mental health, their activities of daily living and their wellbeing, including the ability to work/study, and explore any underlying causes of or contributors to their pain.
- 3. A public health approach is needed based on community need to design and target effective public health interventions to support those who have chronic pain to improve their health and their quality of life.
- 4. Take a strategic, integrated population health approach to **commissioning** pain services ensuring money transcends organisational boundaries, focussed on the provision of a range of chronic pain support options and intervention allowing for personalisation
- 5. There should be early access to treatment for painful conditions to minimise pain becoming chronic, including rapid diagnosis, which is important to people.
- 6. Integrated physical and mental health support for people with MSK pain conditions should be available and every CCG should include MSK chronic pain in IAPT for Long Term Conditions with staff who have joint expertise in both physical and mental health and understanding of chronic pain.
- 7. Understand health inequalities, discuss and implement levers for change. Systems and services should allow equity in access, experience of using NHS services and equity of outcomes for all groups. Systems and services should be inclusive and culturally sensitivity.
- 8. **Social prescribing** to provide supported self-management at scale.
- 9. Every person with chronic pain should have access to peer support and be signposted to the patient organisations relevant to them.
- 10. Healthcare professionals **education and training** to include understanding and management of pain and emphasise the personalised biopsychosocial approach and communications skills training to support them to have good conversations.
- 11. Public education including employers, public attitudes to increase health literacy and understanding of pain.

### 1. WHY PAIN IS IMPORTANT

Chronic (persistent or long-lasting or recurrent) pain is life-changing; It can significantly impact individuals, their families, and carers. Chronic pain affects family life, ability to work and education, social, emotional, travel, mobility, and all parts of life. Pain often goes hand in hand with other symptoms - low mood, fatigue, and memory impairment. Chronic pain is linked to deprivation and health inequalities.

Pain is one of the most common symptoms experienced by people with musculoskeletal conditions, for example, over 10 million people in the UK have back pain<sup>12</sup>. Of people with a musculoskeletal condition, 81% report being in chronic pain. Around 10–14% of people experience moderate to severely disabling pain<sup>13</sup>. The prevalence of chronic primary pain is unknown, but is estimated to be between 1% and 6% in England<sup>14</sup>.

You cannot see pain, it is invisible. Despite affecting so many people, pain is under-represented in terms of the public and health professional awareness of it. With an ageing population, it is likely that the prevalence of chronic pain will increase and the need for pain management will grow.

### CHRONIC PAIN: A DEFINITION

No single definition of chronic pain is universally accepted. Chronic pain is usually taken to mean pain that is persistent, long-lasting, or recurrent pain, lasting longer than three months<sup>15</sup>.

The new World Health Organisation's 11th International Classification of Diseases<sup>16</sup> has a systematic classification of clinical conditions associated with chronic pain. The new list of diagnostic codes covers the most common painful clinical entities and divides them into subgroups defined by etiology or affected organ system. In International Association for the Study of Pain<sup>17</sup> explains the ICD distinction of chronic primary and chronic secondary pain. Chronic primary pain represents chronic pain as a disease in itself. Chronic secondary pain is chronic pain where the pain is a symptom of an underlying condition.

Chronic primary pain is characterised by disability or emotional distress and not better accounted for by another diagnosis of chronic pain. This includes chronic widespread pain, chronic

musculoskeletal pain previously termed "non-specific" as well as the primary headaches and conditions such as chronic pelvic pain and irritable bowel syndrome.

Chronic secondary pain is organised into six categories including chronic secondary musculoskeletal pain which is chronic pain in bones, joint and tendons arising from an underlying disease classified elsewhere. It can be due to persistent inflammation, associated with structural changes or caused by altered biomechanical function due to diseases of the nervous system. With the implementation of this systematic classification, ICD-11 signals the significance of chronic pain as a health problem of enormous epidemiological, economic, and sociological impact.

The latest NICE guideline<sup>18</sup> defines chronic primary pain as "pain with no clear underlying cause, or pain (or its impact) that is out of proportion to any servable injury or disease." It also says that chronic primary pain and chronic secondary pain can co-exist<sup>19</sup>.

People with chronic pain define it in more emotional terms and the fact that the chronic pain does not ease or go away over time can be the most difficult to come to terms with.<sup>20</sup>

For consistency and for the purposes of this report, we use the term **chronic pain** throughout this report, with the understanding that the important issue is the impact of pain on a person and the risk of poor outcomes and quality of life.

### WHO IS THIS REPORT FOR?

- This report is a resource for health professionals, policy makers, public health leads and anyone interested in MSK health.
- While chronic pain affects people in all countries, for the purpose of this report, we focus on chronic pain in England.

### 2. FACTS AND FIGURES

The Public Health England, Chronic pain in adults 2017, Health Survey for England reported:

- 34% of adults in England reported chronic pain in 2017<sup>21</sup>, that's around 15.5 million people<sup>22</sup>.
- 81% of people with a musculoskeletal condition report being in chronic pain<sup>23</sup>.
- The most common reported sites of chronic pain was pain in the respondents arms, hands, hips, legs or feet (55%), followed by back pain (42%) and neck or shoulder pain (24%)<sup>24</sup>.

The Global Burden of Disease Study 2019 study:

- reaffirmed that the high prominence of pain and pain-related musculoskeletal conditions is the leading cause of disability in the UK and globally<sup>25</sup>.
- Low back pain remains the top cause of years lived with disability (YLDs) in the UK.

Other facts and figures include:

- People with low back pain generally stop seeking medical attention within three months, however 60% to 80% of people still report pain or disability a year later and up to 40% of those who have taken time off work will have future episodes of work absence.<sup>26</sup> <sup>27</sup>
- Nearly three quarters of people with osteoarthritis report some form of constant pain, with one
  in eight describing their pain as often unbearable<sup>28</sup>

# 3. CHRONIC PAIN LINKS TO HEALTH INEQUALITIES AND DEPRIVATION

The COVID-19 pandemic markedly highlighted the real and severe impact of health inequalities<sup>29</sup>. The Public Health England report, *Chronic pain in adults 2017, Health Survey for England,* set out the overall prevalence of chronic pain amongst the general population as well as identifying differences between sub-groups. The report concludes, "Despite ...limitations, this report does show clearly that chronic pain affects many adults in England and certain groups are affected more than others.... *Inequalities in chronic pain suggests more can be done within the health system to understand why certain groups are affected more than others. This will allow a focus to be placed on these groups to reduce the overall burden of chronic pain." [italics ours]*.

Health inequalities can be defined as the unfair and avoidable differences in people's health across social groups and between different population groups. Some of the central causes of health inequalities lie in the unequal distribution of income and power. These central causes can influence the distribution of wider environmental influences on health, such as good quality housing, work, education, access to services. The wider environment of where people live and work, their education, shapes individual experiences of, for example, low income, poor housing, discrimination and access to health services. This results in the effects of unequal and unfair distribution of health, morbidity and mortality<sup>30</sup>. To really make a difference to health inequalities, there needs to be fair and equitable access to good quality housing, education, health and other public services. A public health approach is required, taking into account a complex set of factors across the life course, including deprivation, socioeconomic factors, unequal burden of symptoms and other wider determinants of health.

ARMA will be producing an in-depth report on health inequalities. Here, we spotlight some of the links between chronic pain and health inequalities:

### 3.1 SYSTEMIC INEQUALITY

- Build Back Fairer, the COVID-19 Marmot Review from the Health Foundation and Institute of Health Equity says, "Long-standing evidence shows that structural racism is at the heart of worse living and working conditions for BAME communities, which leads to worse health in turn this will lead to a higher risk of COVID-19 mortality). BAME groups face discrimination in different spheres of their lives, such as employment, working conditions, education and earnings, which leads to lower incomes, higher levels of stress and higher poverty rates than those experienced by White British populations, and high rates of some health conditions. BAME populations also face discrimination in access to decent housing, community services and other services and resources."
- The 2017 and 2019 British Social Attitudes survey found that respondents who identified as Black reported lower levels of satisfaction with the NHS than respondents who identified as White, so different social groups might also have systematically different experiences within the services that they use.
- There can be inequalities in access to and inequalities in experience of health services with poorer outcomes<sup>31</sup>.

### 3.2 CHRONIC PAIN AND ETHNICITY

Reporting on chronic pain and ethnicity, the PHE report *Chronic pain in adults 2017, Health Survey for England* says:

- "All ethnic groups showed similar reporting of chronic pain to the figure for all persons of 34%, except for people in the Black ethnic group who reported a significantly higher prevalence at 44%."
- Also, "Among those with chronic pain, people in the Asian ethnic group (42%) were more likely
  to report pain that had a high interference on their usual activities than the White group (33%).

### 3.3 CHRONIC PAIN, GENDER AND AGE

Reporting on chronic pain, gender and age, the PHE report Chronic pain in adults 2017, Health Survey for England says:

- Women (38%) reported a higher prevalence of chronic pain than men (30%).
- The prevalence of chronic pain increased with age ranging from 18% among those aged 16-34 years to 53% among those 75 years and over.

### 3.4 CHRONIC PAIN, DEPRIVATION AND GEOGRAPHICAL AREA

- Those living in more deprived areas were more likely to report having chronic pain (41%) than those in the least deprived areas (30%)<sup>32</sup>.
- There are geographical differences in chronic pain prevalence, pain intensity and opioid utilization across England—with evidence of a 'pain divide' with people in the North of England more likely to have 'severely limiting' or 'moderately limiting' chronic pain<sup>33</sup>.
- People in the most deprived areas are more likely to report back pain at every age compared to
  the least deprived. Those people in the most deprived areas experience back pain at a relatively
  young age: people of working age (45-64 years) are almost twice as likely to report back pain
  (17.7%) as those from the least deprived areas (9.1)<sup>34</sup>. This impacts on the ability to
  work/education and can put people at greater risk of poverty and exacerbates inequality.
- More deprived areas tend to have lower rates of admission to elective care than less deprived areas, despite having a higher disease burden<sup>35</sup>.

### 3.5 CHRONIC PAIN, INCOME AND JOBS

Work and education is central to lives and all economies. For individuals, good work can provide structure and meaning, is good for health, wellbeing and financial health, benefits families and supports social inclusion<sup>36</sup>. For those with chronic conditions or disability, good work is (generally) therapeutic and can lead to better health outcomes, it can help promote recovery and rehabilitation, minimising the unwanted and harmful effects of long-term sickness absence. Good work reduces the risk of chronic disability and long-term incapacity<sup>37</sup>.

Living with chronic pain can adversely affect work and education. The report *Chronic pain in England:* unseen, unequal, unfair from Versus Arthritis says that chronic pain reduces people's economic wellbeing. Compared to people with no chronic pain, those with high-impact chronic pain are:

- about half as likely to be in paid work
- twenty times more likely to say they are permanently unable to work because of long-term sickness or disability.

The Health Survey for England (2018) found that:

- 43% of adults in the lowest income group in England had chronic pain compared to 27% in the highest income quintile<sup>38</sup>. Chronic pain is more prevalent among people in lower income groups<sup>39</sup>.
- 25% of people with chronic pain lose their jobs<sup>40</sup> and the longer a long term sickness absence persists, the greater the likelihood an individual does not return to work following their absence<sup>41</sup>.

Once a worker with a long-term or chronic health condition loses their place in employment, it is very difficult for them to return<sup>42</sup>.

Explaining why chronic pain is more prevalent among people of lower income groups is complex. Occupation is closely intertwined with income. People with lower incomes may have physically demanding jobs with limited autonomy, and low job satisfaction, which may increase chronic pain rates. There's some research that lack of work autonomy and job modifications predict chronic pain disability<sup>43</sup>.

People often report that their musculoskeletal disorders (especially problems affecting the back, upper limbs and neck, or lower limbs) are caused or made worse by their work. Those occupations most commonly associated with being caused or made worse by work involve manual handling, working in awkward or tiring positions, keyboard work or repetitive activities. Therefore, the highest burden of days lost due to work-related musculoskeletal conditions are in the construction, transport and storage and human health and social work industries. The specific occupations affected include skilled trade occupations, process, plant and machinery operatives and elementary occupations<sup>44</sup>.

More can be done by employers in all sectors and all organisational sizes, small to large, to improve awareness of musculoskeletal health and minimise the impact of chronic pain on people's working lives. Employer support can make a positive difference for people with chronic pain, for example, through flexible working, adjustments, and grants available through the Access to Work scheme – although many people are unaware of this scheme. There are also resources available to employers that can help, such as the Musculoskeletal health in the workplace: a toolkit for employers<sup>45</sup>.

In addition, Government, health professionals, clinical commissioning groups, charities, arms-length bodies, research institutions, peer groups, occupational health professionals and trade unions can all play a pro-active, positive part in supporting people with chronic pain with their working lives.

# 3.6 INEQUALITIES IN LIFE EXPECTANCY, HEALTHY LIFE EXPECTANCY AND DISABILITY-FREE LIFE EXPECTANCY

- There is clear evidence that persons with chronic widespread pain experience excess mortality<sup>46,47</sup>. There are inequalities in life expectancy, healthy life expectancy and disability-free life expectancy<sup>48,49</sup> with people in more deprived areas spending more of their shorter lives in ill-health than those in less deprived areas<sup>50</sup>. The Marmot Review<sup>51</sup> also reported that the amount of time people spend in poor health increased in England since 2010.
- Much of this poor health will likely be due to painful musculoskeletal conditions, since they are the leading cause of disability in the UK and globally<sup>52</sup>.
- Musculoskeletal conditions and multimorbidity are more prevalent in more deprived populations compared to the least deprived populations.

#### 3.7 SUMMARY

The Versus Arthritis report, Chronic pain in England, Unseen, Unequal, Unfair says, "It is not clear why some minority ethnic groups are more affected by chronic pain. Factors such as social disadvantage and psychological distress seem to increase people's risk of developing chronic pain, including high-impact chronic pain. People from minority ethnic groups often face racism, often live in socially deprived geographic areas, are more likely to be unemployed or in poorly paid manual jobs, may have fewer opportunities to be physically active and are more likely to have multiple long-term conditions. These differences in the prevalence of chronic pain demand the attention of senior leadership within our public health, health and social care systems. To tackle the chronic pain inequalities that Black people and people from other ethnic minority communities face, this disparity must be better recognised, and its causes and impact better acknowledged and understood. This links to Public Health England's 2018 Local action on health inequalities which calls for "the central role of racism [to] be acknowledged, understood and addressed". A comprehensive approach to tackling racism throughout society will be needed to address inequalities affecting minority ethnic groups in the prevalence and impact of chronic pain."

The links between chronic pain and health inequalities are complex. Some differences result from gender, age, geography, income, racism, also conscious and unconscious bias play a part. To make a difference, health inequalities need to be understood, discussed and we need to rapidly implement levers for change. Systems and services should allow equity in access, experience of using NHS services and equity of outcomes for all groups. Systems and services should be inclusive and culturally sensitive.

### 4.IMPACT OF PAIN

### 4.1 THE INDIVIDUAL

The impact of chronic pain is huge, affecting daily living, reducing quality of life, hampered by lack of clear guidance and where to seek help. It affects:

- Family relationships, intimacy and sexual relationships, socially, leading to social isolation, people worry about impact on children
- Sleep
- Finances and work/education
- Physically difficulty travelling and moving; fatigue
- Emotionally mood, suicidal thoughts, poorer self-image<sup>53</sup>.

The problem of chronic pain is often invisible, so people with chronic pain face regular disbelief from friends, family, neighbours, even healthcare professionals, and this adds to its damaging impact.

### 4.2 ECONOMIC IMPACT

The economic impact of pain is high due to sickness days away from work or education, presenteeism and lost productivity and people who live with chronic pain and their carers leaving the workforce or reducing working hours. However, with the right support and adaptations, people with arthritis can thrive in the workplace.

The cost of working days lost due to osteoarthritis and rheumatoid arthritis was estimated at £2.58 billion in 2017 rising to £3.43 billion by 2030.<sup>54</sup>

Back pain is the second most common cause of short–term absences after minor illnesses (such as colds, flu and sickness).<sup>55</sup>

### Beverley – impact and a future with constant pain

Beverley is a senior level HR and Resourcing Director. She has two children aged four and eight.

### She explains how she's been living with constant pain and the impact it had on her life.

"After over 30 years of very regular patella dislocations, in February 2017 I dislocated both my patella and elbow at the same time. Although I was used to living with constant pain, this scenario and the fact that it left me using a wheelchair (one arm in plaster so I couldn't use crutches) left me in a spiral of constant pain, with an eight-month old baby and a toddler. I could do absolutely nothing for myself or my children and was stuck on the sofa day after day. Only days before I had a hectic, fun life and a busy work schedule. With no ability to move about, self-care or cook, I found myself in a situation of no hope. At one point I begged my consultant to amputate my leg to take the pain away. As well as losing life as I knew it, I also lived in constant severe pain. This was exacerbated by the fact that psychologically I was protecting my knee and elbow from further injury so would let nobody near them. This made hospital consultations almost impossible, I was passed around endlessly from clinician to clinician who didn't know what to do. This was particularly insulting as an intelligent person. There was no help available to assist, and nobody took the time to understand my issues at this stage. My body, once active despite the dislocations, was failing me and there was nothing I could do."

#### **IMPACT**

Beverley explains the impact her condition had on her life. She says, "My life as I knew it ended. I was signed off long term sick from work (I had never been off before at all), my husband left me, I was ashamed of my wheelchair so did not see friends. I was housebound and could not see light at the end of the tunnel. I spent hours researching online and found a consultant who understood endless dislocations, I also met a new local orthopaedic consultant who asked me to contact a sports therapist who may or may not be able to help. The healthcare professional understood a very complex situation and created a solution to help me. This was painstaking, progress seemed impossible, it took time, knowledge and commitment to help me. Even just one finger lightly touching my foot demonstrated my body's over-reaction to any sense of touch causing pain – that is how bad it was."

#### A FUTURE

"Now nearly four years later I feel that the musculoskeletal healthcare professional literally saved my life and has given me a future. I can walk, I can work and, although I wear a brace, I can function. I can take my kids to school, I can go out for the first time in years. I also have the physical strength I need for the surgery I so desperately need. The result is I have a life that four years ago seemed impossible, I gained confidence in my joints (albeit I know how bad they really are), I am no longer in such pain, I fully use my elbow and mostly my knee. I am a different strong person."

#### **EDUCATION IS KEY**

When asked what was the one thing she would change, Beverley said, "I also feel as an human resource professional that employers need to understand this type of issue. To give an example, my employer - one of the world's largest companies - told me to come in for a meeting - I hadn't left the house for months! You can only imagine the mental

stress that put on me. Education and understanding is the key. I feel so strongly about this that I began a company helping people with disability and employers to enable them. This is on the hope that people do not suffer like I did. Education and healthcare help."

### 5. UNDERSTANDING PAIN

Pain is poorly understood on several levels including:

### 5.1 PAIN IS NOT RECOGNISED AS IMPORTANT

For people with pain, the day-to-day concerns of living with and managing pain are of the highest importance, more so than the underlying condition, if there is one. However, understanding and recognition of the impact of musculoskeletal pain is low. Specific reasons for people's dissatisfaction with support for chronic pain include:

- Pain being undervalued and seen as a symptom of something else, such as arthritis.
- Healthcare professionals do not always appreciate the severity, duration or impact pain can have<sup>56</sup>.
- People living with chronic pain not being offered specific, proactive or the right information and support for chronic pain for example, what the pain is, what they can do about it, treatment options, long-term implications and the time to discuss this with the healthcare professional.<sup>57</sup>
- This can result in long term reliance on health services and people's inability to manage their own health. 58

The NICE publication *Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain<sup>59</sup> says "A comprehensive assessment should elicit an understanding of the effects of the pain, and how this is viewed by the person and those around them. Understanding what is important to the person is the first step in developing a care and support plan."<sup>60</sup>* 

### 5.2 PAIN AND THE EMOTIONAL IMPACT

Pain isn't just a physical sensation (nociception<sup>1</sup>) – it has emotional effects too, especially so if the cause of the pain is unclear and standard treatments are not working. Pain can be physically and mentally exhausting, which can have a serious impact on mental health, especially when pain prevents people from doing what they want to do. Chronic pain can fluctuate may not be predictable. This aspect may make it harder to manage, with greater adverse impact on mental health.

There is often co-existence and a complex interaction between mental health and painful musculoskeletal conditions. Chronic pain and depression share some of the same neurotransmitters - so there may be physical reasons for the link<sup>61</sup>.

<sup>&</sup>lt;sup>1</sup> Nociceptive pain, is pain triggered by, for example, injuries such as bruises, burns, fractures, sprains or inflammatory conditions such as arthritis, and detected by pain receptors in our skin, bones and other tissues.

Living with a chronic pain from musculoskeletal conditions can lead to depression, anxiety, and suicidal ideation<sup>62,63</sup>. There is a high prevalence of depression in people with chronic pain<sup>64</sup>. People with chronic pain who were depressed also had a greater number of absences from work and were more likely to not work at all due to ill health<sup>65</sup>. People with chronic pain also experience anxiety - anxiety disorders are the second most diagnosed disorder after depression in those with chronic pain<sup>66</sup>.

People with long-term physical health conditions are two to three times more likely to experience mental health problems. Many people with long-term conditions are affected psychologically when learning of their diagnosis, living with symptoms and with the effect on their work/education or social role, or managing side effects.

Social isolation is also a factor. Chronic pain can lead people to cancel social engagements and eventually seeing their social circle dwindle. Some conditions will also cause changes in physical appearance such as posture, deformity and severe weight loss.

It's important to treat chronic pain and mental health conditions like depression or anxiety at the same time. Considering one without the other is unlikely to resolve the overall issues. However, when the two occur simultaneously, it can be harder to treat.

There is currently a **lack of mental health support** for people dealing with chronic pain conditions. The provision of support on the psychological aspects of physical illness often do not meet people's needs. Access to mental health support varies by location, some areas have good support and others have hardly any. Mental healthcare provision may not often be integrated into existing pathways and services and there is not often co-location of physical and mental healthcare provision. Sometimes people who have an undiagnosed chronic pain condition are told that it is 'all in their head'.

People with chronic pain would like to have more time with health care professionals and would like to be asked more explicitly about their mental health and well-being, being referred to additional support services earlier on.

How healthcare professionals ask questions about mental health and wellbeing of people with chronic pain is important. People with chronic pain can feel the pain is effectively dismissed, if the healthcare professional suggests the pain is caused by emotional and psychological issues, rather than pain causing emotional and psychological issues. This leads to people's reluctance of disclosing mental health and wellbeing impacts, because there is a fear the pain will be labelled as 'imaginary'. The NICE publication *Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain* says, "When communicating normal or negative test results, be sensitive to the risk of invalidating the person's experience of chronic pain."

Given the recognised links between chronic pain and mental health, commissioners should ensure that NHS services are able to address the mental health needs of people with chronic pain in the population they service, with a personalised approach and that these are *available earlier* to the person with chronic pain. Mental health provision should be integrated into existing pathways and services, with access to specialist support as needed.

### 5.3 CHRONIC PAIN CAN BE A CONDITION IN ITSELF

While pain frequently presents as a result of a condition or an injury, it can be a separate condition in its own right, with its own classification system.

### 5.4 RESEARCH AND PAIN DATA

There is limited understanding of chronic pain and the impact it has on a person's life. Research into the complexity of pain is underfunded.

Smith et al 2018, in their paper, *Pain and Mortality in Older Adults: The Influence of Pain Phenotype* <sup>68</sup> found that pain that interferes with daily life was associated with an increased risk of mortality. One of the research implications following the study is to understand what it is about interfering pain that causes premature mortality.

For people with multimorbidity, MSK conditions can impair their ability to maintain health and independence, leading to physical and social decline. The complex needs of the growing group of people affected by multimorbidity with a MSK component must inform the research agenda.<sup>69</sup>

Versus Arthritis has established a partnership with NIHR through Programme Grants for Applied Research to address pain roadmap priorities in disease management and applied health research to help understand, treat and prevent pain.<sup>70</sup>

### 6. PREVENTING PAIN

# 6.1 PREDICTORS AND RISK FACTORS AFFECTING DEVELOPMENT OF CHRONIC PAIN

There are many risk factors for chronic pain, including socio-demographic, psychological and biological factors <sup>71</sup> <sup>72</sup> The best predictors of risk around pain transitioning to become chronic are psychosocial. These can include factors such as unhelpful beliefs about pain, emotional responses such as worry, fears, or anxiety, living in deprived boroughs, lack of access to safe secure housing, inability to access appropriate health services, work-related stressors, and poverty.

The term 'yellow flags' is used to describe psychosocial predictive factors for the development of disability following the onset of musculoskeletal pain. Understanding and identifying risk factors and 'yellow flags' may prompt the application of specific prevention and management approaches that consider these predisposing factors and the impact of pain on people affected.

There are screening tools such as StartBack<sup>73</sup> that can be used to identify people at risk of developing chronic pain and help prevent this.

#### **STarTBack Tool**

Simple, low-cost innovations can be transformational in healthcare. Versus Arthritis provided funding to Professor Elaine Hay and her team at Keele University to develop the STarTBack Tool, a short questionnaire for GPs to use to assess an individual's physical, psychosocial and psychological risk factors for chronic back pain and match patients to the treatment which is most appropriate for them. STarTBack led to a significant reduction in disability and halved the time off work without increasing health care costs. Following publication of the STarTBack trial outcomes in 2011, the West Midlands Academic Health Science Network worked in partnership with Keele University to support rollout. The return on investment from STarTBack was estimated to be £226.23 for every £1 spent, and the approach has subsequently been adopted across the UK and internationally.

### 6.2 EXERCISE/PHYSICAL ACTIVITY

Physical activity is one of the best things people can do for their musculoskeletal health from childhood. Everyone can benefit from some form of physical activity, including people with a painful musculoskeletal condition. A wide range of physical activities have been shown to be beneficial in reducing overall risk of musculoskeletal pain, pain intensity, disability. Physical activity can improve quality of life. The NICE Guideline 177 osteoarthritis care and management advises people with

osteoarthritis to exercise as a core treatment irrespective of age, comorbidity, pain severity or disability. The guideline emphasises that clinicians should advise based on individual needs, circumstances and self-motivation. NICE Guideline NG65<sup>74</sup> for Spondyloarthritis advises referral of people with axial spondyloarthritis to a specialist physiotherapist to start an individualised, structured exercise programme, which should include 1) stretching, strengthening and postural exercises 2)deep breathing 3) spinal extension 4) range of motion exercises for the lumbar, thoracic and cervical sections of the spine 5) aerobic exercise.

While most people are aware of the benefits of physical activity and want to be active, many people with pain and long-term conditions find physical activity hard to do. Pain, fear, fatigue and a lack of time are some of the barriers that prevent people from incorporating physical activity into their lives. How a person feels from day to day can change, and so staying active can be a real struggle. Campaigns such as 'Love activity, hate exercise' <a href="https://www.csp.org.uk/public-patient/keeping-active-and-healthy/love-activity-hate-exercise-campaign">https://www.csp.org.uk/public-patient/keeping-active-and-healthy/love-activity-hate-exercise-campaign</a> and 'We are undefeatable' <a href="https://weareundefeatable.co.uk/">https://weareundefeatable.co.uk/</a>, backed by expertise and insight, seek to support and encourage finding ways to be active that work with each person's long-term conditions, not against them.

Public health teams and professionals should not see people with joint, muscle or back pain and musculoskeletal conditions as excluded from participation.

All health professionals in any setting can be involved in recommending physical activity- this tool can assist with guiding consultations: <a href="https://movingmedicine.ac.uk/consultation-guides/condition/adult/primary-prevention/">https://movingmedicine.ac.uk/consultation-guides/condition/adult/primary-prevention/</a>

#### 6.3 OBESITY

Obesity is a complex and incompletely understood disease<sup>75</sup>. Its development is not inevitable and can be prevented.

Seven in ten people who report having a musculoskeletal condition are overweight or obese<sup>76</sup>. Weight control is important to people who have problems with their musculoskeletal system and extra weight can lead to aggravated pain and discomfort.

Obesity is widely acknowledged as a risk factor for both the incidence and progression of musculoskeletal conditions such osteoarthritis. Obesity is the largest modifiable risk factor for knee osteoarthritis – compared to someone of healthy weight, obese people are more than twice (and up to 4-6 times) as likely to develop knee osteoarthritis compared to people of a healthy weight<sup>77</sup>. Children who are overweight or obese are at greater risk of developing musculoskeletal conditions, and adolescents who are obese are more likely to experience persistent or recurrent joint pain<sup>78</sup>.

Losing weight can be hard, especially when joints are stiff and sore, or when medications impact weight, or when it hurts to exercise.

People with obesity or weight concerns can experience stigma and blame for being obese, when there are many factors that increase the likelihood of obesity (such as geographical area and deprivation). People with obesity may feel an internalised stigma or belief that their excess weight is entirely self-inflicted and shameful.

Health professionals need to be aware of the stigma around obesity and what can actually help to achieve weight loss.

### 6.4 TREATING UNDERLYING CONDITIONS ASSOCIATED WITH PAIN

Many cases of chronic pain are related to an underlying condition such as rheumatoid arthritis, osteoarthritis or axial spondyloarthritis. Treating the underlying condition is therefore important.

For instance, for people with severe osteoarthritis, **joint replacement surgery** is usually very effective at reducing pain and restoring independence. A delay in surgery may result in people living with daily pain<sup>79</sup>, plus barriers to mobility and independence, compromising their wellbeing and quality of life. Delays to treatment can lead to worse outcomes for people<sup>80</sup>. The COVID-19 pandemic has resulted in significant lengthening in waiting times for joint replacement surgery from an already long waiting list. Reducing waiting times is therefore important as is actively supporting people on waiting lists to help with the pain.

# 6.5 PHARMACOLOGICAL TREATMENTS FOR UNDERLYING CONDITIONS ASSOCIATED WITH PAIN

Pharmacological treatments (e.g. biologics) that could help chronic pain are not always accessible to all people due to their cost against a background of restricted health care budget. In comparison to Europe, the UK has low access to biologics<sup>81</sup>, however, in recent updated guidance from NICE<sup>82</sup>, doctors can now prescribe the biological treatments adalimumab, etanercept, and infliximab for patients with moderate rheumatoid arthritis who have not responded to conventional therapies, previously, this was restricted to people with severe rheumatoid arthritis. Some CCGs limit access to appropriate rheumatoid arthritis treatments based on the number of prior treatments, counter to the provisions of the *NHS Constitution*. See the <u>RMOC Advisory Statement</u><sup>83</sup>. Also, people with moderate rheumatoid arthritis are excluded from access to biologics despite clinical trials demonstrating the efficacy of biologic therapies in people with DAS28 >3.2.

Ailsa has lived with severe inflammatory polyarthritis for 40 years and is now on her ninth biologic/advanced therapy

Founder and CEO of the National Rheumatoid Arthritis Society from 2001 until mid-2019, when she stepped down and took on a part time role as

### National Patient Champion to continue work in specific areas of particular interest.

Ailsa lived with refractory disease that has not responded to any DMARDs and is now on her ninth biologic/advanced therapy. She says,

"The pain has been a pretty constant companion for most of the last 40 years and the most significant problems have been in trying to find a treatment that works successfully. When you go onto a new treatment, your hopes and expectations are high that this will work for you and when it doesn't it can be overwhelmingly disappointing and crushing. About 10-12 years ago I developed uveitis and this has led to the loss of useful sight in my right eye.

"The key challenge for me has always been to find a drug that works and works over time. About 7-8% of patients in the UK with rheumatoid arthritis (RA) have refractory disease like me and in spite of RA seeming to some to be 'fixed' due to the large number of effective drugs which have come to market in the last 20 years, there remains significant unmet need.

"If I could have had a crystal ball at the start of my journey and see what I was going to have to deal with over the subsequent 40 years (and the journey is not over till I die!) I would have been truly terrified and possibly have experienced suicidal ideation.

Every part of my body is affected and I have had 20 operations including bi-lateral ankle, knee, hip, wrist and elbow replacements, neck fusion and four lots of eye surgery. This is not a benign disease – the impact is truly massive on all areas of your life and it also impacts on your partner and wider family. I have substantial disability and my major problem currently is that the pain (due to damage) in my feet and ankles is such that I cannot walk any distance or stand for long. RA chips away constantly at your independence."

#### What helped

"Going back onto the only drug that has really helped for the third time in July 2020 has brought my disease under better control. Prior to that I had gone through two other advanced therapies in the year before that and my disease was out of control causing significantly higher levels of pain as a consequence of their not working with odd spells of temporary relief from steroid injections.

"My inflammatory markers are now much lower and whilst life is certainly not pain and stiffness free (I wish!!) but it is better than it was in the first six months of 2020 and that is a major relief. I had found myself becoming slightly depressed prior to going back onto the TNF in July because I had been in such pain for so long without a break, and that is not like me at all. I am normally positive and a glass half full kind of person.

Looking back at what could have been done better, Ailsa says,

"Sadly at the time I was diagnosed in 1981, there were no advanced therapies, no treat to target strategies. I was given pain killers and NSAIDs for three years and the RA became an aggressive disease, during which time I had surgery, even before I was given a steroid. MTX didn't work for me, nor did any of the other DMARDs. I had to have low

dose oral steroids for 20-years-plus which have caused damage. I managed to get off steroids once I was established on biologic therapy. Hopefully today we won't be creating patients with the level of damage I've sustained due to better treatments and better and earlier ways of treating people."

If there was one thing she could change, she says,

"Being diagnosed later in life after biologics came along. I must say however, that founding NRAS and having the privilege of working with many patients and health professionals all over the UK for the last 20 years has been a wonderful experience. I wouldn't change that!"

#### 6.6 FALLS PREVENTION

Chronic pain is associated with recurrent falls in older adults. Co-morbidities like hyper and hypotension (POTS in Ehler Danlos Syndrome), reduced body perception awareness (proprioception) as a symptom of pain in different parts of the body, medication side-effects are all some of the many aspects between falls and chronic pain. Foot and chronic pain were particularly strong risk factors for falls<sup>84</sup>, and clinicians should routinely inquire about these symptoms when completing falls risk assessments. In older adults, NICE Guidance CG161<sup>85</sup> says that older people reporting a fall or considered at risk of falling should be observed for balance and gait deficits and considered for their ability to benefit from interventions to improve strength and balance, including foot and ankle exercises<sup>86</sup>. The NICE guidance says that older people who present for medical attention because of a fall, or report recurrent falls in the past year, or demonstrate abnormalities of gait and/or balance should be offered a multifactorial falls risk assessment.

Individual footwear advice is more important than previously thought for the prevention of structural foot pathology for some people<sup>87</sup>.

#### 6.7 EDUCATION

Public education that is 'myth-busting' about exercise, especially for people with a musculoskeletal condition like back pain or sports injury can prevent pain becoming chronic. The Lancet low back pain group highlighted how misconceptions about pain rooted in the biomedical model play an important role in the development and maintenance of persistent pain<sup>88</sup>. These misconceptions act as a considerable barrier to the delivery of, and engagement with, evidence based active physical and psychological therapies that are in keeping with the biopsychosocial model and contemporary pain science. Thus, there has a been a call to action for new public health strategies that will address these myths on a mass scale. Public health interventions have been shown to be effective for changing beliefs at the public level in the field of back pain<sup>89</sup>. More recently, public health interventions targeting chronic pain focused around contemporary pain science education, which has been shown to reduce pain related psychological distress<sup>90</sup> have emerged (e.g. Pain Revolution). These campaigns aim to increase public understanding of pain, increasing pain related health literacy, to facilitate more informed healthcare choices.

# 7.SUPPORTING PEOPLE WITH CHRONIC PAIN

People with chronic pain consult their GP around five times more frequently than those without, and chronic pain is a presenting condition in around 22% of primary care consultations. <sup>91</sup> Other people with chronic pain might see a private practitioner, self-care. The complexity of chronic pain and the significant distress and disability associated with it can influence clinical interactions. <sup>92</sup> People often expect a clear diagnosis and effective treatment, but these are rarely available. <sup>93</sup> GPs face hurdles at almost every stage of treating and managing chronic pain and there is huge variation by patient presentations and comorbidities. GPs may be unaware of what different options exist for people with chronic pain, or when GPs were more aware of different options that existed they felt a sense of frustration by the lack of or minimal access to pain clinics, pain management, mental health services and holistic therapies and there is concern about long waiting times <sup>94</sup> likely exacerbated by the impact of COVID-19. GPs often felt very much on their own, with no support or consultation with other health care professionals <sup>95</sup>.

### 7.1 DISJOINTED SERVICES AND DELAYS

Many people neither receive or need a referral. People who are referred have various referral pathways. People can be referred to either pain clinics, orthopaedics, allied health professionals, neurosurgery or rheumatology. People with chronic pain are vulnerable in this complexity of **disjointed services** and often face **delays** when trying to gain access to treatments and services. Before the COVID-19 pandemic some people waited years to get the right support, causing worsening of condition in the process, such as people with axial spondyloarthritis, a painful, progressive form of inflammatory arthritis, with a delay to diagnosis from when symptoms start of about 8.5 years. For Ehlers Danlos Syndrome and Hypermobility Syndromes, this is similar, with years or decades to **correct diagnosis**. The waiting times to get access to services is likely to be longer following the impact of the COVID-19 pandemic on health services. Correct, rapid diagnosis guides proper management of the syndromes, avoids inappropriate medication, unhelpful treatments, and joint damage.

People can feel they are passed between services or fall between services e.g. they may not be able to access a psychologist until they have been to the pain clinic, adding delay. Specialists in pain management are commonly frustrated by delays in accessing them, the level of coordination between services and a **lack of a multidisciplinary approach**. <sup>96</sup> A joined-up approach is needed. For example, individuals with back pain are more likely to experience mental health issues. By joining-up and integrating mental health support (such as Improving Access to Psychological Therapies (IAPT) services or pain management programmes) in the treatment pathway alongside physical health services, the NHS can provide better joined-up support, achieve better outcomes, and support the individual better.

The StartBack trial demonstrated statistically significant reductions in anxiety, depression and SF12 mental component scores (a screening measure for depressive disorders) at 12 months in the intervention group where psychologically-informed physiotherapy was delivered to a high risk group compared to usual care for the control arm. Supporting and training MSK clinicians, especially in primary care, to increase their skills and confidence in psychologically-informed, personalised approaches and in self-management approaches may achieve better outcomes for people with chronic pain<sup>97</sup>.

Not all primary care services are adhering to such practices as recommended in NICE *Low back pain and sciatica in over 16s: assessment and management* guideline, the NICE guidelines should be adopted.

### 7.2 BIOMEDICAL MODEL VERSUS A PERSONALISED APPROACH

Pain is individual and multifaceted. Pain can fluctuate over time and flare-ups can occur. Pain may be due to inflammation and/or related mechanical factors, including muscle weakening, pain may be affected by poor sleep, depressed mood, job loss, relationship problems. Pain is complex involving a range of systems in the body including the nervous, and immune systems.

Therefore, the traditional biomedical approach, which assumes the disease fully accounts for the pain<sup>98</sup> is not sufficient. In fact, treatment of underlying conditions, while improving quality of life and management of pain, does not always eliminate the pain. For example, in rheumatoid arthritis biologics may successfully treat the underlying condition of pain, but pain may remain. Instead of a purely biomedical approach, a personalised approach is needed, considering the person, the social, psychological, environmental and economic context in which the person lives. The NICE publication *Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain<sup>99</sup> says, "Be sensitive to the person's socioeconomic, cultural and ethnic background, and faith group, and think about how these might influence their symptoms, understanding and choice of management."* 

When a person first experiences pain, the underlying cause, diagnosis and appropriate interventions should be explored but a personalised approach should be taken from the outset. The NICE publication says, "It is important for the healthcare professional to understand how pain is affecting a person's life and viceversa." Identifying and beginning any appropriate treatment should be prioritised ahead of referral to a pain service.

As pain is individual – to the person, their biology (even different joints can be affected differently), the social, psychological, environmental and economic factors that affect a person living with chronic pain, a different combination of therapies will work for each person. Pharmacological and non-pharmacological therapies, such as exercise for muscle strengthening and manual therapies can all play an important role in reducing people's pain. It is therefore important to have a range of support options available.

Many studies indicate exercise improves quality of life<sup>101</sup> However, people do not always get referred to exercise/physical activity services because of **lack of availability or knowledge of the benefits of exercise**. Also, people with chronic pain may find it difficult to be physically active.

Health beliefs are a fundamental driver of behaviour. The public understanding of musculoskeletal pain may often be that it is always an indicator of damage and that movement should be avoided in case of causing further damage. <sup>102</sup>

Ultimately, health professionals, rather than giving primacy to biological factors alone, should be aware of the range of factors contributing to a person's pain experience and seek ways to mitigate those for which they have the appropriate skills and influence. Health professionals' knowledge, skills, decisions and actions should be **personalised** for each person living with chronic pain.

### 7.3 SUPPORT OPTIONS

Pain is individual, each person knows their own pain. No single treatment works for everyone. It is therefore important to have a **range of different treatment and therapy options and combinations** that will best meet the needs of people with chronic pain. Choice of treatment will depend partly on what pain management works for the person and also partly on any underlying causes of the chronic pain. A person's specific needs, preferences and abilities should be taken into account<sup>103</sup>. For chronic secondary pain, the relevant NICE guideline appropriate for the condition should be followed.

Conservative treatments are typically non-invasive and carry less risk, sometimes eliminating the need for surgery and therefore should be an early consideration for treatment.

The COVID-19 pandemic resulted in significant increase in waiting times for joint replacement surgery – some people are waiting two years for surgery – with pain. It is therefore important to both reduce joint replacement surgery waiting times and also to provide active support and options to those on waiting lists to reduce and/or prevent worsening of pain.

The range of support options that people use for chronic pain treatment and pain include (this is not an exhaustive list, neither is each option appropriate for every condition):

**Non-pharmacological** - exercise programmes; surgery such as joint replacement surgery; manual therapies (manipulation and stretching, mobilisation and soft tissue techniques such as massage); ; hydrotherapy; psychological therapies including cognitive behavioural therapy, Acceptance and Commitment Therapy (ACT) and mindfulness; supported self-management; transcutaneous electrical nerve stimulation (TENS); and acupuncture.

**Pharmacological** – analgesics; non-steroidal anti-inflammatory drugs (NSAIDs); steroids; other drugs such as antidepressants and anticonvulsants; nerve blocks.

### 7.4 GOOD CONVERSATIONS AND SHARED DECISION-MAKING

The complexity of chronic pain and the significant distress and disability associated with it can influence clinical interactions. <sup>104</sup> There is evidence of shortcomings in people's experience of consultations with healthcare professionals <sup>105</sup>. People often expect a clear diagnosis and effective treatment, but these are

rarely available.<sup>106</sup> There needs to be honesty about the uncertainty of the prognosis<sup>107</sup>. For chronic pain, there are often treatment options without a clear best choice.

People with chronic pain would like more time with their health care professional to discuss their symptoms and treatment options.<sup>108</sup> Time constraints can mean that people are rarely asked general questions about their state of health, impact on their emotional wellbeing, or quality of life in relation to pain.<sup>109</sup>

Good conversations and shared decision-making between people with chronic pain and health professionals is a fundamental element of people's experience of care<sup>110</sup> and the successful management of pain.

Differences in language used for pain can occur at all levels – people with pain, clinicians and researchers all refer to pain differently, for example, chronic, acute, persistent, therefore, there is a need to ensure there is clarity for people with chronic pain. Clear language is needed to explain treatments and help people to manage their health in the best way possible. The things that a healthcare professional says may be quite different from what the person with pain interprets. Language and messages given by the healthcare professional can affect what the person with chronic pain believes about their pain and can influence how they deal with their pain and their behaviour. Some language, such as, for example, 'Your back is damaged' may not be helpful. How healthcare professionals ask questions about chronic pain is important, the patient should not be left feeling the pain is 'all in their head' or 'their fault'. Language that promotes resilience and is positive can help drive helpful behaviours. Thus good communication and relationship building play an important role between a health professional and a person with chronic pain<sup>111</sup>.

### 7.5 COMMUNITY PAIN SERVICES

Only a very small percentage of the population currently access specialist pain services, whereas the need for pain services in the population is much higher, with millions in chronic pain. Currently, people with chronic pain tend to be passed between the wrong services for their need until they eventually reach the right service for their need.

There are opportunities in primary care for everyone to be offered a holistic assessment of the symptoms, including a review of the impact on their physical and mental health. Easy to access community pain services with specialist input (where needed), mental health, peer support, support from social prescribing link workers and connecting people with chronic pain to local healthy lifestyles, would all help people with chronic pain get the right treatment earlier.,

### 7.6 COMMISSIONING AND FUNDING

Currently, commissioning is often limited by organisational boundaries and is a barrier to a networked, integrated approach and requires changes to support people with chronic musculoskeletal pain.

A strategic, integrated, population health-based approach is needed so that money is directed to ensure we have the right balance of services from peer support, public health, supported self-management, primary care and specialist services. So, for example, rather than singly funding a hospital trust, a mixture of services should be commissioned;, supported self-management, community pain clinics – based on the needs of persons with chronic pain. This requires adapting the way services are commissioned, designed and delivered. Commissioning should cut across organisational, traditional boundaries and funding should be pain population based. People with chronic pain need to be catered for from least complex to most complex

cases. Specialist centres and pain clinics have expertise in a range of conditions and still need to be commissioned, with the ability to provide care across boundaries. Care in the community and primary settings needs to be better supported with a seamless pathway across all settings.

Services should be coordinated so people can access them easily. While Integrated Care Systems and Primary Care Networks could deliver on some of these opportunities, implementation is variable.

#### 7.7 MULTIMORBIDITY

If musculoskeletal conditions are present as one of multiple long-term conditions, they make overall life harder. Among people living with multimorbidity, musculoskeletal conditions are very common. The prevalence of chronic pain increases with the number of long-lasting illnesses reported, with multimorbidity defined as having two or more long-lasting illnesses. Of those that reported two or more long-lasting illnesses, 65% said they were in chronic pain, with 41% of those reporting one long-lasting illness being in chronic pain<sup>112</sup>.

Having multiple physical health problems can impact on mental health and vice versa, with a cycle of everworsening pain and can also lead to social isolation. Having multimorbidity has a big impact on people's lives, with people often experiencing pain and disability. People with multimorbidity see an array of health and care professionals in the home, in the hospital and in the community. Some conditions are harder to treat when multimorbidity is present<sup>113</sup>. Policy makers should ensure that consideration and assessment of pain and impact on people's lives and also functional abilities are included in tools and interventions to identify and support people with multimorbidity and pain. Healthcare professionals should consider and record and discuss pain in their care and support planning conversations. Joined-up care and consistency in treatment is essential to ensure that pain is treated in the most effective way.

### 7.8 SUPPORTED SELF-MANAGEMENT AND PEER SUPPORT

There is growing evidence that meeting others who experience similar conditions and pain for peer support is very important and beneficial for people living with chronic pain. While the evidence for self-management is not strong, there is evidence that it works as part of an overall management strategy. The NICE publication *Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain* speaks of having a "Discussion about self-management earlier in the pathway." Pain management programmes are designed to equip people to self-manage. Self-management needs to be supported to be effective and some people will need a lot of support. People also need to be supported to improve health literacy and confidence to self-manage.

Commissioners should include funding for supported self-management and peer support in their plans, as there are limitations on what peer support and supported self-management can be provided on a voluntary basis.

### 8.SOLUTIONS

### 8.1 A NETWORKED, MULTIDISCIPLINARY, APPROACH

Pain is complex and the solutions are not linear steps or siloed. Effective pain management approaches are diverse and multidisciplinary. Different health and care professions, including from across primary, community and secondary services and from voluntary organisations and link workers, need to work together to help people living with chronic pain 'join the dots' and navigate the system to get the support they need.

There is an opportunity to develop support for people with chronic pain in primary care. Multidisciplinary teams can share resources across silos, and are better equipped and coordinate with oneanother. This multidisciplinary teamworking approach is available in some areas but is not the standard. Currently there are limited community services available for chronic pain.

Moving the support out of hospital and into the community but still working in the same way will not deliver the change that is needed. Services and professionals need to knit together so that they work as one team no matter where they are located. Teams need the support of colleagues when dealing with difficult problems or complex cases.

More needs to be done to embed the benefits of a multi-disciplinary, personalised approach to managing chronic pain in in primary care and community settings.

### 8.2 PROVIDING A RANGE OF SUPPORT OPTIONS

Pain is individual, each person knows their own pain. No single treatment works for everyone. A range of different treatment and therapy options and combinations will best meet the needs of people with chronic pain and should be available. Choice of treatment will depend partly on what pain management works for the person and also partly on any underlying causes of the chronic pain. A person's specific needs, preferences and abilities should be taken into account A personalised approach requires the availability of a range of services. People living with chronic pain, and often healthcare professionals, don't always know what options are available. In most areas, biopsychosocial community services are unavailable or underdeveloped. Addressing this is vital, as is ensuring that first contact practitioner professionals and link workers know what is available and how to refer with clear pathways. It needs to be made just as easy to prescribe social interventions as to prescribe medication, which will require

availability of a range of peer support, self-management support and community facilities with capacity and confidence to support people living with chronic pain.

There also needs to be a lot more focus on 'physical literacy' for adults as people living with chronic pain often don't have the confidence and knowledge regarding how to be more active. Involving professionals with expertise in pain and physical activity such as physiotherapists, podiatrists, sports and exercise doctors, sports rehabilitators, sports therapists, can be helpful.

# 8.3 UNDERSTANDING HEALTH INEQUALITIES, DISCUSSING AND CHANGING THEM

The pressure points, challenges and the strengths in the system in relation to health inequalities need to be clearly understood at a national and community level, whether there exist inequalities in access, experience, or outcome for different groups such as minoritised groups, black and ethnic minoritised groups, women, people living in deprivation, or people with disability. To enable change, health inequalities need to be openly discussed, even if this feels uncomfortable. Designing the system and services so that they are inclusive, avoid unnecessary barriers, and are culturally sensitive is essential. Levers for change should be identified and actioned.

#### 8.4 COMMISSIONING

A strategic, population health approach is needed so that money is directed to ensure we have the right balance of services from peer support, public health, supported self-management, primary care and specialist services. Services should be coordinated so people can access them easily. This requires adapting the way services are commissioned, designed and delivered. The *Musculoskeletal Health: A 5 year strategic framework for prevention across the lifecourse*<sup>115</sup> provides a roadmap for a joined-up, unified plan.

### 8.5 EDUCATION AND TRAINING

Health professionals, rather than giving primacy to biological factors alone, should be aware of all factors contributing to the illness providing a personalised approach. Their knowledge, skills, decisions and actions should take into consideration social factors (including deprivation, solation, lack of access to services), emotional factors (including anxiety, distress, previous trauma), expectations and beliefs, mental health (including depression and post-traumatic stress disorder) and biological factors. Health professionals need to be able to understand and assess how the pain is affecting the person's life and vice-versa.

Understanding pain should be prioritised as core content at **undergraduate training level** for doctors, nurses, allied health professionals and musculoskeletal health professions and in GP registrar training.

Healthcare professionals need the skills and confidence to have **high quality**, **good conversations** with people about chronic pain and to enable shared decision-making.

Many people with chronic pain stop working or education, even though they want to work and good work can help them with chronic pain. Educating and supporting employers in understanding of pain would help.

Public attitudes to pain, increasing health literacy, and myth-busting unhelpful beliefs about pain can also help. Involving public health and behavior change experts will also be helpful in this.

Education and training needs reinforcement. The type of reinforcement used to change antibiotic prescribing behaviour is a good example of a type campaign that could support change. Recently, the *We Are Undefeatable* campaign, <a href="https://weareundefeatable.co.uk/">https://weareundefeatable.co.uk/</a>, on encouraging physical activity when managing a long-term health condition, resulted in a proportion of people taking an action as a result of the campaign.

#### ESCAPE-pain:

ESCAPE-pain is a rehabilitation programme for people with chronic joint pain, that integrates educational self-management and coping strategies with an exercise regimen individualised for each participant.

Evaluation shows that ESCAPE-pain reduces pain, improves physical function, improves the psychosocial consequences of pain and reduces healthcare and utilisation costs.

Now delivered in over 240 sites, including virtually, Escape-pain is helping people take control of their joint pain, self-manage their condition, and return to more physically active lives. See participants' personal stories at <a href="https://escape-pain.org/personal-stories">https://escape-pain.org/personal-stories</a>

### 8.6 EARLY ACCESS

Services should be provided further upstream in the pathway, delivered at an earlier stage, including in primary care, to achieve better outcomes and be most cost-effective. This is even more challenging with the backlog of MSK treatment following the COVID-19 pandemic. Self-referral to services can aid early access, and in some cases, Patient Initiated Follow Up (PIFU) can aid early access.

### 8.7 MENTAL AND PHYSICAL HEALTH INTEGRATION

Musculoskeletal pain and mental health are strongly linked<sup>116</sup>, personalised care means taking both into account. Mental healthcare provision should be available and integrated into existing pathways and services, with more co-location of physical and mental healthcare provision.

In every Clinical Commissioning Group (CCG), IAPT (Improving Access for Psychological Therapies), and where appropriate, clinical psychology, for long term conditions should include MSK chronic pain. IAPT should have staff with expertise and competencies in pain, plus links with local pain services.

Risks need to be taken into account, for example, people with depression may find it difficult to self-refer and may need more specialised services; they may need to be guided by healthcare professionals in how to access the higher tiers of service that they require<sup>117</sup>.

People with chronic pain may have co-existing mental health needs and may be taking multiple medications, such as opioids<sup>118</sup>. Pain services are often working with GPs to support individuals with non-pharmacological approaches to assist with tapering medications.

ARMA has a number of policy resources on musculoskeletal conditions and mental health that may be helpful:

- Webinar: How to integrate mental and physical healthcare for long term musculoskeletal conditions https://youtu.be/62smW4Qy2u4
- Webinar: IAPT and psychological Support for people with MSK https://youtu.be/y2Z-RgtO5xo
- MSK and mental health policy position paper: http://arma.uk.net/msk-and-mental-health-policy-position-paper/

### Haringey IAPT for patients with MSK Pain

Haringey IAPT includes psychologists, cognitive behavioural psychotherapists, and psychological wellbeing practitioners, working closely with MSK/chronic pain physical health teams.

IAPT is not intended to replace health psychology where this is required. The service has been providing specialist support for people with long term conditions since September 2017 when people with diabetes and COPD were included. In September 2018 people with MSK/chronic pain were also included, so this aspect of the service is still developing.

The service operates a step model:

Step 1 – educational materials, very basic psycho-educational material

Step 2 – simple behavioural activation and specific strategies used as homework e.g. Haringey & Islington pain group is led at step 2

Step 3 – mostly 1:1, focuses on behavioural change and cognitive restructuring

Step 4 – health psychology directly from the hospital. After an initial telephone assessment, the service may offer:

- Individual Cognitive Behavioural Therapy (CBT)
- Guided Self Help (GSH) there is a module on chronic pain
- Groups
- Computerised CBT
- Self-management courses
- Advice on other services 5 Roundtable

Physical health colleagues find it hard to complete the full mental health assessment so two questions have been developed which can be asked by therapists and provide a good indication of which patients may benefit from the IAPT service.

• Do you often feel anxious or low in mood because of your joint or muscle pain?

• Do you feel confident in managing your joint or muscle pain?

The service also has a partnership with the Shaw Trust, providing employment support. If recovery is not happening for an external reason, e.g. debt, the service can signpost to other sources of support. They can also refer for more intensive therapy where needed

### 8.8 PEER SUPPORT AND PATIENT ORGANISATIONS

There are many patient organisations offering a range of support from local groups, helplines, self-management programmes and online resources. Every patient should be signposted to the patient organisations relevant to their condition.

Everyone should have access to peer support, with a choice of virtual and in person groups. In the case of children and young people, parents and siblings may also benefit from peer support. Local systems need to support these groups as needed, which may include funding, access to meeting spaces or staff time. Everyone should be signposted to appropriate voluntary organisations and patient groups both national and local.

### 9. RECOMMENDATIONS

- 1. Develop multidisciplinary, networked, personalised approaches to pain as standard.
- 2. Develop more community-based approaches to pain. Everyone with chronic pain should be offered a holistic assessment of their symptoms in primary care reviewing the impact on their physical and mental health, their activities of daily living and their wellbeing, including the ability to work/study, and explore any underlying causes of or contributors to their pain.
- 3. A public health approach is needed based on community need to design and target effective public health interventions to support those who have chronic pain to improve their health and their quality of life.
- 4. Take a strategic, integrated population health approach to **commissioning** pain services ensuring money transcends organisational boundaries, focussed on the provision of a range of chronic pain support options and intervention allowing for personalisation
- 5. There should be early access to treatment for painful conditions to minimise pain becoming chronic, including rapid diagnosis, which is important to people.
- 6. Integrated physical and mental health support for people with MSK pain conditions should be available and every CCG should include MSK chronic pain in IAPT for Long Term Conditions with staff who have joint expertise in both physical and mental health and understanding of chronic pain.
- 7. Understand health inequalities, discuss and implement levers for change. Systems and services should allow equity in access, experience of using NHS services and equity of outcomes for all groups. Systems and services should be inclusive and culturally sensitivity.
- 8. **Social prescribing** to provide supported self-management at scale.
- 9. Every person with chronic pain should have access to peer support and be signposted to the patient organisations relevant to them.
- 10. Healthcare professionals **education and training** to include understanding and management of pain and emphasise the personalised biopsychosocial approach and communications skills training to support them to have good conversations.
- 11. Public education including employers, public attitudes to increase health literacy and understanding of pain.

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