



Chronic Pain Lived Experience Panel

Project 1 Report

Prepared for:



Scottish Government
Riaghaltas na h-Alba
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1. Introduction and policy context

Introduction

- 1.1. This report presents findings from a series of consultations with the Scottish Government Chronic Pain Lived Experience Panel between August-September 2022.
- 1.2. The consultation work was undertaken by The Lines Between (TLB), who were appointed to recruit and engage with the Panel to inform the development of the Scottish Government (SG) Pain Management Framework and Implementation Plan¹.

Context

- 1.3. Chronic pain is a pain that is persistent, lasting beyond normal healing times, or recurring for over three months, and while it can present alongside other conditions, it can also develop on its own. It can affect any age group, can present anywhere in the body and is more likely to develop in people after times of unhappiness or stress². NHS Inform estimate that 20% of people in Scotland are affected by chronic pain³, 5% of whom report severe chronic pain that is detrimental to their quality of life, impacting a person's ability to work, affecting daily activities, and harming mental health⁴.
- 1.4. The Scottish Government's 2020 Programme for Government included creation of a new framework to assist those living with chronic pain. In 2021, in consultation with the National Advisory Committee for Chronic Pain (NACCP), the draft Framework for Pain Management Service Delivery was developed, ~~making Scotland the first country in the world to develop guidelines for the care, assistance and support of those who suffer from chronic pain.~~
- 1.5. Four overarching aims are laid out in the Framework:
 - to create person-centred care;
 - to enhance access to care;
 - to improve support for those living with chronic pain; and
 - to invest in pain management services.
- 1.6. The efforts to create a comprehensive framework and implementation plan was holistic, spanning:
 - detailed work by policy teams;
 - engagement with a range of stakeholders, including a national consultation exercise; and
 - input from people with lived experiences of chronic pain.

¹ <https://www.gov.scot/publications/framework-pain-management-service-delivery-implementation-plan/>

² <https://www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/chronic-pain#:~:text=Chronic%20pain%20affects%201%20in,times%20of%20stress%20or%20unhappiness.>

³ <https://www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/chronic-pain#:~:text=Chronic%20pain%20affects%201%20in,times%20of%20stress%20or%20unhappiness.>

⁴ <https://www.gov.scot/publications/draft-framework-chronic-pain-service-delivery/pages/5/>

- 1.7. According to the charity Mind, involving people who have lived experience in policy development processes provides an essential 'deep understanding of the needs'⁵ of the target group. A speaker for a webinar on lived experience panels hosted by the Wellcome Trust noted 'that policies and practices that [do] not adequately involve the very same people [they are] deemed to help is not effective and it's not truly in the interest of its people. Involving lived experience experts bridges the gap between theory and experience for a more holistic and ultimately a more useful approach to policy development and its eventual implementation'⁶.
- 1.8. This report on the findings from engagement with people with lived experience will ensure their voices shape the planning and delivery of the Pain Treatment Framework.

Report structure

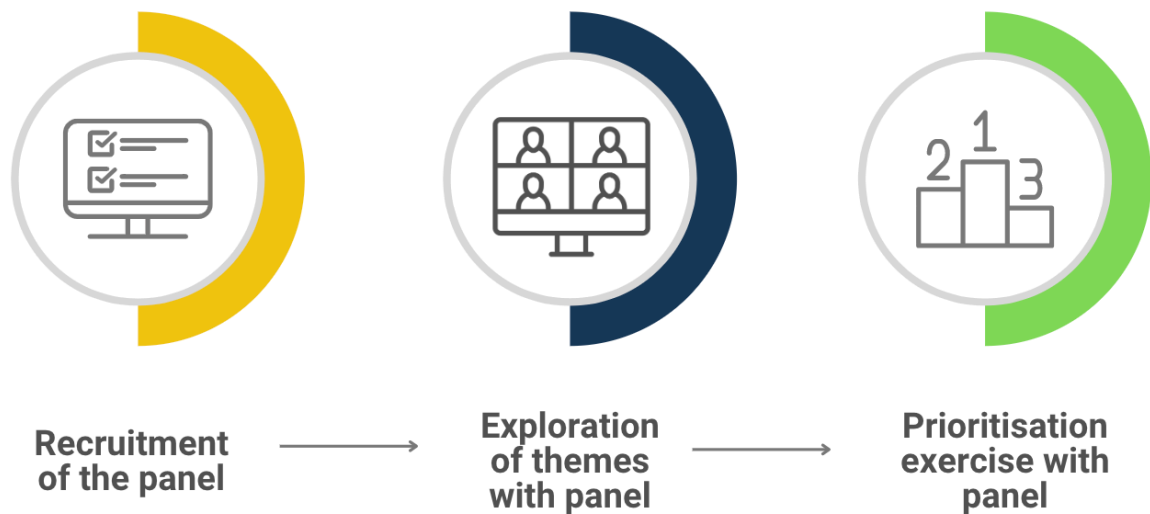
- 1.9. This report is structured as follows:
- Chapter 2 explains the methodology used
 - Chapter 3 presents qualitative findings from consultation with the panel
 - Chapter 4 contains an analysis of the consensus work undertaken
 - The final chapter presents conclusions on this project.

⁵ <https://www.mind.org.uk/media-a/4743/mind-lived-experience-influence-and-participation-policy.pdf>

⁶ <https://wellcome.org/news/webinar-putting-lived-experience-mental-health-heart-policy-and-practice>

2. Methodology

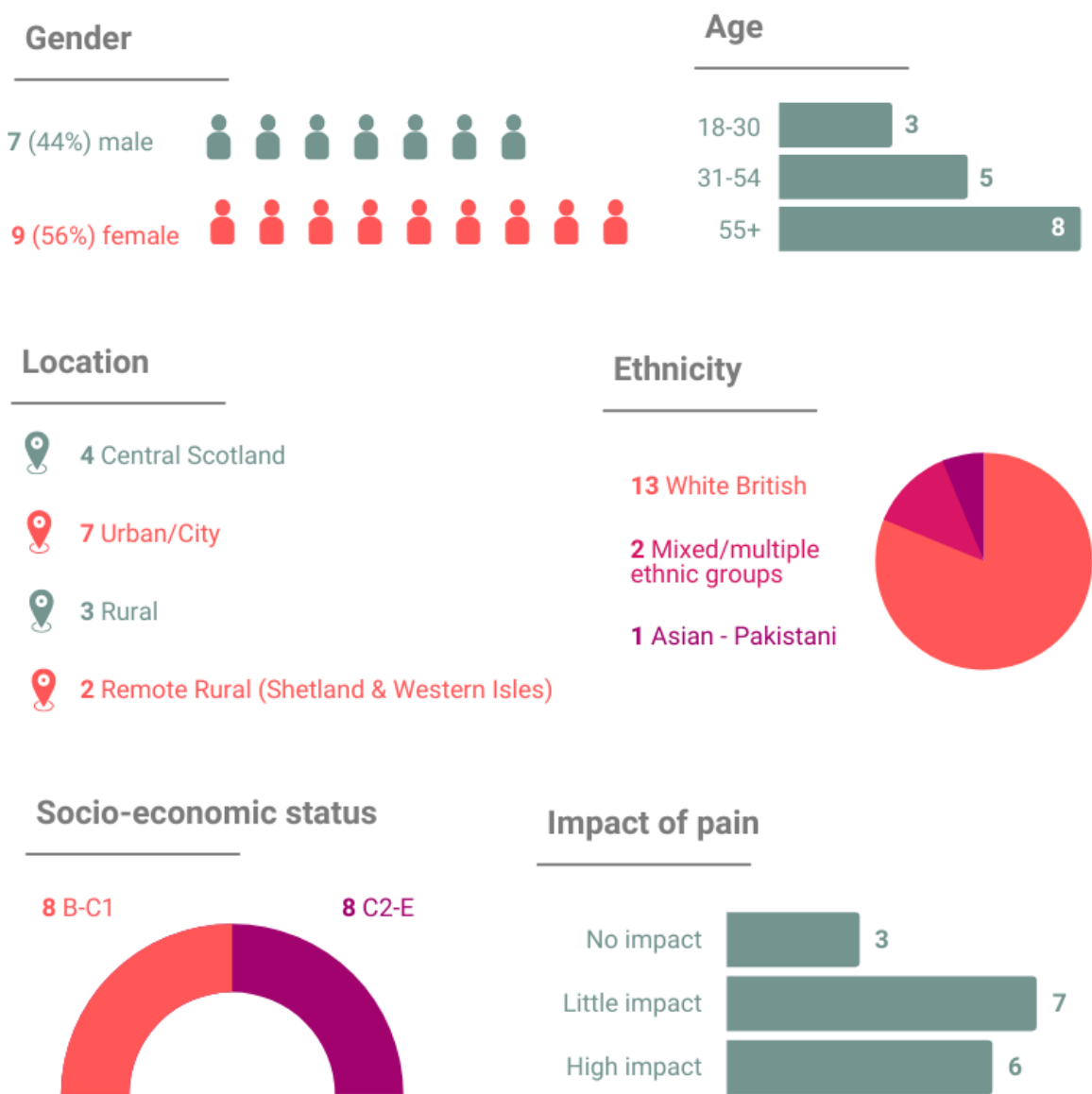
2.1. Our approach to delivering this work followed a three-stage process:



Recruitment

- 2.2. For this project, SG were keen to gather feedback from seldom heard voices within the chronic pain community, i.e. individuals who have not been involved in previous research or advocacy work related to chronic pain.
- 2.3. TLB worked with an external recruitment agency, Taylor Mackenzie, to recruit members of the panel. Taylor Mackenzie promoted the opportunity to contacts within their research database, and took interested parties through an eligibility screener which was designed by TLB.
- 2.4. A sampling framework was designed to ensure diversity within the panel across participants' experiences, circumstances, and characteristics. A panel of 16 individuals from across Scotland with lived experience of chronic pain was assembled; the demographics of the panel are shown in Figure 1.

Figure 1: Panel demographics



- 2.5.
- During the recruitment stage, panel members were asked to indicate their upcoming availability (e.g. if they would be free morning, afternoon or evening), and focus groups of 3-6 people were arranged based on these preferences.
- 2.6.
- Some members of the panel found taking part in a virtual focus group difficult (either through availability or technical difficulties) and opted to take part in a one-to-one telephone conversation instead.

The Delphi method

- 2.7.
- Engagement with the panel was conducted through an approach known as the Delphi method. This is a structured process that uses a series of activities to gather information from a panel of experts in a complex area. It is an approach rather than a fixed method

and is adapted to meet the research needs⁷. In general, there are two or three meetings of experts on a topic. The Delphi first meeting involves an open discussion around a range of key themes which are summarised. The second, and any subsequent meetings, consists of presenting themes from the first round of consultation to the group and asking them to reach a consensus or prioritise the key themes.

Exploration of themes with the panel

- 2.8. In the first engagement session, panel members shared their experiences with chronic pain services, discussed enablers and barriers to treatment and their views on person-centred care.

Prioritisation exercise

- 2.9. Following analysis of the first round of consultation with the panel, four overarching themes were identified as areas for further exploration:
- What support participants find most useful in managing pain.
 - What the biggest challenge or barriers are to accessing support.
 - What helps participants feel more in control of their pain.
 - What they consider most important in the delivery of chronic pain services.
- 2.10. TLB devised a list of priorities under each theme based on the learning from initial engagement sessions with panel members, and asked members of the panel to rank each in terms of the importance or relevance they attached to them. These priorities are set out in Chapter 4, which presents our analysis of the prioritisation exercise.

Data limitations

- 2.11. The findings are based on interviews and focus groups with a sample of 16 people across Scotland with lived experience of chronic pain. The sample, while limited, was designed to reflect the population of those living with chronic pain⁸ (in terms of age, ethnicity, socio-economic status and impact of pain). This provided an opportunity to gather detailed qualitative information, but it is a small sample, and the findings should not be interpreted as representative of the wider population.
- 2.12. Focus groups as a method to gather data have many benefits; they allow people to share experiences, identify points of consensus or mixed views, and develop ideas in an iterative process. However, this forum limits the time each person has to talk about themselves and may influence how much personal information participants choose to share.

⁷ H. A. Linstone and M. Turoff, "Introduction," in *The Delphi Method Techniques and Applications*, H. A. Linstone and M. Turoff, Eds., pp. 3–12, Addison-Wesley Publishing Company, Reading, Mass, USA, 1975.

⁸ Based on data from Public Health England: <https://www.gov.uk/government/publications/chronic-pain-in-adults-2017>

3. Qualitative findings

- 3.1. Seven overarching themes emerged throughout discussions with the Pain Panel:
- Experiences of support and the range of organisations and services they have engaged with
 - Impact of chronic pain on life
 - What good, effective support looks like
 - Barriers to treatment
 - Enablers to treatment
 - Views on the person-centred care approach
 - Reflections on research into chronic pain

- 3.2. This chapter presents a summary of the key discussion points under each theme.

Experiences of Support

- 3.3. Panel members described different aspects of support for living with chronic pain. In these conversations, they reflected on experiences with health services, practical, financial and emotional support, and the overlap between different needs. The importance of maintaining control, independent living and self-agency was raised by panel members, and many described challenging experiences during the pandemic. Some shared specific positive or negative treatment and support experiences they felt policy makers could learn from.
- 3.4. Details of the specific sources of support accessed by panel members is provided at Table 1.

Table 1: Support accessed by panel members

Type of support	Examples of services/treatments accessed
Medical services provided by NHS	GP Practice Nurse Pain management clinic Diabetes clinic Multiple Sclerosis (MS) clinic Podiatrist Physiotherapy Hyperbaric oxygen therapy
Private/self-funded health care	Bowen treatments Kinetic Chain Release (KCR) treatments Chiropractor Massage TENS machine
Alternative/complementary pain management therapies	Acupuncture Meditation Exercise, including swimming, walking and yoga Hypnotherapy and Neuro-linguistic programming (NLP) Essential oils Herbal remedies CBD products
Third sector	Puffin Hydrotherapy Pool in Dingwall Maggie's Centre Macmillan; befriending and household help services Beatson Cancer Centre MS Society
Digital services	Flippin' Pain webinars Zoom consultation with doctors Online peer support groups for chronic pain sufferers
Phone services	Telephone consultations with doctors

3.5. Key themes in the discussion of support and examples are presented below:

Experiences with health services

3.6. Engagement with GPs, physiotherapists, hospitals and pain clinics were frequently mentioned in the discussion of experiences of support. GPs were described as a key source of contact; in some cases, GPs were the only health care provider a panel member had engaged with. For others, GPs were a key route to referrals to a range of other services, including alternative therapy sources.

- 3.7. Panel members described different frequencies of support from health services – some are in regular contact with health providers, and others access services intermittently. Sources of health support also vary; some use a combination of services provided through the NHS and privately funded therapies.

“ *Well, as far as I'm concerned, I just deal with my GP. I haven't been referred on to anybody else. That's as much support as I have had. [Female, 75, Stirling, C1, low impact⁹]*

“ *I'm trying various things like TENS machines. I've paid for loads of treatments like Bowen, KCR, massage everything under the sun. [Female, 47, Falkirk, C1, high impact]*

Practical support

- 3.8. Practical support was often mentioned by panel members, including the blue badge scheme, mobility aids and adaptations. During these conversations several panel members highlighted the challenge of travelling to appointments, linked to pain, exhaustion and lack of mobility. They stressed how valuable different forms of practical support had been to them.

Financial support

- 3.9. A small number mentioned the value of welfare benefits as a valued source of financial support; one noted that their initial application for PIP had been rejected and was only approved with support from their MP. This person had also received financial support from MacMillan to fund a cleaner, because their mobility issues affected the extent of what they could do at home.

Emotional support

- 3.10. Some panel members talked about experiences of accessing mental health treatment from health services, including talking therapies and medication to deal with anxiety and depression. In these conversations, others said while they had no experience of such support, they would have valued it.
- 3.11. The importance of social and peer support for mental health was also highlighted by panel members; some described the importance of care from their partner or family members; others mentioned involvement with forums specifically for people with chronic pain.

“ *Obviously the more you're down in the dumps about things the sorer you feel ... I'm quite lucky that my family is all wound about me and I find that that helps keep me going because if I'm gonna be sitting down in the dumps and in one of them comes in with the kids or whatever, you automatically perk up a wee bit before you realise the pain is not away but it's not as severe. [Female, 64, Renfrewshire, D, high impact]*

⁹ Throughout the report, we have included information about the panel member who provided each quote. The details provided show: gender, age, Local Authority area, socioeconomic group classification and the impact of pain on their life.

- 3.12. Experiences with peers differed – while some had positive engagements with peer groups, a panel member recently diagnosed with chronic pain found the encounter upsetting. They explained that their aspirations and expectations about managing pain differed from those who attended the peer session; some peers in the group were self-managing pain through cannabis and this panel member did not want to engage in illicit substance use.

Maintaining control, independent living and agency

- 3.13. Some panel members mentioned an ongoing desire to maintain independence. Strands of discussion on this theme varied; some focused on their physical ability to do things and organise their lives; a few talked about wanting a sense of agency and control over their medication and health services, noting their own research into effective treatments and therapies.

“ I'm quite independent and I keep trying to be because if I don't then I've given up, you know, that's when bad things start happening to you. [Female, 73, Inverness, C2, no impact]

“ I want to be able to continue to work for a long time. I'm in complete denial about what's wrong with me. [Female, 47, Falkirk, C1, high impact]

Chronic pain during the pandemic

- 3.14. Panel members often reflected on the pandemic's impact on access to treatment. For example, some who had previously received treatments in hospital or clinics now accessed support from the GP; a few praised the introduction of remote access to healthcare services which they felt was a better use of time and resources.
- 3.15. One older person said that a healthcare practitioner had not physically seen them since the pandemic began; a few highlighted that capacity at their GP surgery had become so stretched that they could not get appointments; as a result, one person had changed GPs. Others highlighted that access to some therapies such as yoga and physio had stopped during the pandemic, noting the ongoing backlog in waiting lists.

“ If there was something wrong with you, either email you or they will, you know, where you can send pictures they have WhatsApp. That's the kind of facilities that they should have. [Female, 52, Glasgow, C2, high impact]

“ I desperately needed contact with somebody but I couldn't even go to the surgery. It was so difficult to get an appointment. [Male, 55, Dumfries & Galloway, D, high impact]

Specific positive or negative treatment experiences

- 3.16. Panel members were asked about specific positive or negative experiences they felt could be learned from. Discussion of positive experiences typically revolved around the attitude and approach of healthcare practitioners; people who listened, were available

when you needed them, and were keen to bring about change and find solutions that reflected their individual circumstances. Examples include:

- The significant contribution of a new consultant who reviewed her medical history and investigated the cause of her pain. He identified the issue and arranged surgery to resolve her condition; until then, she had spent more than two decades using pain medication to live with the pain.
- Experiences of pain management offered by a university included peer support, yoga sessions, alternative therapies and direct access to a clinician for students living with chronic pain
- A doctor who offered flexible ways to engage with their surgery asked their patients to complete a questionnaire to establish if patients preferred contact in person, or by email, telephone or video conferencing.
- Health care practitioners who take an interest in people and don't make them feel rushed or that they are wasting time.

3.17. Specific negative experiences centred on inaccessible services or services inappropriate for a person's condition or treatment history. Examples include:

- One person described their referral to a pain clinic as a 'waste of time', feeling that the service offered only common-sense solutions that were patronising for a person who had lived with a pain condition for a long time.
- Lengthy waiting lists or cancellation of appointments.
- Some described practitioners who they perceived to be patronising or disinterested.

Impact of chronic pain on life

3.18. The negative impacts of chronic pain was described by some panel members, including: loss of active lifestyle; disruption to life and plans; loss of income and impediments to employment and volunteering activity; sleeping difficulties sleeping; strong reactions to medications such as feeling dazed, sluggish and sleepy; lack of ability to concentrate; and mental health struggles.

3.19. Some reported a loss of independence, needing help with daily tasks like getting dressed and opening jars; in this discussion, a few mentioned feelings of shame and embarrassment.

3.20. Frustration and a lack of autonomy and feeling they had to go through hoops was also mentioned by some panel members. Examples include being told they needed to meet specific eligibility criteria or try different medications before they could move on to the support they most wanted.

“ *The person was like you can't get referred to the pain clinic unless you've tried various different medications for your back. I've only ever been on amitriptyline and have had my dose increased and I said I'm not prepared, they wanted me to go onto gabapentin. And just what I dread I didn't want to go on it. Because of what my work is I've got to drive and be with it.*
[Female, 47, Falkirk, C1, high impact]

What does good, effective support look like?

- 3.21. Swift access to medical appointments was raised as a priority by several members of the panel. A few suggested that being able to contact their GP by email could cut down on the delays they face when calling their local surgery.
- 3.22. Access to chronic pain specialists with in-depth training and knowledge about chronic pain conditions and treatments than their GP might have was another vital element of good, effective support raised by the panel.

“ *It feels like there's enough people with chronic pain to warrant a specialist section of the NHS just for chronic pain. So that if you're diagnosed with chronic pain long term, you would have, not just your GP, but the chronic pain specialist, who you go to because they'll have a better understanding of your condition and which route to go down; whether it's medication, or mental or physical help. That's what I would like to see.* [Male, 55, Dumfries & Galloway, D, high impact]

- 3.23. Some said that in an ideal world, support for chronic pain would be delivered in a joined-up, holistic approach, so that service users had one point of contact for financial, physical and emotional support. Access to free counselling, a range of different physiotherapies (e.g. Bowen therapy) and equipment (e.g. TENS machines) through the NHS was noted as a priority for some.
- 3.24. Others mentioned that home visits from medical professionals and prescription deliveries would be welcome. However, there was recognition that limited NHS resources could be a barrier.
- 3.25. A few stressed the importance of access to socialising opportunities for people experiencing chronic pain, noting that they often face barriers to an active social life such as mobility problems and poor mental health, which increases their risk of social isolation. The panel suggested that people living with chronic pain should be referred to local peer support groups, and transport provided in cases where individuals cannot organise this themselves.

“ *Send them a letter and say, 'we've got this little group going'. If they could send that to people with chronic pain...it would get them out of the house for a little while. Even if they couldn't make their own way there, get an ambulance or share a pickup for a few of them. Take them there and let them get out a bit. Instead of sitting in the house. We could do a wee bit more to make people aware of what's happening and that there are things for them. So they don't have to be on their own.* [Female, 73, Inverness, C2, no impact]

Person centred care

- 3.26. Panel members had mixed reactions to the short video and explanation of person-centred care. Some felt that this approach was reflected in their experiences of accessing support for chronic pain, noting that some of the doctors and nurses they had interacted with spent time getting to know them and more about their lives and personal circumstances.

“ *Yes, these things have happened to me and it's good. It shows that they care. ...It's showing an interest. They're not just there to see what you've gone in for that day, they are looking back and asking you how you feel then and is it still the same or is it any better, and it just helps you. [Female, 73, Inverness, C2, no impact]*

“ *I recognise that, not from my normal GP, but the younger ones that come in, they give you the time. They ask and stuff as if it's a bit more person-centered on the bigger picture. [Male, 55, Glasgow, C1, low impact]*

- 3.27. A few members of the panel had experiences of being involved in decisions about their health and care plans. For example, one was given a list of different medications for MS with information on each and asked for the input in selecting one.

- 3.28. However, others did not feel that their support experiences aligned with person-centred care, and argued that the aspirational approach seems unrealistic given the time and caseload demands of health care professionals.

“ *Yeah, that's a pipe dream compared to the experience I've had the last couple times I've been in hospital. [Male, 49, Glasgow, E, high impact]*

“ *They're looking at you as a number; they want you in and out the door as quickly as possible. They don't have the time to sit and do this just now, because they don't have the staff, they can't recruit the staff. It's what we should be getting, but it's not what we will get. [Male, 52, Western Isles, E, high impact]*

“ *It's like the opposite. If you showed GPs or hospitals that they would laugh you out the room. They haven't got the resources to do the basics, nevermind whatever that is. [Female, 42, Edinburgh, B, low impact]*

- 3.29. There were mixed experiences of how treatment plans had been explained to the panel in the past. Some shared instances where they felt well-informed, and others described experiences of being left with little to no information.

- 3.30. A few suggested that it would be helpful if they received a short letter or email summarising what had been discussed after each of their medical appointments, which would make them feel more well-informed. The panel also noted consistency (seeing the same health care professional at each appointment) and kindness were important aspects of person-centred care.

Enablers

- 3.31. The primary enabler to accessing services discussed by the panel was the confidence and ability to advocate for yourself when seeking support for chronic pain. Some described repeatedly requesting referrals, further testing and new treatments from medical professionals.

“ *That's how I found out about the pain clinic – I had to kind of fight a battle to get that referral done. [Female, 47, Falkirk, C1, high impact]*

“ *I think if you don't fight for it they just kind of leave you to it. If you don't say 'I want this, this and this' they'll just go, 'alright we can get away with giving them this' and then just kind of brush it off. [Male, 29, West Dunbartonshire, D, low impact]*

“ *I had to go back to the doctors about three times to see if I could get physio. [Female, 64, Inverness, B, no impact]*

- 3.32. One panel member commented that free prescriptions are an enabler in that they remove affordability barriers for people with chronic pain when accessing medication.
- 3.33. Across discussions, it appeared that panel members who were being supported by progressive health care practitioners felt they were receiving better quality care than their peers; that this care was more flexible and appropriate to their needs.

Barriers

- 3.34. The panel shared experiences of various barriers to accessing support for chronic pain in the past. These included limited NHS resources, concerns over reliance on painkillers masking the root cause of pain, physical and emotional barriers, lack of empathy and understanding from healthcare staff, lack of awareness of services and barriers linked to identity/protected characteristics.

Limited NHS capacity/resources

- 3.35. Several panel members noted barriers related to NHS capacity and resources. They described struggling to get an appointment with their doctor and facing lengthy waiting times to access health services.

“ *GPs seem to be so stressed right now, you can hardly even get an appointment to see them. So it's very frustrating, really, when you are in an awful lot of pain. There's nobody there to help you. [Female, 75, Stirling, C1, low impact]*

“ *I've got stage four endometriosis, and the waiting list for anything related to endometriosis or anything like that is horrific, absolutely horrific. So I had to wait for the first Stobhill appointment that was four and a half months it was, for that one to then be cancelled. [Female, 25, West Dunbartonshire, E, high impact]*

“

I was on a massive waiting list to be seen at the chronic pain clinic and that took six months to get a phone consultation. [Female, 47, Falkirk, C1, high impact]

- 3.36. A few commented on the limited services and medications available on the NHS compared with private healthcare, and one noted difficulty securing medication due to supply shortages.

“

We are hitting another big problem now. I'm struggling a lot of times to get the medication... I've got to phone round chemists to see who's got what I'm looking for in stock because there's such a shortage of medication out there now. [Female, 64, Renfrewshire, D, high impact]

Concerns over medical reliance on painkillers and lack of focus on root cause of pain

- 3.37. Some panel members described experiences of presenting at health services with chronic pain, and being dismissed with painkillers with little effort to explore or identify the root cause of the pain. In some cases, this linked to how long a person had been living with a chronic pain condition – a feeling that health care services were not looking for a solution, and that they were expected to manage, through a reliance on painkillers.

“

It shouldn't be a case of, 'oh well just keep taking the tablets.' I feel that the hospital people could investigate... look a bit further and see if there's anything else that can be done for them, because if you've got chronic pain, you would like to get investigated. [Female, 77, Inverness, C1, no impact]

“

Mine was really severe migraines and then the sciatica I got I could hardly walk. And they just gave me painkillers and said, 'Oh, go away.' [Female, 64, Inverness, B, no impact]

- 3.38. The over-reliance on pain medication triggered concern with the panel, many of whom were reluctant to take strong painkillers for long spells of time, fearing addiction, loss of cognition or other side effects interfering with the demands of their lives, e.g. work and tasks like driving. Some members of the panel lost confidence in health services as a result.

“

If you're taking all these heavy painkillers as well then it has an effect on your day-to-day life because then you are sluggish you don't feel as if you want to get up and do anything because you are medicated. [Female, 25, West Dunbartonshire, E, high impact]

“

I was 150 milligram Amitriptyline which is absolutely huge, so I was a total zombie and I thought I just can't live like this...I'd lost confidence in the GPs, so I didn't go back and ask these kind of questions.” [Male, 55, Glasgow, C1, low impact]

“

“I've only ever been on Amitriptyline and have had my dose increased and they wanted me to go onto Gabapentin. And I just dreaded it. I didn't want to go on it. Because part of my work is I've got to drive and be with it.” [Female, 47, Falkirk, C1, high impact]

Physical barriers

- 3.39. Mobility issues associated with chronic pain made it difficult for some to access in person services.

“ *Another barrier would be - depending on where your surgery is - trying to get there. If you don't have a car or transport, it's quite awkward, especially if they have to walk with a stick or if their mobility is not good. [Female, 77, Inverness, C1, no impact]*

- 3.40. Those in rural areas noted distance to services along with poor public transport infrastructure as barriers to accessing support.

“ *I did try and join a support group...but I'm 17 miles here for a pint of milk, in the middle of nowhere, you know, in the hills. If we want to go to the meetings, I've got to go to 100 miles to Edinburgh... I certainly can't afford to travel 100 miles to go to a support group. [Male, 55, Dumfries & Galloway, D, high impact]*

Emotional barriers

- 3.41. A few said that spells of poor mental health affected their motivation to access support.

“ *You've maybe just got to a stage where you just resign yourself to, this is me, you know? I'll try as hard as I can not to let it get any worse but I genuinely don't believe I can get any better. [Female, 64, Renfrewshire, D, high impact]*

Lack of empathy and understanding from medical practitioners

- 3.42. A few panel members felt as though their pain hadn't always been taken seriously by medical practitioners and said they had often been dismissed or made to feel as though they were exaggerating their pain.

“ *I think, at the very beginning that you are sometimes made to feel like a hypochondriac. [Female, 64, Renfrewshire, D, high impact]*

Lack of awareness of services

- 3.43. Some pointed to a lack of awareness of services as the reason they had not accessed any support. A few said they were unaware of any support outwith their GP, and a small number said they had never heard of the pain clinic.

Barriers related to identity/protected characteristics

- 3.44. While the topic was raised in all discussions, very few panel members had direct experience of any barriers in accessing support which related directly to their personal identity or protected characteristics.

- 3.45. One panel member shared how he felt that as a man, he had been raised to 'grin and bear' his pain. One of the younger members of the panel said that he felt his chronic pain was not taken as seriously as that of an older person, noting his doctors assumed that he had strained his back through exercise as opposed to something more long term and in need of deeper investigation.

Further research into chronic pain

- 3.46. One participant called for more investment into research about chronic pain conditions.

“

There needs to be more research into certain types of illnesses and chronic pain... they don't know the answers, they don't know the best ways to deal with them. There needs to be more research into why people are experiencing these pains and what can be done to remedy it and help people live their day to day lives. [Female, 25, West Dunbartonshire, E, high impact]

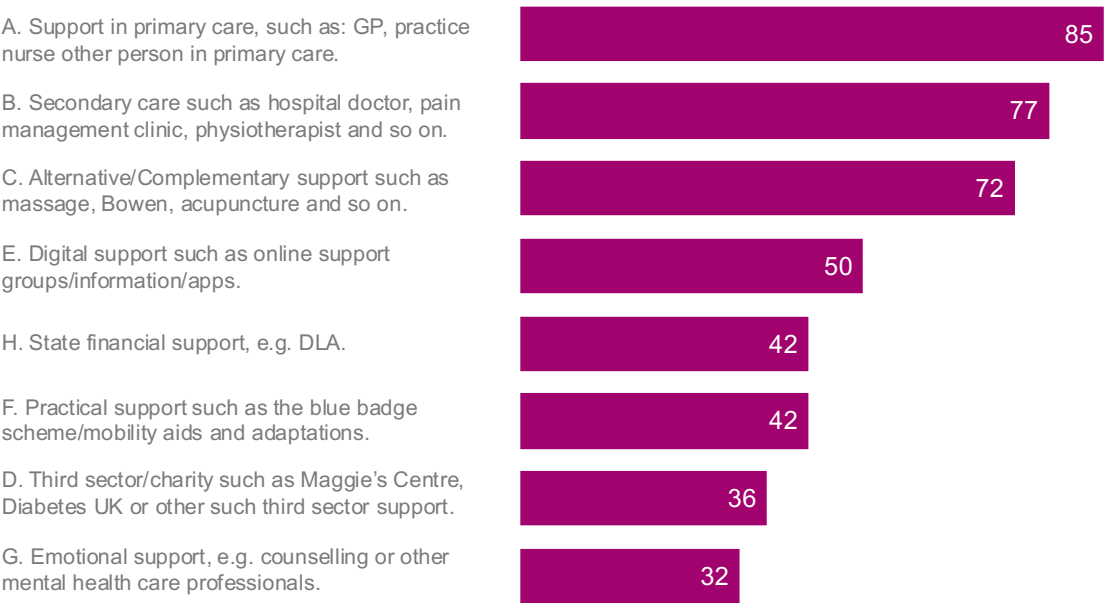
4. Quantitative findings from the second phase of Delphi engagement

- 4.1. Building on the emerging findings from open discussion with panel members, the second stage of the Delphi process was delivered. This involved presenting the panel with themes from the first round of consultation and asking them to reach a consensus or prioritise the key themes using a scoring system. The exercise covered four key questions:
- What has been the most useful support that you have received up to now?
 - What have been your biggest challenges or barriers to accessing support?
 - What has helped you feel more in control of chronic pain?
 - What is important for effective delivery of person-centered care?

Useful support

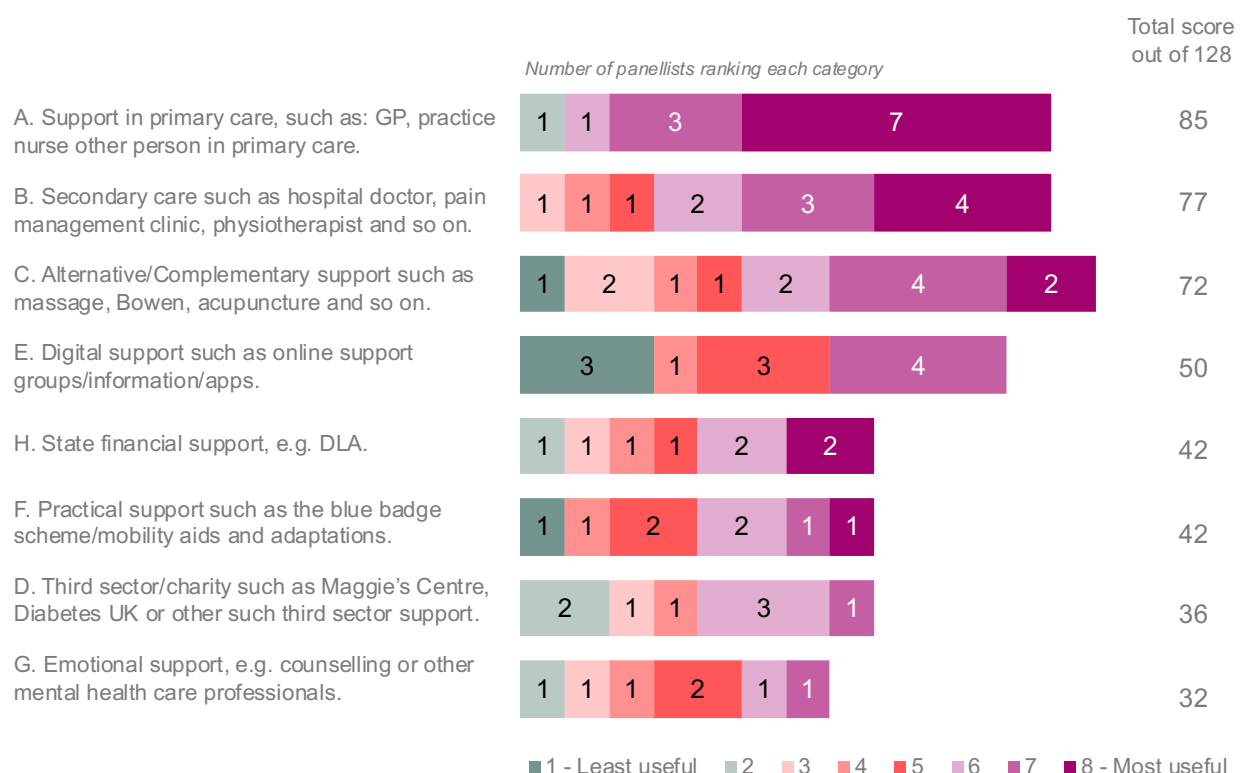
- 4.2. Panellists were presented with the eight forms of support identified in the open discussion and asked to rate them from the most to least useful.
- 4.3. A score of 8 was assigned to the support rated as most useful, with the least useful assigned a score of 1. The highest score that any one form of support could achieve would be 128, if all 16 panellists rated the same support as the most important.
- 4.4. Figure 4.1 shows the total score recorded for each type of support, out a total potential score of 128. Support in primary care was rated the most useful with a score of 85. This was followed by secondary care with a score of 77, and alternative or complementary support with a score of 72. The remaining five forms of support (digital, finance, practical, third sector or emotional support) were broadly considered less useful, scoring 50 or less.

Figure 4.1: Usefulness of support – total score for each support out of 128 (n=16)



- 4.5. To better understand the breadth of ratings for each support form, Figure 4.2 shows how each panellist rated each type of support. Not all rows add to 16 because some panellists either had not received or did not rate each kind of support.
- 4.6. For example, support in primary care achieved the highest total score because seven of the 16 panellists rated it as most useful, with a further three rating it as second most useful, highlighting the importance of this approach. Secondary care was rated as most useful by four panellists and second most useful by three. Two panellists rated alternative or complementary or state financial support as most important. Though no panellists rated digital support as most useful, the combination of other panellists' ratings gave it the fourth highest total score.

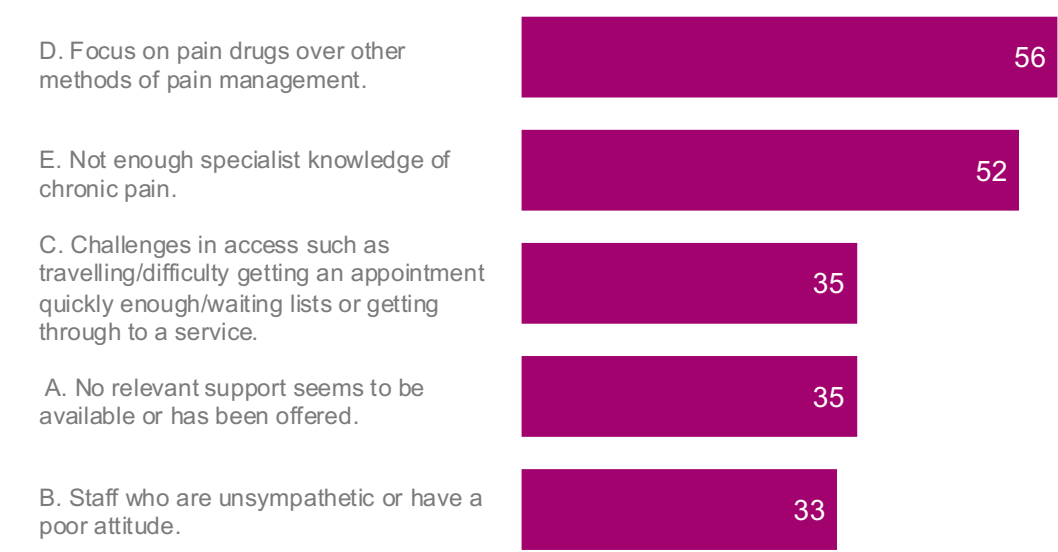
Figure 4.2: Usefulness of support – breakdown of panellist ratings (n=16)



Challenges or barriers to accessing support

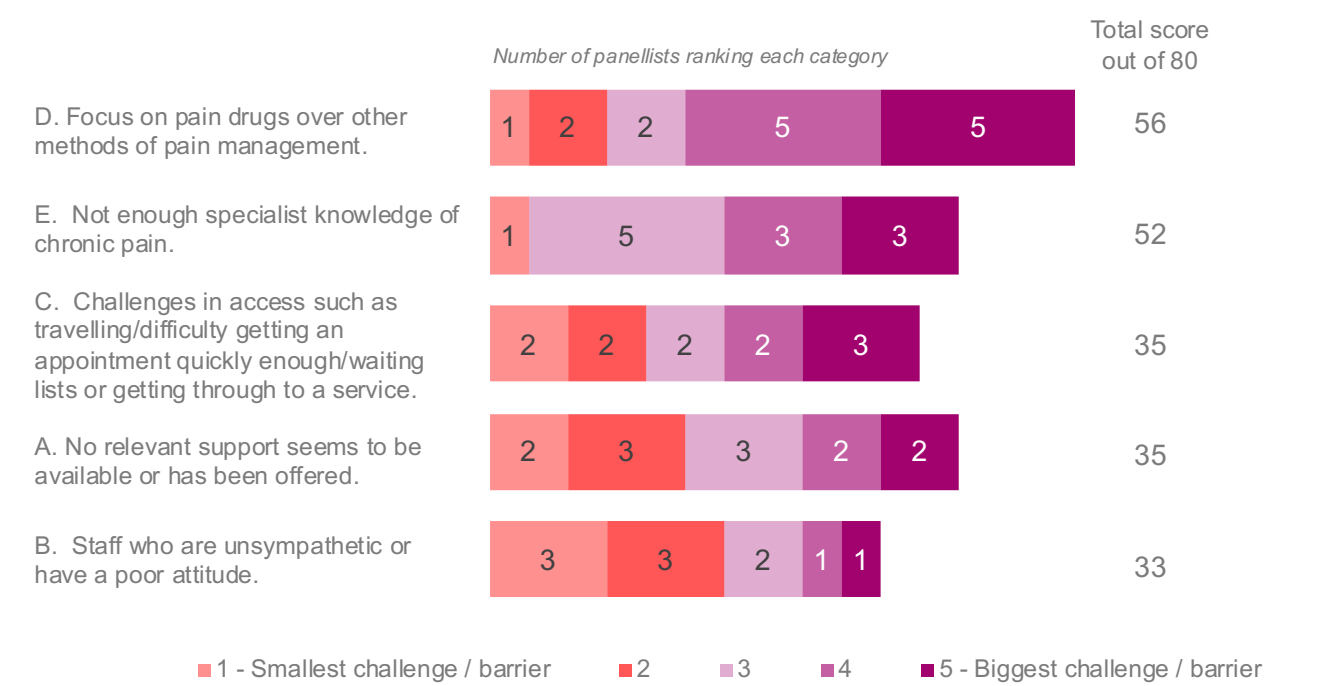
- 4.7. Panellists were presented with five challenges or barriers to accessing support for chronic pain and asked to rank them from the most to least challenging.
- 4.8. In this exercise, the barrier rated as most challenging was assigned a score of 5, with the least challenging assigned a score of 1. The highest score that any barrier could achieve would be 80, if all 16 panellists rated the same barrier as the most challenging.
- 4.9. The total score recorded by each barrier is shown in Figure 4.3. Panellists considered focusing on pain drugs over other pain management methods the biggest barrier, scoring 56 out of 80. Only slightly behind this was a concern that there is not enough specialist knowledge of chronic pain which recorded a score of 52. The three other barriers included in this exercise recorded similar scores of 33 to 35.

Figure 4.3: Challenges or barriers – total score for issue out of 80 (n=16)



4.10. A breakdown of the panellists’ ratings is shown in Figure 4.4. This illustrates the prevalence of concerns about the focus on drugs over other pain management methods, and lack of specialist knowledge. Ten of the 16 panellists rated a focus on pain drugs as the biggest or second most significant barrier to accessing support, while six panellists rated lack of specialist knowledge as the biggest or second most significant barrier.

Figure 4.4: Challenges or barriers – breakdown of panellist ratings (n=16)



Controlling chronic pain

4.11. Panellists were presented with five approaches that may have helped them feel more in control of chronic pain and asked to rate them in order of most helpful to least helpful. A maximum score of 80 was possible. The total scores are shown in Figure 4.5.

Figure 4.5: Controlling chronic pain – total score for each approach out of 80 (n=16)

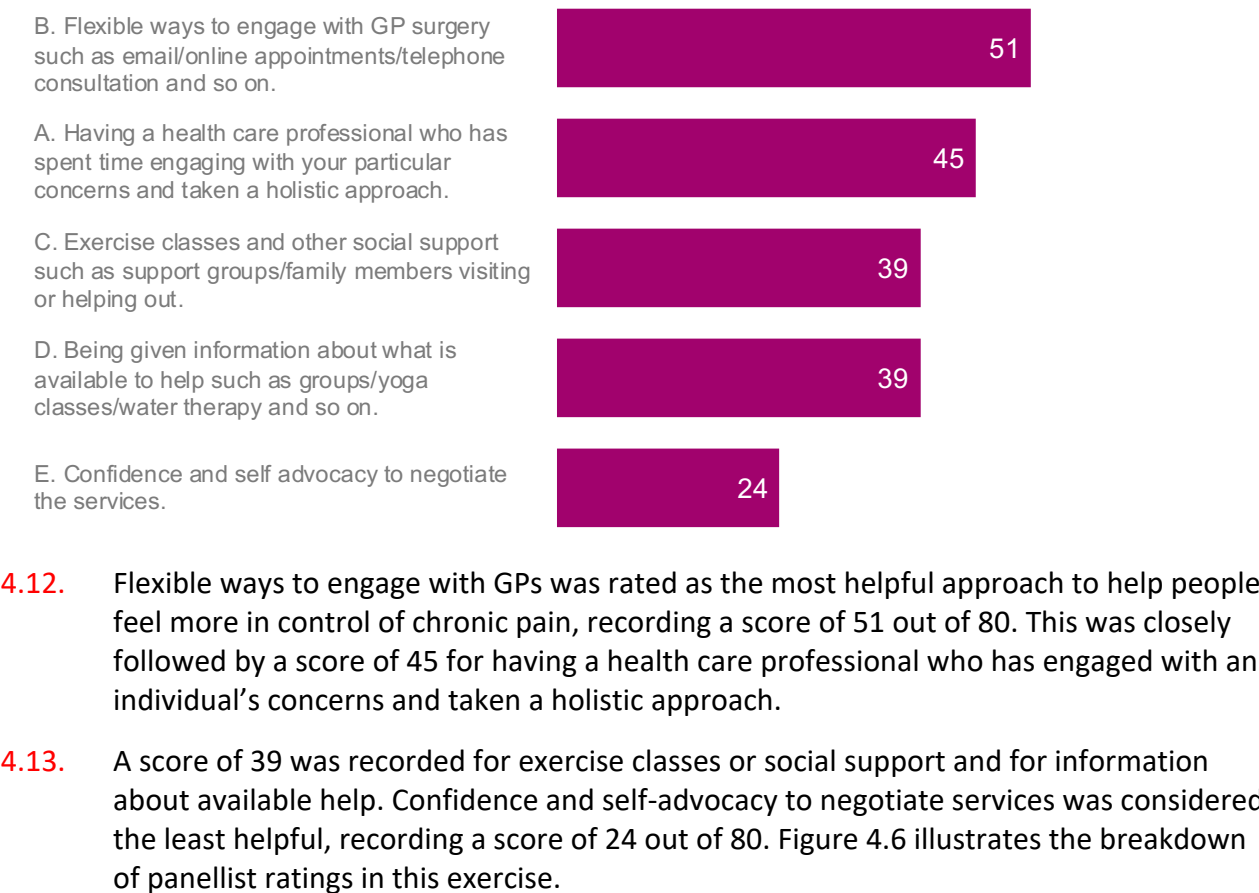
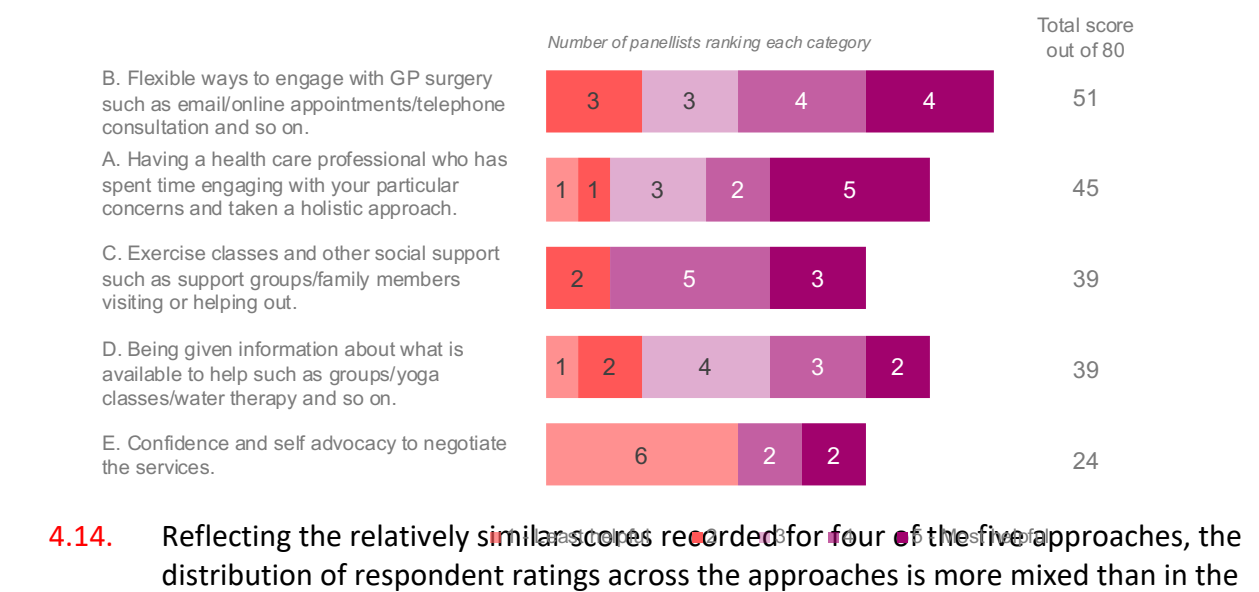


Figure 4.6: Controlling chronic pain – breakdown of panellist ratings (n=16)



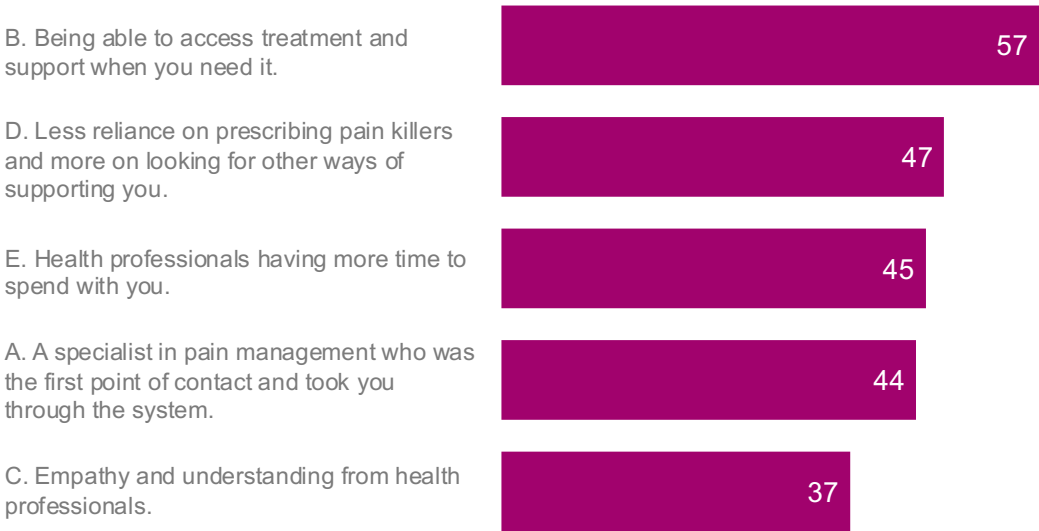
previous two exercises. Half of panellists – eight out of 16 – rated flexible ways to engage GPs as the most or second most helpful approach. While having an engaged healthcare professional recorded the second highest total score, it was rated as most useful by the largest number of panellists – five out of 16.

4.15. Views on confidence and self-advocacy were polarised, with four panellists rating this as most or second most helpful, and six rating it as least helpful.

Delivery of person-centred care

4.16. In the final exercise, panellists were shown five elements of effective delivery of person-centred care. These were ranked from most important to least important, with a maximum score of 80 possibly being assigned to each approach. The total scores are shown in Figure 4.7.

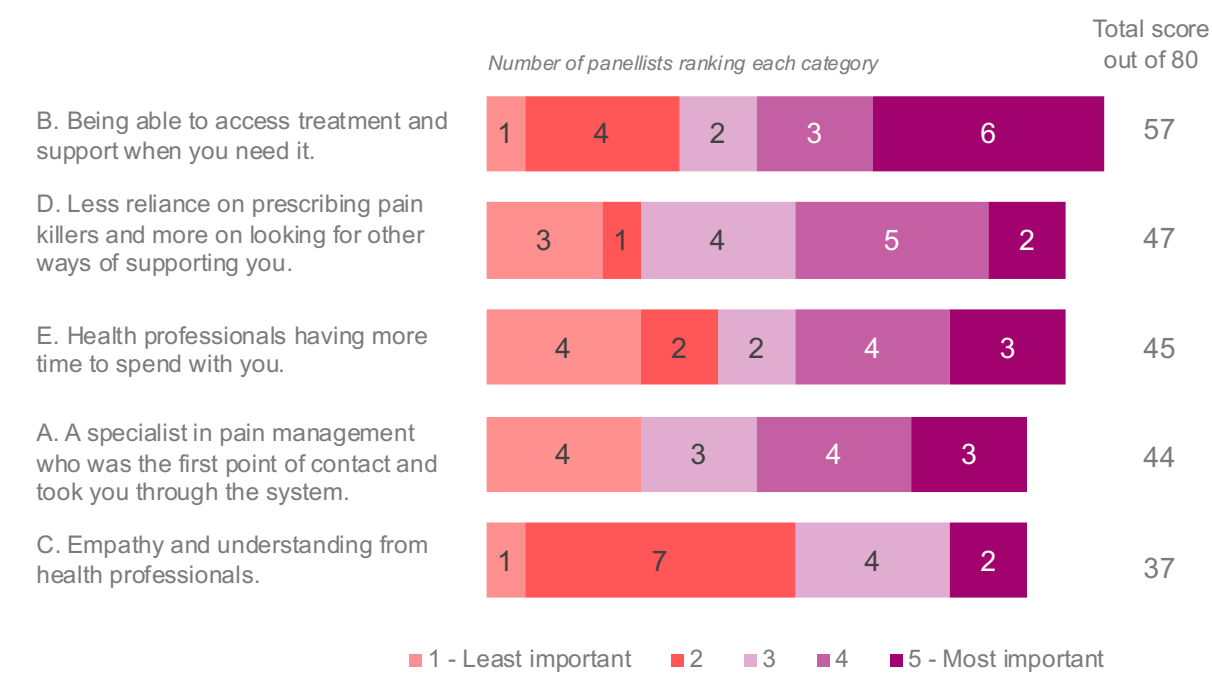
Figure 4.7: Person-centred care – total score for each approach out of 80 (n=16)



4.17. Accessing treatment and support when needed was rated as most important, recording a total score of 57 out of 80. Similar scores were recorded for the next three approaches, with the lowest score of 37 being recorded for the importance of empathy and understanding from health professionals.

4.18. The breakdown of panellist ratings shown in 4.8 reiterates the importance placed on being able to access treatment and support when it is needed. Six panellists rated this as most important, with a further three rating it as second most important. By comparison, each of the other approaches were rated as most important by three panellists.

Figure 4.8: Person-centred care – breakdown of panellist ratings (n=16)



- 4.19. Reflecting the similar total scores, seven of the 16 panellists rated each of the next three approaches as most or second most important. This highlights the breadth of preferences evident across the panel.
- 4.20. Views on the importance of empathy and understanding from health professionals were more negative than positive. While six panellists rated this as most or second most important, eight rated this approach as least or second least important.

5. Conclusions

- 5.1. A diverse panel of individuals with lived experience of chronic pain has engaged with the Scottish Government in developing the Pain Treatment Framework and Implementation Plan.
- 5.2. The panel shared their experiences of accessing support and services, the challenges and barriers they face, and the treatments and aspects of care which make them feel more in control of their pain. These spanned positive and negative experiences and each person's story was unique; there is a diversity of needs and experiences within the community of people living with chronic pain.
- 5.3. Some panel members feel their pain is largely under control, and have received effective treatment and support; for others, their search for effective treatment and support is ongoing. Across their contributions, panel members shared many moving stories of times when they endured great difficulties, including pain, loneliness, anxiety, distress and frustration. They welcomed the opportunity to share their feedback with the SG and inform future work on the Pain Treatment Framework and Implementation Plan.
- 5.4. Results from the Delphi process provide the SG with a clear steer on the aspects of care that are of greatest priority to the panel and the most prominent challenges they face. Primary care services were viewed as the most useful and important source of support for the panel (although not unanimously), while the biggest barrier to accessing support was the focus on painkillers over other pain management methods.
- 5.5. The panel needed to be relatively small and diverse to be an effective working group that could provide feedback based on their own experiences and expertise. It included people who experience different levels of pain, with a range of demographic characteristics. The iterative nature of engagement and detailed group work necessitated engagement with a limited number of individuals. However, the relatively small sample size means that the qualitative evidence from this group cannot be interpreted as statistically significant, nor can we draw conclusions about the wider population of people living with chronic pain; rather it has provided rich insights into the lived experience.
- 5.6. Some of the experiences shared by panel members pose questions that provide scope for further research. For example:
 - The role of technology:
 - a. In providing faster access to care and information
 - b. In delivering access to treatment in a way that is better suited to people's lifestyles
 - c. In paving opportunities for engagement with peer support
 - How to support people who may:
 - a. Be experiencing adverse mental well-being impacts linked to:
 - i. feeling excluded or isolated because the extent of the pain they experience makes it difficult to leave home or be in company

- ii. feeling that they have to rely on others for emotional or physical support
 - iii. experience anxiety about their finances or ability to maintain employment while living with a chronic pain condition
- b. Feel encouraged by peers to use illegal substances (cannabis) in self-directed pain management
- Potential inequalities linked to:
 - a. Age – for example, concerns being minimised based on someone's young/older age
 - b. Length of living with a pain condition – the potential for a person to be living with the legacy of a historic diagnosis that has not been revisited or explored in light of new medical advances
 - c. Location – different levels of pain medication availability and exposure to different knowledge/training/attitudes towards chronic pain, based on service access linked to locality models.

5.7. While the experiences and insights shared by the panel have generated a useful evidence base for the Scottish Government to draw upon, research with a larger number of participants is required to further understand the needs and experiences of people with specific characteristics. In future work to explore the needs and experiences of people living with chronic pain panel, offering in-person opportunities to participate may be worthwhile, if budget and timescales enable this, for a fully inclusive approach.

Next steps

- 5.8. The next stage of this work will focus on user experience testing, with insight from the user research team at NHS24.
- 5.9. All panel members have agreed to remain engaged with the project. During conversations, some remarked that they found participating in the research enjoyable, thought-provoking and rewarding, expressing appreciation for having the opportunity to feed into the formation of the chronic pain framework and implementation plan.



I think it's great that they're doing this. Hopefully, some good will come out of it. [Female, 75, Stirling, C1, low impact]



Thank you for caring to ask. [Female, 73, Inverness, C2, no impact]

- 5.10. As we learned in the first phase of engagement with the chronic pain panel, a few participants faced difficulties using technology in a group work setting, so they engaged by telephone. This choice in participation methods will also be offered in Project 2.