

Scottish Government Pain Management Panel

Report on Phase 2 of engagement with the panel

September 2023

Ministerial Foreword

Jenni Minto MSP, Minister for Public Health and Women's Health:

“I welcome this report which presents the findings from the second phase of engagement with the Pain Management Panel, which is made up of a diverse sample of people with lived experience of chronic pain across Scotland. The report has been commissioned by the Scottish Government and delivered by an independent provider. It offers an insight on the information and resource needs for people living with chronic pain, as well as the opportunities to improve their experience of care and services. This builds on the [previous work](#) of the Pain Management Panel which explored some of the challenges faced by people with chronic pain.

“This report reaffirms the vital role of online information for people living with chronic pain as a key element of their care and support, sitting alongside GPs and primary care services. The main focus of this report is to present views on the current information services for people with chronic pain provided through the NHS Inform website and the NHS self-help guide in order to enhance these to better meet people's needs.

“The report sets out positive examples of support and services people have experienced, as well as their expectations for what information services for chronic pain should look like. The feedback in this report is valuable and assists us to improve our resources for people with chronic pain.

“The Scottish Government remains committed to improving information services in our ambition to improve the quality of life and wellbeing for people with chronic pain. Involving people with lived experience remains a priority to help inform the improvement work we have set out in our [Framework for Pain Management Service Delivery – Implementation Plan](#). The Pain Management Panel has been a crucial part of this, but we recognise that this is not exhaustive and we will continue to engage with a range of diverse voices of those living with chronic pain across Scotland as we continue to develop and deliver the Framework.

“We will continue to work to ensure everyone with chronic pain has better access to the right information, at the right time, to engage the support and services they need.”

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Executive Summary

In August 2022, the Scottish Government commissioned The Lines Between to recruit, support and engage with a cross-section of people with chronic pain across Scotland to inform the development of the [Pain Management Framework and Implementation Plan](#). With support from a research recruitment partner, a diverse panel of 16 individuals was assembled.

Two phases of engagement with the panel were undertaken between August and November 2022. The first phase explored experiences of accessing chronic pain support and services, the challenges and barriers panel members have faced, and the treatments and aspects of care which make them feel more in control of their pain. A [report](#) on the first phase of consultation with the panel was published in November 2022.

This report presents findings from the second phase of engagement with the panel which focused on chronic pain information needs and resources. Through focus groups and one to one interviews, the panel shared their experiences of searching for information about chronic pain, including the reasons why information is sought, sources of information, and their preferences.

The panel described various information needs; for example learning new ways to manage their pain, finding out about potential side effects of new medication, and researching how their condition will affect their long time health. For some panel members, seeking information about chronic pain has become a regular part of their life.

Various information sources are used by the panel. Some prefer the convenience and breadth of information that online searches offer, having been disappointed with the level of information available through GPs and other health services. Others felt that in-person contact with a health care professional is the most reliable source of information, expressing some scepticism over the veracity of online information sources.

The panel also participated in an exercise to provide feedback on two official NHS Inform resources: the webpage on chronic pain, and the chronic pain self-help guide. Responses were mixed; there was agreement that both the chronic pain webpage and self-help guide are well-designed and easy to use, and both offer relevant information that would be helpful for those in the early stages of their chronic pain condition.

However, the panel felt that the information was quite basic, and few were able to point to any information that they had not seen before. The need for information in offline formats was stressed; one panel member was unable to provide feedback on the NHS Inform resources as she did not feel comfortable or skilled enough to access them on the internet. There were also calls for lived experience to be better reflected in the resources.

1. Introduction

This report presents findings from a series of consultations with the Scottish Government Chronic Pain Lived Experience Panel. These discussions formed the second phase of engagement with the panel; a [report](#) on the first phase was published in November 2022.

Context

In August 2022, The Lines Between were commissioned by the Scottish Government to recruit, support and engage with a cross-section of people with chronic pain across Scotland to inform the development of the [Pain Management Framework and Implementation Plan](#). With support from a research recruitment partner, a panel of 16 individuals was assembled.

Further information on the context for this project is contained in the Phase 1 report.

Phase 2 engagement

There were two primary aims for the second phase of engagement with the panel:

- 1) To explore the panel's experiences of searching for information about chronic pain, such as what kind of information they search for, which sources they use and why they use them.
- 2) To gather user feedback on the NHS Inform chronic pain webpage and self-help guide.

The panel were consulted twice throughout November 2022. The first engagement was an open discussion exploring information needs, followed by a brief task whereby panel members were asked to access the NHS Inform [chronic pain website](#) and provide feedback on the design, content and accessibility of the page.

After the first session, panel members were asked to work through the NHS chronic pain [self-help guide](#) in their own time. Once panel members had completed this task, they took part in a second session, and provided feedback on the guide.

Demographics of the panel

The demographics of the panel are shown in Figure 1.

In order to increase the impact and address inequalities facing people with chronic pain, the Scottish Government sought to increase the range and diversity of voices of lived experience of chronic pain to inform implementation of the Framework. For this project, the Scottish Government 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.

More detail on the recruitment of the panel is available in Report 1.

Figure 1: Panel demographics

Demographic	Breakdown
Gender	44% male (7) 56% female (9)
Age	19% aged 18-30 (3) 31% aged 31-54 (5) 50% aged 55+ (8)
Ethnicity	81% White British (13) 13% mixed/multiple ethnic groups (2) 6% Asian – Pakistani (1)
Location	25% Central Scotland (4) 44% Urban/City (7) 19% Rural (3) 13% Remote rural (2)
Socio-economic status	50% B-C1 socioeconomic group (8) 50% C2-E socioeconomic group (8)
Impact of pain ¹	19% No impact (3) 44% Little/low impact (7) 38% High impact (6)

Report structure

This report is structured as follows:

- Chapter 2 explores the panel's experiences of seeking information about chronic pain
- Chapter 3 presents the panel's feedback on the NHS Inform chronic pain website
- Chapter 4 contains feedback on the NHS Inform chronic pain self-help guide
- Chapter 5 offers conclusions on this project.

¹ The 'impact of pain' field was based on a question in the Scottish Health Survey (2022). Panel members were asked the following question: 'Over the past 3 months, how often did your pain limit your life or work activities?' Those who selected 'a lot' were categorised as 'high impact'; 'a little' were categorized as 'little/low impact'; and, 'not at all' were categorised as 'no impact'.

2. Experiences of seeking information about chronic pain

This chapter sets out the panel's experiences of seeking information about chronic pain. It covers what they look for, when and why they look for it; which information sources are used and trusted; the devices and formats used; barriers to seeking information; and other relevant points about the need for and value of information.

Chapter overview:

- The most common driver for seeking information described by the panel was in response to a flare up of pain.
- Some panel members said they had recently searched for advice and answers to specific questions, including:
 - What is causing my pain and what are the best ways to manage it?
 - How is my condition going to affect my work?
 - How many painkillers is it safe for me to take, and are there any side effects?
- For some, there is no specific trigger or prompt to look for information; they said that researching about their condition, new treatments and pain management has become part of their daily life. A few follow online discussions about their condition, others regularly browse forums for new information.
- A mix of information sources are used; some panel members showed a strong preference for receiving information directly through face to face consultation with medical professionals (GP, consultant, nurse, physio), but others reported finding more depth/greater breadth of information available using online sources.
- The majority of the panel had searched for information about chronic pain online. They use a range of sources including forums, social media (Twitter, YouTube & TikTok) and Google searches. However, a small number were wary of online sources due to concerns over scams and the veracity of information. One group felt those with chronic pain can be particularly vulnerable to scams, as some may be in a desperate position and therefore willing to try anything to ease the pain e.g. 'miracle cures'.

Reasons for seeking information

Panel members described when and what prompts them to seek information about chronic pain. Searching at the time of a pain flare up or some other health concern was most frequently referenced. They described looking for ways to manage the pain, or a wish to investigate the cause of an issue; for example, a side effect of a new medication, or linked to something else.

A recurring theme in the discussion was that living with a chronic pain condition involves constantly looking for answers and information. Panel members said this learning journey began at the point of their diagnosis, or during their efforts to get a diagnosis, when they

undertook their own research to explore their symptoms or find out information about their condition and any medication they have been prescribed.

“ Now if I get any medication that's different, or they try something, I always Google it to see what the side effects are and what it should do for me. [Female, 64, Highland, B, no impact]²

Many described an ongoing search for information to stay abreast of any new treatments and learn about self-management or how their condition may impact them or change.

“ Rather than medication it's like, what behaviours do I have to take? What self-care do I have to do? [Female, 48, Edinburgh, B, low impact]

“ I follow on social media, specifically Twitter, one of the leading professors in the field, who is very, very good at sharing the latest updates and the latest information, and putting things out there for general discussion within the community. And you know that if he is saying something, it's worth looking at and going through, because part of it might not affect me, but in the next five to 10 years, some of it may start to manifest itself on me and then I know, I'm forewarned about this. [Male, 52, Western Isles, E, high impact]

“ Constantly googling. You know, if anybody's saying, 'oh, this might help', then it's googling about that. My diagnosis is fairly new, it's only been a year. So I've done loads of research and tried to find out what this is and how I can maybe get some sort of a relief for the pain. Whenever somebody mentions something that's been helpful, that's me off on a tangent to research whatever it is. [Female, 47, Falkirk, C1, high impact]

“ I'm still trying to come to terms with what's actually going on with my own body which is frustrating. I'm a 26 year old girl and I'm told that I might never have kids, so like I'm researching into the possibilities of will that happen? What's the best space to make that happen? I'm ready to have kids but my body just won't allow it. So it's looking at like different therapies ... It's just researching and you end up down the rabbit hole... at three o'clock in the morning sitting googling all different things that you can do. [Female, 26, West Dunbartonshire, E, high impact]

Which information sources are used and trusted

Panel members described using a range of information sources:

- Online; including search engines, social media, NHS websites, international sources, online academic journals, chat forums, YouTube, blogs and podcasts.
- Medical practitioners; seeking information from their GP, nurse, physio, consultant or other relevant clinician.

² Throughout the report, we include 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.

For those using online sources, a typical search for information might involve firstly looking something up online, and if clarification is needed or the search has been fruitless, seeking support from a GP or consultant to find out more.

“ You can't get an appointment with a doctor so what's the point. You're as well doing it yourself and looking into it yourself. [Female, 26, West Dunbartonshire, E, high impact]

“ I go to research papers so I'm constantly looking for new research... looking for up to date information. [Male, 55, Dumfries & Galloway, D, high impact]

Conversely, one described a clinician who encouraged them to look up some of the information that had been shared at the appointment, to learn more about their condition.

“ When I was diagnosed by the neurology department, they basically said, 'right, we can tell you a brief bit, but this guy has been researching this for the last 25 years; go and read his website and it will give you an understanding better than what we can tell you face to face, because by the time you've left here, you will have forgotten 90% of what we told you. Go and learn and have a look.' [Male, 52, Western Isles, E, high impact]

A small number highlighted that online information was a useful way for others in their lives, including family members and clinicians, to learn about their condition.

“ [Discussing their dentist]. I said, 'have a look at this website'. The next time I saw him, he went, 'I get it now. I understand where you're coming from. It must be a bit of a sod to live with'. And I went, 'that's a good understanding'... we've got a great relationship. Rather than him saying, 'I don't understand it [fibromyalgia], I'm not going to find out about it'. [Male, 52, Western Isles, E, high impact]

Some said they had stopped looking for information online or preferred not to do online searches, because what they learned had frightened, depressed, distracted or confused them, or because they did not trust the sources. These panel members preferred to speak to a clinician if they had questions.

“ I don't want to read too much. I think it goes way back to when I was first diagnosed nearly forty years ago, and they treated me at the beginning for lupus and basically I was told at the time, don't go and look up at libraries... because they're only telling you the worst case scenarios. If I get a new tablet... I'll listen to what the doctor and the chemists [say] are the main side effects. I don't go reading what else could be there because I think it just gets you totally depressed thinking what could be wrong with you. [Female, 64, Renfrewshire, D, high impact]

“ I think it's best to speak to a human and ask questions and see what they think. Sometimes if you looked it up online, and you wouldn't know what to do for the next step. Then you're sitting worrying what should you do. [Female, 77, Inverness, C1, no impact]

Quality, trust and clear communication were themes in conversations about information sources. Most held the information from clinical practitioners in high regard; while many wanted greater access to their clinicians, a small number highlighted how easy to reach and supportive they found their doctors or nurses.

“

I bought stuff online and it's a load of rubbish. So I'd rather just go to my doctor, look him in the face, have the human contact, and for them to advise me and diagnose me with what they think is the best, best thing for me. [Female, 75, Highland, C1, low impact]

“

I know that there's loads of stuff around CBD and helping with pain. I've asked two different GPs that I've seen fairly recently and they've both said to avoid it and I suppose that it's from medical point of view. So I am quite reluctant when it comes to it, although folk are saying it's great. [Female, 47, Falkirk, C1, high impact]

“

My doctor's brilliant, give them a phone at the drop of a hat and I'll get three or four different consultants in different areas for the conditions I have. So I don't feel I need to use online. [Male, 49, Glasgow, E, high impact]

“

Technology has improved so much. And, you know, you don't have to see your consultant face to face. You can do it, like we're doing just now [referring to the online focus group]. You can, you know, physio appointments, over COVID were done like this, one to one with a physio. And I'm like, this is brilliant. This is so much better. [Male, 52, Western Isles, E, high impact]

“

The nurses have more time to sit with you and tell you to try different things. I think you're maybe more relaxed with a nurse. They're also very knowledgeable and try to talk you through what you can do to help yourself. [Female, 77, Inverness, C1, no impact]

However, some questioned their clinician's levels of knowledge, or expressed cynicism about the medical model.

“

I haven't tried the CBD... but you know, it's like, everybody's kind of swearing by it, or a lot of folk anyway. And yet, you see your GP and they're like, 'no!' Yet right away, you'll get offered co-codamol at high strengths, you know, that is completely addictive. When I've had sciatica, trapped nerve in my neck and stuff, that was the automatic thing - here's a high strength of co-codamol and just take it every day. If I'd done as was advised, I would be completely addicted to co-codamol. [Female, 47, Falkirk, C1, high impact]

“

I got put on a new antibiotic, I'm just thinking, I'm gonna ask the practice, do they do they get paid for drug trials of that antibiotic and is that why I went on it? [Male, 55, Glasgow, C1, low impact]

“

I went to my friend and got some simple information, it was just a simple herbal medicine. But you know, I wish the doctors had told me about it. [Female, 52, Glasgow, C2, high impact]

Many mentioned the value of learning from peers.

“

When I was at uni, the university were quite helpful and kind of brought people together and that created a kind of space. We all keep in contact that way. [Male, 26, Glasgow, C1, low impact]

However, in these discussions panel members noted that individuals could have different responses to treatments and medications; what works for one person might not work for another.

Preferred devices and formats

Most panel members use their phone to access online information when scanning documents or doing general searches, and some use a tablet or laptop to look at more detailed resources. In these conversations they highlighted the value of online access to a huge array of information.

“

You can do it from your house; it's simple. [Male, 29, West Dunbartonshire, D, low impact]

When discussing how online information is presented, different preferences emerged. For example, one panel member strongly dislikes information presented in a video format; another feels swamped by too much text, and prefers short summaries of information; one liked webpages that allow you to expand sections to get more detail, if needed.

A small number described the value of receiving information in a paper format. They explained the struggle to process and retain new information explained by a clinician at an appointment; having information on paper, to refer to later, was helpful. One said a trusted book could be shared with peers.

“

I get the one to one with my doctor or consultants. When I see the consultants, they'll tell me what they're going to do whether to change meds, or I need to try another exercise but then I get a copy of that sent to me just to confirm exactly what was said at that meeting. It works really well. If it's one of these ones you've forgot as there's so much [information], then they send a letter on just to confirm. [Male, 49, Glasgow, E, high impact]

“

Get an appointment and see somebody, and they are really quite thorough. For me anyway, I find that it's the best communication for me. And they will send me emails, which I'll read, or they'll send me letters on the diagnosis, which is really helpful as well. [Female, 75, Highland, C1, low impact]

“

Having a book there is great, because you can pass it on to other folk. And you know it, it's not the same condition but the same techniques that are in that book can help other folks. So you make folks aware of it,

pass it around. ...if it's a trusted avenue, then I'm all for it. [Male, 52, Western Isles, D, high impact]

Barriers to seeking information

Across conversations with panel members, many described their wish to receive information from or discuss it directly with their clinicians. Many comments on barriers to seeking information centred on the difficulties of getting an appointment, or the challenge of accessing the right specialist; however, some stressed the availability and willingness of clinicians to answer questions.

“

I was sent to a professor, done one session with him at a local clinic. He said he'd get back to me with an appointment for between 4 and 6 weeks' time. That was pre-Covid and I'm still waiting on the contact. [Male, 49, Glasgow, E, high impact]

“

I was going on a treadmill between various different hospital departments to try and find out what was going on. And you would come up with the, 'oh, you're not us; go and see so-and-so'. So then you get an appointment to go to the next department, then that department will take one look at you after a while and go 'no you're not ours - we're gonna punt you back' and eventually you end up back at square one. [Male, 52, Western Isles, D, high impact]

“

GPs are so general; they have to see so many different people for so many different problems. How can they specialise? That's what it comes down to. With chronic pain it's such a complicated area... it's looking more like it now from the statistics that we need a chronic pain management clinic in every, you know, catchment area". [Male, 55, Dumfries and Galloway, D, high impact]

Some comments on barriers to seeking information centred on the challenges of online searches. This included research fatigue due to the volume of information to review, or encountering sources that are not comprehensive.

“

Sometimes it can be really fragmented, like a Google search brings up pages after pages after pages and you can just get totally lost. That can kind of be a barrier in some ways...you just get almost bogged down and then yeah, you can't find what you're looking for or you do find it but there's like conflicting information. It's just too much stuff sometimes. [Male, 26, Glasgow, C1, low impact]

“

The barrier for me was not knowing where to look for the information. [Male, 52, Western Isles, D, high impact]

A small number of panel members reflected that despite some positive experiences, overall access to information from the NHS can feel reactive, rather than proactive:

“

I was lucky with a specialist physio neurological physio she said, just email me if you've got any questions and I'll book you in kind of right away... Sometimes you'd want to have another chat with them to see right I'm at this stage a couple of years on, what can I do myself to help. Is there any advances in knowledge or treatment? But I feel like that's not available as a general thing. I feel like I have to wait until something happens before I can do that. [Male, 55, Glasgow, C1, low impact]

“

I would like to speak to a physio, perhaps every couple years or something and just get advice, prevention. [Male, 26, Glasgow, C1, low impact]

“

The problem with it is that I feel they should talk to you more, especially complex conditions. Like when I came out of hospital after the cancer left severe nerve damage, couldn't walk and all the rest of it and the GP was leaving it to the consultant, the consultant was leaving it to the GP. [Male, 55, Glasgow, C1, low impact]

Acting on information

Conversations about information that participants have acted on mainly centred on self-management approaches. Some of this information was provided by clinicians. Other panel members had implemented self-management approaches including diets, exercises and use of CBD products, through online investigation, including engagement with peers.

“

I've tried new exercises...it helps in the long run. It helps. I think that's what it's all about. Giving you a way to get through your pain, instead of having to dope yourself with medicines. [Female, 73, Highland, C2, no impact]

Other relevant points raised

Other issues linked to the lived experience of chronic pain emerged in conversations about information seeking.

A small number described being victim of scams and online fraud, noting that because of their pain, they were vulnerable to exploitation:

“

You're a bit like the wee drowning man who will reach for anything to try and save themselves. And if something comes along that says 'here, this is a miracle cure, this will help you'...then you suddenly realise that you've bought a packet of gummy bears that allegedly contain cannabis. And I paid 25 quid for them. And then two weeks later, they're taking 75 quid off your account, because it's a con... What you think is the magic bullet... you will jump at it no matter what it is. And that's the problem with chronic pain. You think 'oh good they're offering me a solution'. It might not be the solution. It may cause you more problems at the end of the day. [Male, 52, Western Isles, D, high impact]

“

Well, I'm terrified to take things off the internet or whatever because there's so many things happening, there's so many scams, and sometimes I'm terrified to even go online. [Female, 73, Highland, C2, no impact]

In conversations about information, some noted that their extensive online searches reflected the amount of stress, fear and anxiety of living with a chronic pain condition. In these discussions, a sense of loneliness was shared:

“

You feel quite alone. And nobody's really got answers to it. So it's a lot of self-research through Google. [Female, 47, Falkirk, C1, high impact]

“

Nobody cares. That's what I say to my son. Nobody cares about your health. Other than you so you better get yourself sorted out so that's why I've taken it into my own hands. [Female, 48, Edinburgh, B, low impact]

“

It's a fear of the unknown when you don't know what it is and you don't know how it's going to progress and it is such a worry. [Female, 75, Stirling, C1, low impact]

3. Feedback on NHS Inform chronic pain website

This chapter sets out the panel's feedback on the design, accessibility and content of the NHS Inform chronic pain website.

Chapter overview:

- The panel complimented the design and layout of the website, describing it as clear and easy to navigate. They also agreed that the language is simple and understandable.
- A few panel members raised concerns that those without the access to the internet or sufficient digital literacy will not be able to use the website. They suggested that the information should be made available in offline formats, for example through leaflets at doctors surgeries.
- The content was described as helpful but basic; few said that they had learned any new information from the website.
- Some thought that the content of the webpage places too much emphasis on activity and exercise, arguing that this doesn't fully reflect the reality of living with chronic pain.
- The list of external resources included at the bottom of the page was welcomed by the panel.

Design

Panel members were generally complimentary about the design and layout of the page. They felt it was well structured and easy to navigate, with clear headings and sub-headings. The panel also agreed that the size, colour and font of the text was easy to read.



It was broken down into nice bite sized chunks. [Male, 26, Glasgow, C1, low impact]

Language

The language used throughout the webpage was described by the panel as 'simple', 'clear', 'straightforward' and 'easy to read'. They did not highlight any examples of phrases or words that were too jargonistic or overly technical.

Format

While most members of the panel found the website format appropriate for themselves, it was recognised that there may be demand for the information to be provided in alternative formats, such as audio or video.



Some people might not want to sit and read through all of that. So a video might suit some people better than others. [Female, 52, Glasgow, C2, high impact]

A few raised concerns about the accessibility of the website, pointing out that those without access to the internet will not be able to use the resource in its current format. One felt this was particular concerning given the higher prevalence of chronic pain among older people, a population who are more likely to be digitally excluded. This concern was shown to be valid through our engagement with the panel – one member in her 70s opted out of the task as she did not feel comfortable or skilled enough to access the website.



If you've got internet access, NHS Inform is a great website to start to look at and get pointers. But if you don't have the technology, and you're not comfortable using the technology, folk are going to be missing out. [Male, 52, Highland, D, high impact]

There were calls for the information on the website to be made available in offline formats too, for example through leaflets offered at doctors surgeries.

Content

Feedback about the content on the webpage was mixed, with some praise, and some more critical comments. There was general consensus the webpage provides a lot of relevant information, and is a useful resource for those in the early stages of their chronic pain condition.



That's an informative page for the beginning of your journey. [Male, 55, Dumfries and Galloway, D, high impact]

The list of external links at the bottom of the page was highlighted as particularly helpful by the panel, who said that they had not been aware of some of the resources and expressed an interest in revisiting the page at a later date to access them.

However, many thought that the information on the page was fairly basic, describing the content as 'common sense', 'bog standard' and 'generic'. Few were able to give examples of any new information that they had learned from the site.



It's very straightforward. I think we all know all this anyway. I certainly do because I've been through it all. [Female, 75, Stirling, C1, low impact]

Others were quite critical of what they felt was an over-emphasis on using activity and exercise to manage pain, noting that this doesn't reflect the reality of living with a chronic pain condition. Some described experiencing days where their pain and exhaustion is so severe that activity and exercise are not an option, and could actually do them harm.



I mean, it's a good read but all it's really saying is like, exercise, exercise, exercise... The page doesn't take into consideration that if you're at the point of desperation and you're in actual agony, then you're not going to be able to join the walking club and do all these other things... At my darkest point, when I was in that state, this would not have helped me. [Female, 48, Edinburgh, B, low impact]

“

There's a bit about planning your day and trying to do things and exercise. But the thing is, for people that are in chronic pain, that's the last thing they want to do... I think it depends what kind of pain you're going through. For some pain, exercise will help, but for some pain, I don't think exercise is the answer. [Female, 52, Glasgow, C2, high impact]

A few panel members criticised the inclusion of the following statement on the site:

“It isn't possible to tell in advance whose pain will become chronic. But we know that people are more likely to develop chronic pain during or after times of stress or unhappiness.”

They expressed concern that the statement appears to draw an unhelpful association between stress and pain, and potentially undermines the physical side of their condition by linking its onset to an emotional issue.

“

At the beginning, it said that stress and anxiety can cause pain, which I think myself is a load of rubbish... I found that quite insulting. With the illness I've got, some people think, 'well it's because she's a worrier that she's sore.' I didn't like that sentence at all. [Female, 48, Edinburgh, B, low impact]

“

I read some points that I didn't really agree with. It says most people develop chronic pain during a time of stress and unhappiness, which I don't think is right. It may be in some scenarios, but not in all scenarios. I think chronic pain can happen because of different things. But I don't think I agree with saying it's precisely to do with stress and unhappiness. [Female, 52, Glasgow, C2, high impact]

The inclusion of the statement “Chronic pain can also affect people living with diabetes, arthritis, fibromyalgia, irritable bowel and back pain” was also debated by a few panel members. They felt that the list of health conditions provided is very limited, highlighting the absence of both Ehlers Danlos Syndrome and Fibromyalgia. It was suggested that an additional sentence should be added, clarifying that the list is not exhaustive and there are many other conditions which are associated with chronic pain.

The panel suggested some other improvements to the content of the webpage, including:

- One panel member noted that there is no section on diet, which they considered to be an important part of managing their pain and general health.
- There were calls for a reference on the statistic stating that chronic pain affects 1 in 5 people in Scotland; some were surprised it was so high, others thought it was a low estimate.

4. Feedback on NHS Inform chronic pain self-help guide

This chapter presents the panel's feedback on the NHS Inform chronic pain self-help guide.

Chapter overview:

- The self-help guide was described as well set out, and easy to read and navigate. Panel members also felt the language was clear, and some praised the tone of the guide, describing it as positive, empathetic and non-judgemental.
- The graphs used throughout the guide were described as 'filler' and some panel members suggested they should be removed or replaced with more informative graphics.
- There was general consensus among the panel that at 18 sections, the guide is too long and should be condensed or adapted from its current format.
- There were calls for the information and advice contained in the guide to be available in different formats, including video, paper copies and an app for mobile phones.
- Overall, the content of the guide was seen as fairly informative and helpful. The panel generally agreed that the information and advice in the guide would have been useful at the onset of their pain, especially in a collated form such as this.
- The disclaimer included at the beginning of the guide (which states that the guide is intended for people with 'mild-to-moderate mental health issues') attracted some criticism from the panel. It was described as a 'presumptuous' and 'discriminatory' statement which erroneously conflates chronic pain with mental health issues.
- As with the webpage, the panel did not think that the guide content fully reflects the reality of living with chronic pain. They called for more 'lived experience' examples to be included in the guide.
- While the panel appreciated that the guide did not focus on painkillers or medicine as the only way to manage pain, they did highlight the lack of information available about alternative therapies for managing chronic pain, such as herbal remedies and acupuncture, and suggested this should be incorporated.

Design

The guide was described as well set out, and easy to read and navigate.

One panel member welcomed the inclusion of the ReachDeck toolbar (as shown in Figure 2)³, but called for more attention to be drawn to it. They advised that the guide should

³ ReachDeck is a website accessibility tool which has a range of functions such as a screen reader and text enlarger. It is important to note that ReachDeck is not just a feature of the self-help guide but is available on every NHS Inform webpage.

include a sentence highlighting the tool and explaining its purpose. The need for this was reinforced by others in the group who said they had not noticed it and did not know what it was for/how to use it.

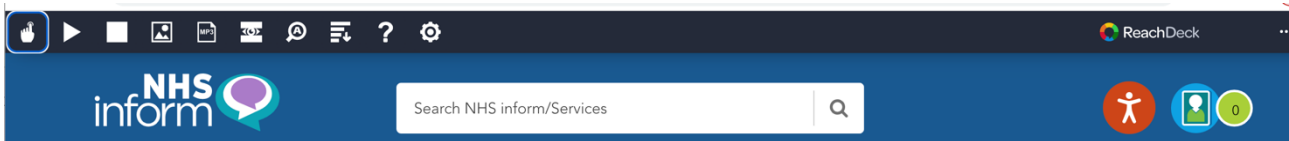
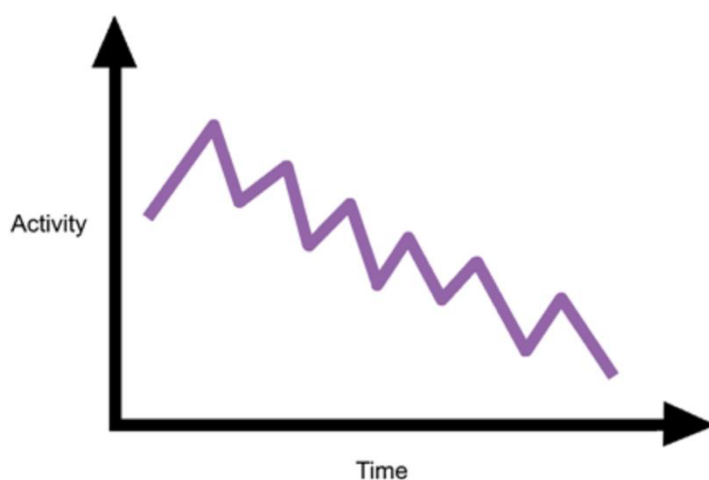


Figure 2: ReachDeck function

While the panel recognised the benefits of including graphics to break up the text, they were generally unimpressed with the graphs used throughout the guide (such as the example presented in Figure 3). The graphs were described as ‘filler’ and lacking any meaningful context, insight or data.

Figure 3: Example of graph in the self-help guide



Language

The panel agreed that the language used throughout the guide was simple and easy to understand. They did not point out any examples of phrases or language that they found to be too technical or jargonistic.

Some praised the tone of the guide, describing it as positive, empathetic and non-judgemental.

“

The way it was written was empathetic. Saying things like, ‘It’s not unusual that you are in pain’, those kind of words. It’s useful to hear that... The way it’s put across, it definitely was worded in an empathetic way. [Male, 55, Glasgow, C1, low impact]

“

I felt the whole thing was very positive and actually gives you a bit of hope. [Female, 75, Highland, C1, low impact]

Format

Length of the guide

There was general consensus among the panel that at 18 sections, the guide is too long and should be condensed or adapted from its current format. Concerns were raised that people who are experiencing pain will not have the will or concentration to complete the guide in its entirety.

“

18 sections... if you're in pain, the last thing you want to do is have to sit through it all. Even with stopping and starting, you may start it and not use it again. You just may just give up on it. [Male, 52, Western Isles, D, high impact]

“

They might just look at that and think, I don't want to read all that, you know? It might be too long winded. At the end of the day, you want a quick answer, a quick solution to your problem... it's much better to be precise, have something you can click on to get a bit of help quickly, rather than have to scroll through it all. I would keep it as short as possible. [Female, 75, Highland, C1, low impact]

A few said that had it not been for the 'homework' task they'd been set, they would have quit quite early on, noting that there was a lot of content to persevere through. Some did not appreciate sections of the guide which direct users to other NHS Inform resources⁴. They argued that this makes a lengthy guide even longer, and suggested that instead of 'outsourcing' these parts, summaries should be put into the guide, with links provided to the other resources for those who would like more detail.

Suggestions for other formats

There were calls for the information and advice contained in the guide to be available in different formats; the panel explained that their condition means that they sometimes struggle with attention span and reading long chunks of text, and so video or audio can be a more manageable and effective way for them to consume information.

“

Definitely a video. I think that's less invasive. If you're in pain and you're listening and watching, I would say you can deal with that better than sitting there reading... The video definitely is the first and foremost thing that should be on it. [Female, 75, Highland, C1, low impact]

Others called for the guide to be made available in a paper copy. A few recognised the option to print the guide as a PDF, but noted that a lot of people do not have access to a printer, and so advised that there should be an option included for people to request a paper copy is posted to them.

A few suggested that the guide would work best as an app, which would mean they could save their progress as they worked through the sections. However, others appreciated the simplicity of interacting with the guide in its current form; grateful that they didn't have to download a new app, register for an account and create a password.

One respondent proposed a change to the structure of the guide, suggesting that it moves away from its current linear format (whereby participants work through sections in order

⁴ For example, Section 15: Sleep directs the user to the NHS Inform Sleep problems and insomnia self-help guide, which is made up of 14 sections.

from 1 to 18), and a navigational tool is used instead, so that users can direct themselves to the sections of the guide that they find most relevant.

Content

Overall, the content of the guide was seen as fairly informative and helpful. In similar feedback to the chronic pain website, the panel said they had seen or heard a lot of the content before, but agreed that the information and advice in the guide would have been useful at the onset of their pain, especially in a collated form such as this.

“ On the whole, I thought it was really good. I think their information on chronic pain was really, really good and useful. The tips about breaking things into manageable chunks - that's exactly what I try and do on a daily basis. [Female, 47, Falkirk, C1, high impact]

Some sections were flagged as particularly helpful, including the explanation of chronic pain, the action plans and the section on emotional reasoning.

“ I find a lot of value in the part about patterns of unhelpful thinking. It's not something I'd ever explored before. So things like the emotional reasoning, that is pretty new to me. When talking about treatment in the past, it's not something that's ever come up.” [Male, 26, Glasgow, C1, low impact]

A few said they appreciated that the guide did not focus on painkillers or medicine as the only way to manage pain, welcoming the information about other techniques like physiotherapy exercises and goal-setting.

However, there were some criticisms of the content. As with the webpage, the panel did not think that the guide content fully reflects the reality of living with chronic pain. They called for more 'lived experience' examples to be included in the guide, such as quotes, case studies, and real life stories of successful pain management techniques.

“ Give a real-life example. I've seen other NHS websites where there are real human beings telling their stories. And they're very powerful. [Male, 52, Western Isles, D, high impact]

“ Maybe they could have a wee section saying 'this person lives with pain and this is what they do' to help make the situations or scenarios come alive a bit more. [Female, 77, Highland, C1, no impact]

The disclaimer included at the beginning of the guide (Figure 4) attracted some criticism from the panel.

Urgent help

This self-help guide is intended for people with mild-to-moderate mental health issues.

If you're feeling distressed, in a state of despair, suicidal or in need of emotional support you can phone NHS 24 on 111.

For an emergency ambulance phone 999.

Figure 4: Urgent help disclaimer

The panel agreed that the statement felt out of place; some questioned whether it belonged in the guide at all or whether it was mistakenly copied from another guide. The disclaimer was described as 'presumptuous' and 'discriminatory', as it conflates chronic pain with mental health issues, which undermines the physical effects of their condition. A few raised concerns that people with chronic pain may access the self-help guide, read this disclaimer and decide not to continue using the guide if they interpret that the resource is only for people with 'mild-to-moderate mental health issues'.

The panel also highlighted the lack of information in the guide about alternative therapies for managing chronic pain, such as herbal remedies and acupuncture. They suggested that it would be helpful to include information about such therapies, or at least provide links to external resources about them.

5. Conclusions

Throughout November 2022, the Scottish Government Chronic Pain Lived Experience Panel took part in a series of discussions about their experiences of searching for information about chronic pain, and participated in an exercise where they provided feedback on official NHS Inform resources.

These conversations identified that panel members have various information needs; for example learning new ways to manage their pain, finding out about potential side effects of new medication and researching how their condition will affect their long time health. For some members of the panel, seeking information about chronic pain has become part of their daily life.

Different information sources are used by the panel. Some prefer the convenience and breadth of information that online searches offer them, having been left disappointed with the level of information available through GPs and other health services. Others felt that in-person contact with a health care professional is the most reliable source of information, expressing some scepticism over the veracity of online information sources.

Response to the NHS Inform chronic pain resources were mixed. There was agreement that both the chronic pain webpage and self-help guide are well-designed and easy to use, and both offer relevant information that would be helpful for those in the early stages of their chronic pain condition. However, the panel felt that the information was generic, and few were able to point to any information that they had not seen before. There were calls for the information to be available in additional formats such as paper copies and videos; and for lived experience to be better reflected in the resources.

As with the first phase of engagement, discussions were insightful, and panel members offered thoughtful and valuable contributions. Many reflected positively on the experience of taking part in the Chronic Pain Lived Experience Panel, expressing a willingness to continue engaging with the Scottish Government about their experiences of living with chronic pain.



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