CHRONIC PAIN COMMUNITY ENGAGEMENT REPORT

Based on two community engagement events held in Weston-Super-Mare on 17th September and 19th November 2025

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Contents

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Executive Summary

This report summarises findings from two community engagement events held with people living with chronic pain in Weston Super Mare. The events were held on the 17th of September 2025, at the For All Healthy Living Centre, Bournville Estate (Phase 1) and the 19th of November 2025 at The Stable, Weston Town Centre (Phase 2).

Key Points

- Concerns with the lack of Weston based resources and the need for improving care were highlighted across both events.
- **Phase 1:**
  - Three key themes emerged from the first event:
    - Improving self-management
    - Increasing education and awareness about chronic pain
    - Improving health services

    (See fig. 1)
  - Practical recommendations like having a buddy system, establishing support networks and providing more information resources were shared.
- **Phase 2:**
  - Prioritisation of phase 1 themes revealed the most important aspects to patients:
    - Consistency and collaboration between health care providers,
    - Peer support
    - Increasing education and awareness among GPs.
  - Attendees had differing views on prioritisation based on their individual experiences.
  - Three new themes were generated namely, Biases among health professionals, Patient centred management and support, and A systemic change in support provision.

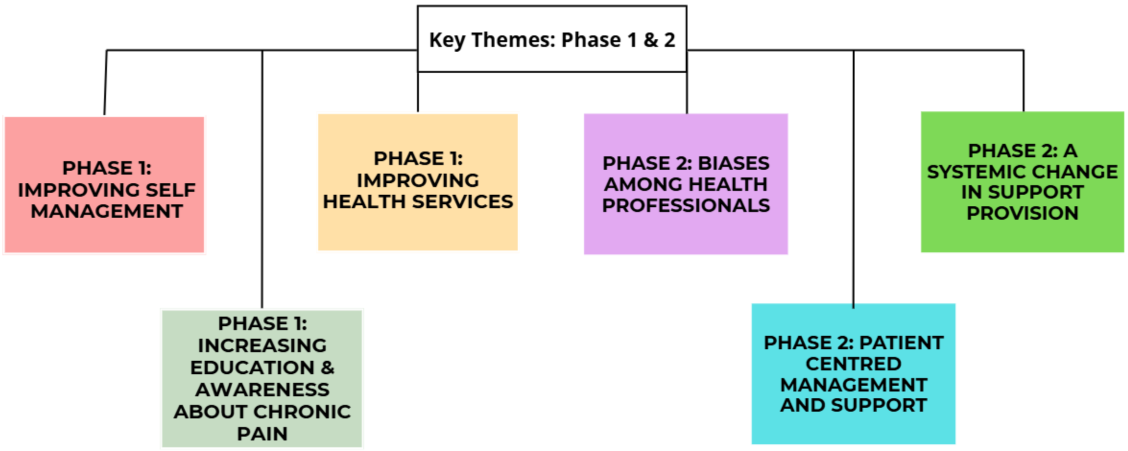

Figure 1. Key Themes from Phase 1 & 2

For a detailed summary of phases 1 and 2 see pages 3 – 16.

Demographics: Phase 1 & 2

Demographic	***Phase 1 (n = 8)***	***Phase 2 (n = 8)***
Gender		
Men	2	4
Women	6	3
Non-Binary	0	1
Age (Range)	35 – 85 Years	20 – 85 years
Pain Duration *Average (Range)*	15 years (3 - 48 years)	5 years (6 months - over 5 years)
Education		
Postgraduate	0	1
Undergraduate	4	2
Trade certification	0	1
GCSE/A Levels/ Equivalent	4	4
Ethnicity		
White	7	7
Black African	0	1
Latin American/ Hispanic	1	0
Working status		
Working (of working age)	3	1
Not Working (of working age)	3	3
Retired	2	4

Phase 1: Methodology

Data presented here was collected as part of a community engagement event for people with pain held at the For All Healthy Living Centre in Weston Super Mare on 17th September 2025.

Recruitment and Attendance

Prior to the event, people from the locality with pain were invited to fill out an expression of interest form for the event via flyers, dedicated presentations at relevant events/ support groups. Additionally, a survey regarding pain experience was shared through the Pier Health Group primary care network. Due to the large response, 14 interested individuals were invited and 8 attended the event. Attendees were selected to achieve a breadth of symptom experience, condition, gender and age.

Data generation

Attendees shared their ideas and experiences primarily through large and small group discussions. These discussions were managed by 3 facilitators of which 2 were researchers at UWE Bristol and one was a patient contributor. Primary points of interest were scribed by one of the facilitators or the attendees on flip chart paper. Additionally, group discussions were recorded and transcribed to further explore the prominent themes.

Phase 1: Detailed Summary

Overarching themes from the event are detailed below.

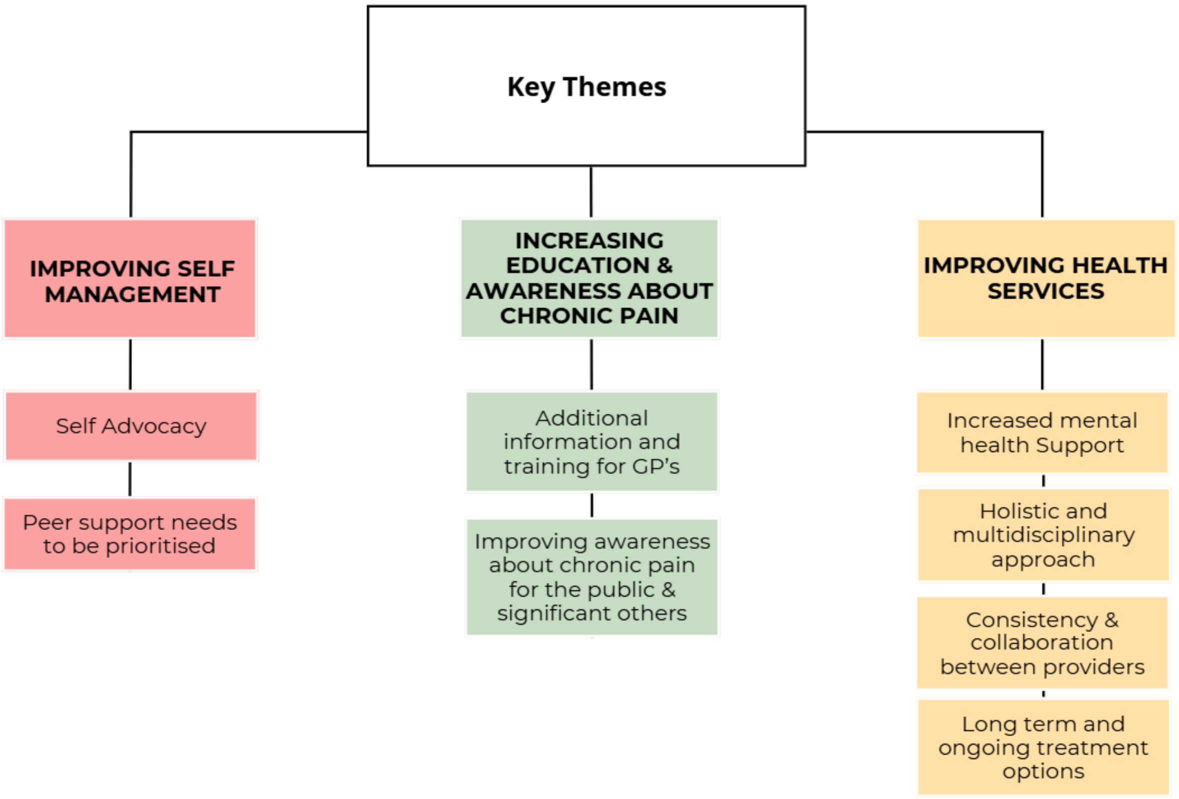

Figure 2. Themes from Phase 1

Improving Self-Management

Attendees were dissatisfied with the care they had received so far. Some suggested that it was important to be a champion for yourself. Attendees discussed ideas that would help improve their existing situation.

Self-advocacy

Attendees suggested that they often felt as though they had to push to receive the care they deserved. Sometimes this resulted in unpleasant interactions with 'gatekeepers' of care like GP's and GP receptionists.

> *"Most of the receptionists think that they're the doctor. And that they have the right to tell me off" (Woman, 35-54)*

Part of this included researching their own condition and educating themselves. Attendees felt that they needed to arm themselves with information to be able to advocate for care that worked for them.

> *"But, in all seriousness, I feel, you know, I've had to fight so hard. Yeah. And I'm very old now and I'm losing my appetite for fighting. But I still don't want to give up" (Woman, 65-84)*

"But if we don't know about [the different treatment pathways], we can't go to our GP and say, can we try this because they they don't wanna tell us if it costs a lot of money, but if we knew about this. Then maybe as a whole, we could come together and and if everybody starts saying I want this, I want this, then they might have to listen." (Woman, 35 – 54)

"If it wasn't for the morphine patches, I wouldn't even get out of bed every day, you know? And that's the end of it. But I had to fight to get all of this on my own." (Woman, 35 – 54)

This was also particularly poignant as many attendees were unaware that there was the option of attending a pain clinic in Weston- Super-Mare. The lack of readily available information regarding treatment options made patients feel as though they were being kept in the dark and had to truly fight to get the care they need.

"Yeah, I didn't even know Weston had the pain clinic" (Woman, 35 – 54)

Peer support

Attendees reiterated the need for meeting others with chronic pain and sharing resources at multiple occasions over the course of the event. Pain groups or networks were described as spaces for understanding and belonging. Attendees described the ease with which they could relate to others with chronic pain, often this came from not having to explain their symptoms, actions (such as needing to sit down or rest) or absence (due to flare ups or otherwise). This played a big role in shaping their social interactions.

"We understand each other very well. If we go out for shopping, we know that we can only do one shop. We need a coffee and then one shop and then it's time to go. I've been on holiday with the same people. And it is a very different experience than going with people that do not understand." (Woman, 35-54)

This mutual understanding allowed for genuine empathy and connection, creating spaces where they did not need to justify or explain their limitations. For many, support groups were the only environments where they truly felt seen.

"It makes you realise that there are people like you who are there... that's why I like going to the fibro [group]. Because there's nobody. There's nobody in my circle that suffers." (Woman, 35-54)

These groups were expressed as key in reducing isolation, offering emotional reassurance and practical advice. Simply talking, sharing resources, or swapping coping strategies was felt to make a significant difference.

"Yeah, group support... even like, yeah, things like these, just like talking to people, sharing resources, it can be really helpful." (Woman, 65-84)

During the discussions, attendees shared some practical steps which they felt would help them navigate their pain and the healthcare system. This included developing a buddy system through GP practices, sharing contact details among patients, or "*a database of support groups to access*". Attendees were keen to foster connection, reduce loneliness, and help people navigate the ongoing challenges of living with chronic pain. This was visible at the event as well, where many attendees shared their contact details with each other.

"And like what we've done, swapping phone numbers and buddies like …oh, you know, I'll put you in touch with [Redacted]. She's gone through this. Have a chat with [Redacted]." (Woman, 35-54)

Increasing education & awareness about chronic pain

Despite the group being a proactive and largely self-selected, the attendees did not always have the information needed around chronic pain. Those that had learned about chronic pain had educated themselves from websites (usually charity based) or from support groups.

Additional information and training for GPs

A consistent theme across experiences was the need for greater understanding of chronic pain and management amongst health professionals. Many described feeling dismissed or misunderstood by health professionals.

"Because I think perhaps most of us when we started experiencing symptoms... we were looked at as if we were crazy and we were making it all up, so I don't think there's enough awareness, not even at the medical level." (Woman, 35-54)

This lack of recognition made attendees feel as though their experiences were not taken seriously and were invalidated by health professionals. Attendees also highlighted that medical responses often focus too heavily on medication rather than addressing the complexity of living with pain. Many suggested that they needed information and direction rather than medication.

"The first thing that the doctors do is give you drugs." (Woman, 35-54)

The attendees expanded on the need for additional education for GPs and healthcare providers, not only around treatment options, but around the nature of chronic pain and what patients can do to help themselves. Specifically, they shared the lack of knowledge and recognition of the global impact of chronic pain from their health providers.

"We'd like to see information provided by the GP when you first present with the pain... Things like the pacing, what you can do to help yourself rather than just here's some painkillers, come back in six weeks. You know, proper, actual, practical things that we can do for ourselves." (Woman, 35-54)

Resources, such as leaflets were suggested by attendees to help them navigate the initial diagnosis and beyond. Attendees felt that even when they were given information about their pain within the initial consultation it was sometimes difficult to digest or recall. Having a resource which could help them easily digest important information about their pain at their own pace, regardless of diagnosis, was important to support self-management.

"[regarding leaflets shared] also it's a good idea to just have something generic like this... When you start the process, you don't know what it is. So just little pointers without scaring you... I think would be beneficial to just keep you going until you are referred to have a scan, some bloods, something whatever it is." (*Woman*, *35-54*)

Attendees also expressed a need for clear, trustworthy information that challenges misconceptions and provides an accurate explanation of chronic pain. While the internet was helpful for many, having evidence-based resources shared by health providers (like leaflets), could ensure a clearer channel of communication.

"I can go on the net, but there's so many different things that are said and they're contradictory and I want a true line. In terms of information." (Man, 55-64)

Improving awareness about chronic pain for the public & significant others

A key concern for many people living with chronic pain was the ongoing misunderstanding from those in their social and professional networks, including family, friends, employers, and the wider public. Misconceptions and stigma around chronic pain remain deeply ingrained, often leaving individuals feeling invalidated or judged.

"My eldest doesn't even believe that fibro exists yet... they call it the lazy person disease." (Woman, 35-54)

Because chronic pain is invisible, others often struggle to grasp its impact or legitimacy. Participants described the difficulty of explaining their needs to employers, colleagues, and loved ones, particularly when symptoms fluctuate or lack visible signs. Many felt pressure to justify their pain or downplay it in professional settings, which often led to misunderstandings, flare ups or lack of support at work.

"And I'm at work. And they're like, oh, can you just go and stand over there for a break. How Long's the break? Half an hour. As long as it's only half an hour. I'm still here. It's been an hour. And that's why I need. Words. [to explain my condition]" (Woman, 35-54)

Improving awareness among significant others, employers, and the wider community can help ensure that people living with chronic pain are believed, understood, and supported.

Improving Health Services

Attendees were acutely aware of the constraints on the NHS and how this impacts their care. They shared some key areas of concern they felt needed addressing.

Increased Mental Health Support

All attendees spoke about how much the emotional and psychological burden of chronic pain impacted them. Although attendees shared a range of negative thoughts and feelings in relation to their bodies their greatest concerns were around grief, suicidal thoughts or self-harm. For some, turning to private practice was the only way to access psychological support at the time they needed it most.

"[We need to address] The loss of the person we were, and I was lucky enough to find a private counsellor who does reduce rates for people on benefits. So, I am treating my diagnosis as having lost someone because I did lose someone who was my old me. Nobody ever thinks of that." (Woman, 35-54)

Having a physical and psychological approach to their treatment was reiterated by attendees. Some shared that even when their emotional distress was brought to the attention of health professionals, it was not addressed adequately.

"Yeah, and my husband said to him, do you know in the last month, [Redacted] said that if it wasn't for me and her children, she would kill herself and my doctor kinda said oh don't be so silly" (Woman, 35-54)

“Obviously, I'm still here [but I took a] deliberate, massive overdose, cutting myself intending to end my life, and it was other people's interventions that saved me.” (Woman, 55-64)

It was clear from these discussions that mental health support needs to be an integral part of the patientcare pathway. Some attendees also felt that the focus on prescription opiates was incredibly harmful. Some suggested that the medication provided them the tools with which they could harm themselves.

“[the doctor] Gives you the drugs... They give you the stuff to do it basically.” (In relation to a conversation around suicide; Man, 55-64)

There was a clear desire for care that goes beyond prescriptions without addressing underlying emotional distress.

“I spoke to a doctor a few weeks ago about this and all they said was here's some amitriptyline. But that's not what I wanted. I need some direction to deal with these negative thoughts.” (Man, 55-64)

Attendees were keen to have more mental health support in any format. Having access to tools that can help patients manage negative thoughts and work through their psychological state were considered imperative to improve patient outcomes. Many attendees agreed the gold standard would be to have a psychologist or counsellor; they were also conscious that it would be unlikely. Instead, attendees discussed the benefits of some self-management tools that had worked for them such as using mindfulness and meditation apps and the 5 Senses technique.

Holistic and Multidisciplinary Approach

Many attendees expressed frustration with healthcare that focuses narrowly on symptoms rather than the person. Patients often feel fragmented, with chronic pain and related concerns treated in isolation rather than collectively. Sometimes this meant the patients have to go back on waiting lists or get new appointments to discuss interconnected issues.

“My thing all along has been that the doctors don't treat the whole of you. There's no holistic approach. So you go and say I've got chronic pain. You know, this hurts, that hurts, that hurts, that hurts, hurts. And they say, well, we can't, we can't do anything about the whole of you.” (Woman, 35-54)

“So it's just wasting valuable money, resources and time or all of it. Rather than looking at you as a whole” (Woman, 35-54)

Especially for attendees with non-specific chronic pain there was a need for doctors to look at their pain as a whole and the knock-on effects it had on the rest of their body. For instance, being treated for ankle pain when it was affecting your gait and straining your joints, would not improve the situation. This often meant that attendees had to book multiple appointments where they could have been supported in one. This delayed their treatment due to long waiting lists to get appointments and often meant they were meeting with different professionals each time.

Consistency and Collaboration between providers

The need for consistent treatment guidelines for chronic pain management was reiterated by this group. Attendees were frustrated at the lack of consistency in treatment across providers. This was particularly relevant when they were referred to specialist services that gave them differing advice to their GP. This made it difficult to trust their providers because they are often stuck between two experts who are managing their condition, often with conflicting advice.

"[They told me] That my GP is wrong. I shouldn't be listening to her. I have to listen to them. She made me feel stupid. And then I went back to my GP, and she was like, no, you need to do this." (Woman, 35-54)

Another aspect that impacted the attendees was the lack of information shared between providers even at the same GP surgery. Attendees were exhausted by having to repeat their story every time they had an appointment. Further, considering the short time they have with the GP they felt a large part of it was taken up discussing their past leaving them with very little time to discuss their presenting concerns.

"And I've been there before, so why do I have to repeat [my story] over and over and over again? it's just knackering." (Woman, 55-64)

Long term or ongoing support

Many people living with chronic pain described feeling abandoned once their allocated sessions or treatment programmes came to an end. Being discharged too soon left participants unsure where to turn next for continued help and support.

"it's a tick box exercise. They ticked me off now and because I finished the group, I did the six sessions or whatever it was... That's it. You're finished with us. If you want to, you can get your GP to refer you back in the future. So as far as they're concerned, that's your file closed." (Man, 55-64)

Others compared their experience to short-term interventions that fail to address the ongoing nature of chronic pain. The short duration of many services does not align with the long-term challenges of managing chronic conditions.

"It's the same as counselling... when your six weeks are finished, you're out there and you just go straight back to Square 1. It's the same situation... Once your physio's finished. It is the same." (Woman, 35-54)

For some, the repeated cycle of being referred, assessed, and discharged created frustration and exhaustion. Attendees highlighted the importance of longer term and ongoing support, so that support does not end abruptly once a set number of sessions have been completed.

"I've had eight years of going back and forth, being pushed from one person to another, nobody wants to own my problem. Nobody wants to help." (Man, 55-64)

Phase 1: Conclusions

Attendees highlighted three key themes that need to be addressed to support their care in Weston- Super-Mare. These included support with self-management, greater awareness and information of chronic pain and improvements within the chronic pain service. Attendees reflected on the need for greater recognition of their pain by health professionals and the wider community as well as the need for local resources to support them. Further, a need to address the psychological and social impact of chronic pain on the lives of patients was evident. Recommendations made by the attendees to enact small changes to better support them have been presented below.

Suggested Recommendations

- Buddy Systems at GP surgeries: Attendees suggested having patients living with certain conditions sign up to a buddy system, allowing GP surgeries to connect people living with similar pain conditions to support one another. This would be beneficial for those dealing with loneliness, social isolation and hopelessness around their new diagnosis or symptoms.
- Evidence based leaflets: Attendees suggested that generic chronic pain leaflets should be available at the point of diagnosis/ investigation around chronic pain. This would allow new patients to digest trustworthy information at their own pace. It can also provide effective strategies for self-management that can be used by patients prior to formal diagnoses.
- Community driven pain management: Many attendees were keen to know out about community resources available in Weston but suggested that these were difficult to find. A database or centralised resource to access community-based methods of pain management was suggested as a possible solution. Attendees felt this should be accessible by patients but also could be something GPs can direct patients towards.

Phase 2: Methodology

Information presented here was collected as part of a community engagement event held in Weston-Super-Mare on the 19th of November 2025 at the Stable.

Recruitment and Attendance

Prior to the event, people from the Pier Health Group Primary Care Network and the Weston Pain Clinic were invited to fill out a survey regarding pain experience their pain and treatment experiences in Weston super Mare. Within this survey respondents were able to leave their email id's if they wish to be contacted for community events regarding pain. Due to the large response, 88 interested individuals were invited, and 8 attended the event. Attendees were selected to achieve a breadth of symptom experience, ethnicity, gender and age.

Data Generation:

Data presented in this report was generated using two methods. First, audio recordings of group discussion were transcribed verbatim and new themes were generated by researchers. Second, ranking and prioritisation of new and old themes were created by attendees and marked on flipcharts to indicate their groups preferences. These rankings have not been altered by the research team.

Phase 2: Detailed Summary

Prioritisation:

Participants were presented with themes and subthemes that emerged from the first community engagement event to rank in terms of importance.

It is important to note that these themes were discussed by three discrete groups as such the ranking represents the importance of the topic to that group. Some of these rankings were contested when presented to the room at the end of the session.

A visual description is provided below.

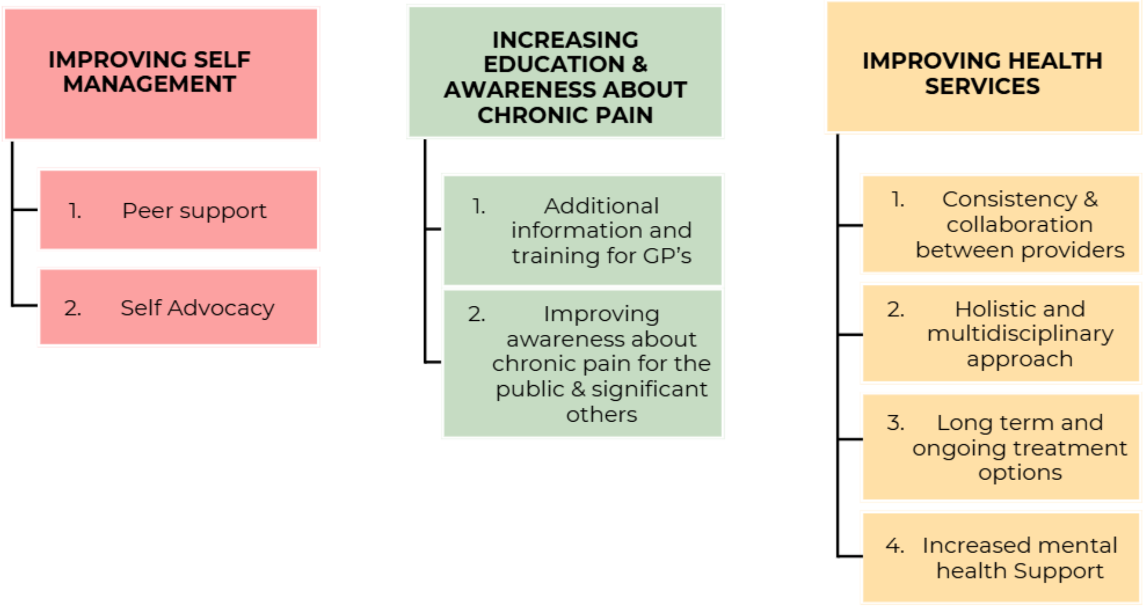

Figure 3. Prioritisation of themes and subthemes from Phase 1

Phase 2: New Themes to explore

Attendees shared a few new aspects that could be added to the existing themes these are detailed below:

Biases among health professionals

Attendees shared experiences of being treated differently or not being taken seriously due to their identity or appearance. They suggested that interactions with health professionals were often clouded by their age, weight, gender etc. resulting in less than adequate care.

"Another thing I was going to raise is age. It's not a justification for pain. It's not synonymous to pain. Because every time they would say, what do you expect? I mean, you are being unfair to yourself. You are 70, you know." (Woman, 65-74)

"We put down, shut down straight away. It's your... It's your weight. It's your age. Straight away, that's what it is. Lose weight." (Woman, 65-74)

"[In conversation regarding a negative experience with a healthcare provider] I said maybe it's because I'm fat I'm black and I'm an old woman, so I checked all the boxes, so I just said oh that's it is that type of difficulty tick tick tick the box." (Woman, 65-74)

"A bit of frustration as I get my age, I think, you know, I might be old, you know, I'm 85 next month, but I'm not senile, you know, I'm treated like I am." (Man, 84 and over)

Attendees suggested that often health professionals were unable to look beyond these characteristics and that their pain was often dismissed due to their age, weight or gender identity.

Patient centred management and support

Although some attendees had received referrals to healthcare professionals that could support their pain, they were unable to engage with these services due to their condition. This left attendees feeling frustrated and contributed to their disengagement.

"I said fine, but a lot of the stuff they want you to either lie down, sit on the floor, or do things like this. That's impossible for some people. So, it's got to be tailored to what the people want and what people can manage. One thing doesn't fit everybody." (Woman, 65-74)

In addition to the inability to engage with some services, exclusion due to a lack of accessible spaces was an additional issue in Weston. Some attendees suggested they were unable to engage with the available services as they had steps or were not wheelchair accessible.

"It's inaccessible and not just to get into places. There's a few groups where they hold meetings, but they hold them in bars that have steps… you can't, you can't do it." (Woman, 75-84)

"I mean, your doctor's surgery is built upstairs." (Woman, 65-74)

The lack of resources available for people in Weston was a recurring point of concern for attendees on the day. Particularly for those with mobility issues who found it difficult to travel both within the city and outside it.

"So I've just been, only just gotten the recommendation for the Nuffield Pain Programme... I'm going tomorrow and I'm still thinking of how I'm even going to get there because usually to get around in my wheelchair, my brother has to push me. Because Weston is just not wheelchair accessible." (Non-binary, under 34)

The actual services available to localites also came into question. Some attendees suggested that while they would enjoy being able to exercise or stretch in a swimming pool or hydrotherapy pool, this was not presently an option.

"I'd like the opportunity for them to say, here's a prescription if you like, six weeks of swimming" (Man, 55-64)

"Yes, it's a sports centre where it's got the only swimming pool really in in Weston by the sea" (Man, 55-64)

"Yeah, I gave up swimming at [the sports centre] …you can never get in there because there was all swimming clubs. It's trying to fit in the lanes and everything, trying to fit round like the times available to go there." (Man, 35-54)

A systemic change in support provision:

This theme particularly highlighted the lack of recognition of chronic pain as a debilitating and complicated condition which impacts all aspects of an individual's life.

Some attendees shared frustrations with how policies are created and then ubiquitously applied to all. For some this meant an inability to apply for blue badges or being denied benefits if they did not fit very specific criteria.

"She has the pain in her hands, legs and everything else, lives on her own, can't do ironing, nobody there to help and all the rest of it. She can't walk that far but can't get a blue badge." (Man, 75-84)

For others this manifested in the inability for health professionals to provide the care they need.

"Because if the policies allow certain things to be as they are, there's nothing that GPs can do. Because they must see you for 10 minutes, isn't it, or 5 minutes. So if they're going to check your nose and your throat and your arm, they are over the limit." (Woman, 65 - 74)

"There's a system of saying minimum care, minimum resources that the government policies are allowed, but everybody I know we want all maximum care, maximum support, but the government says we should be given the minimum so nobody can be done for doing the minimum." (Woman, 65 - 74)

It was clear that attendees were tired of being given the bare minimum to help their pain. They wanted better recognition as well as improved resources which they felt would need to come from the decision makers.

Phase 2: Conclusions

Attendees resonated with the themes generated in the previous event with many similarities in experiences and suggestions. Three new themes were highlighted by this group including biases among health professionals, the need for person centred care and the need for a systemic change in the approach towards health and chronic pain.

In terms of prioritisation and ranking it was evident that having consistency and collaboration between health care providers, peer support and increasing education and awareness among GP's was the most important.

Overall Conclusions

Across both events, people living with chronic pain in Weston-Super-Mare consistently described feeling unheard, unsupported, and poorly informed. Their experiences point to three overarching conclusions:

1. Chronic pain care must become more person-centred and consistent.

Participants repeatedly highlighted inconsistent advice, fragmented care, and a lack of collaboration between providers. They want healthcare professionals to recognise the complexity of chronic pain, treat patients holistically, and work together to provide clear, unified guidance.

2. Patients need better information, understanding, and emotional support.

Attendees emphasised the importance of early, accessible information about chronic pain, practical selfmanagement strategies, and psychological support. Experiences of being dismissed or misunderstood by GPs, significant others, employers, and society, highlight the need for greater awareness and empathetic communication.

3. Systemic barriers limit access, engagement, and long-term wellbeing.

Participants described obstacles such as inaccessible venues, limited local resources, short treatment programmes, and structural policies that fail to reflect the realities of chronic pain. They expressed a desire for sustained support, accessible services, and structural changes that recognise chronic pain as a serious, multifaceted condition.

Overall, the events highlight a clear message:
People with chronic pain want to be believed, informed, and supported through coordinated, long-term, accessible, and psychologically aware care.

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