



PAIN
PEOPLE
ARGYLL
VERSUS
ARTHRITIS



BACKGROUND

The Versus Arthritis Pain People Place project is a rolling programme of engagement activity focused on lived experience of chronic MSK pain across communities in Scotland. The project emerged from previous work on storytelling, which brought together volunteers with lived experience of arthritis to develop their skills in articulating their personal stories with a range of audiences.

Prior to the pandemic, the project was set to develop engagement activities in six locations across Scotland. Our local development staff, working with an external consultant, were planning programmes of local meetings, one-to-one interviews, and joint work with local services with the goal of constructing a picture of how people were living with chronic pain, their priorities, and needs, in different contexts. There was an implicit commitment to follow up the engagement with practical steps, e.g., new support groups, partnership developments, self-management activities.

With the pandemic, these plans were suspended and a range of options for furthering the project aims were

reviewed. This meant rescaling and going online. We focused initially on the Grampian area, producing a report (<https://www.versusarthritis.org/media/23507/va-pain-people-place-report-april2021.pdf>) and establishing an online support group as a result of the engagement work.

Our work in Argyll is built on a history of local partnership work and the commitment of our development staff in the area.

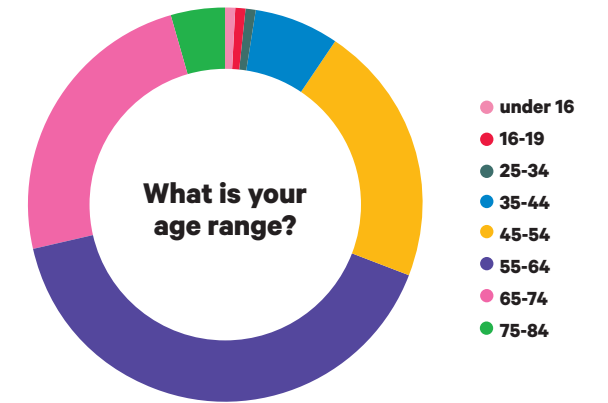
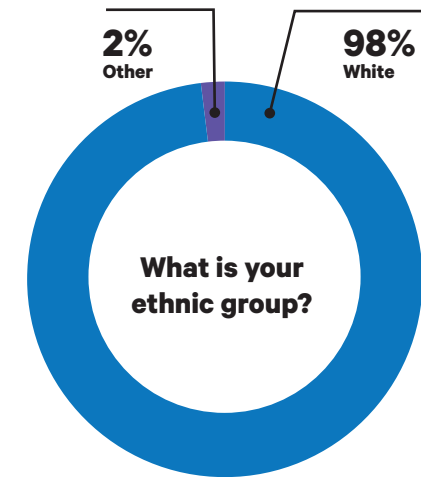
Led by the project consultant, Audrey Birt, and Versus Arthritis Regional Officer for Argyll & Bute, Maggie Clark, over a period of four months (March – June 2022) we conducted a public survey, ran three focus groups and undertook five one-to-one conversations. The surveys were promoted on social media and shared through NHS networks in Argyll & Bute. Focus groups were held through Zoom and recruited by geographical area. One-to-one interviews were held with people who couldn't attend focus groups or where a more in-depth conversation was appropriate.

SURVEY RESULTS

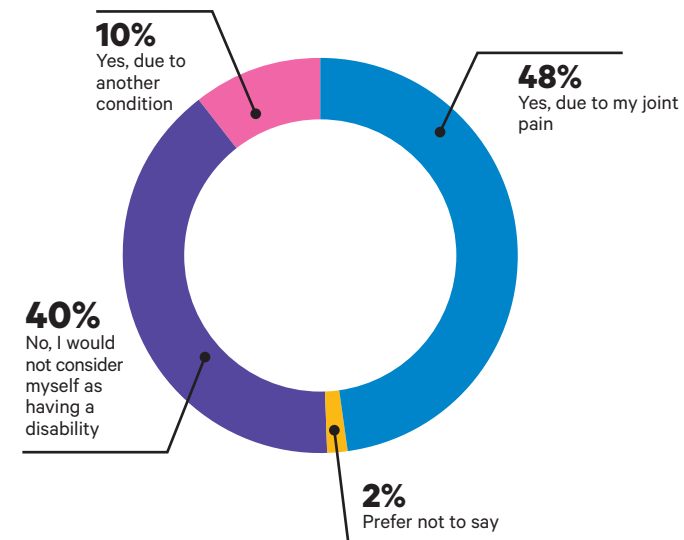


PEOPLE: WHO RESPONDED?

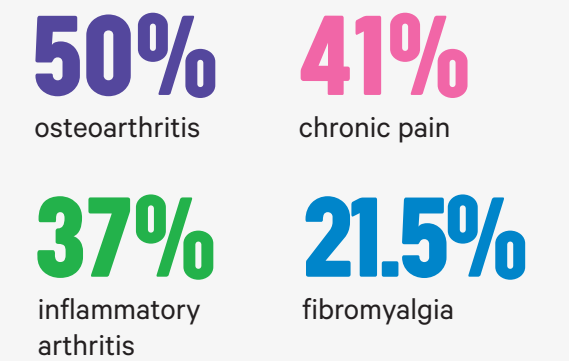
116 people completed the survey from a range of postcodes in Argyll. The majority of respondents identified as white and were female in the 45 to 74 age group.



Just under half of respondents considered themselves to be disabled, which they mostly attributed to joint pain.



The main conditions identified by respondents were:

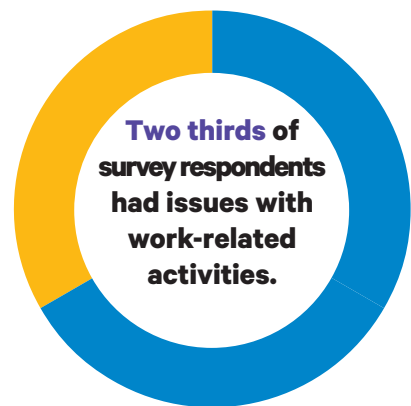
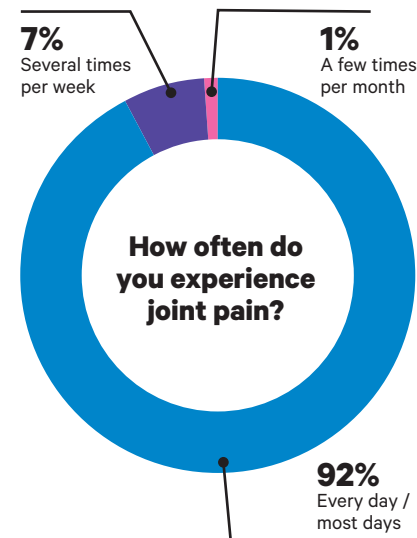
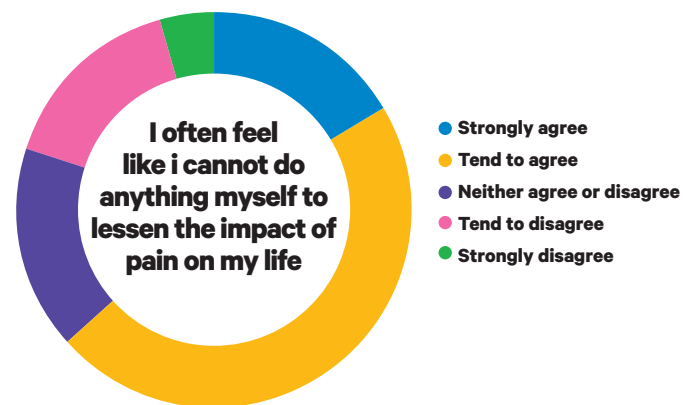


A further 18 people (15.5%) thought that their joint pain may be arthritis related.

PAIN

IMPACT OF PAIN

Most survey respondents felt their pain was either moderate or severe and had a significant impact on their daily life. **9 out of 10** experienced joint pain every day or most days and **two thirds** felt that they couldn't do anything to lessen the impact of pain in their life.

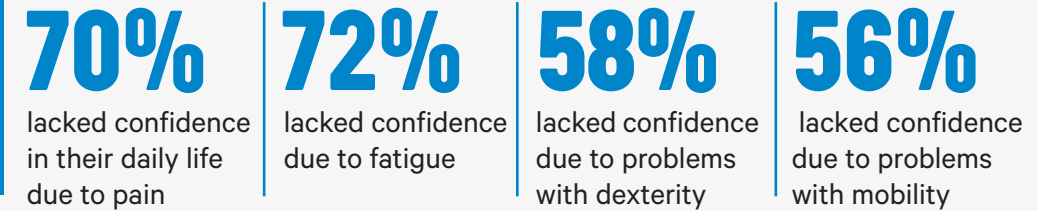


"I AM ABLE TO WORK FULL TIME BUT WHEN MY DAYS OFF I'M SHATTERED AND FIND IT HARD TO RECOVER FROM FATIGUE."

"DUE TO LOW MOOD, ANXIETY AND PALPITATIONS I HAVE BEEN OFF WORK FOR 5 WEEKS AND HAVE A SICK LINE FOR A FURTHER 4 WEEKS. I WANT TO WORK BUT AT PRESENT I CAN'T FACE THIS DUE TO LOW MOOD."

The survey provided a snapshot of the impact of pain on daily life:

CONFIDENCE



STAYING ACTIVE

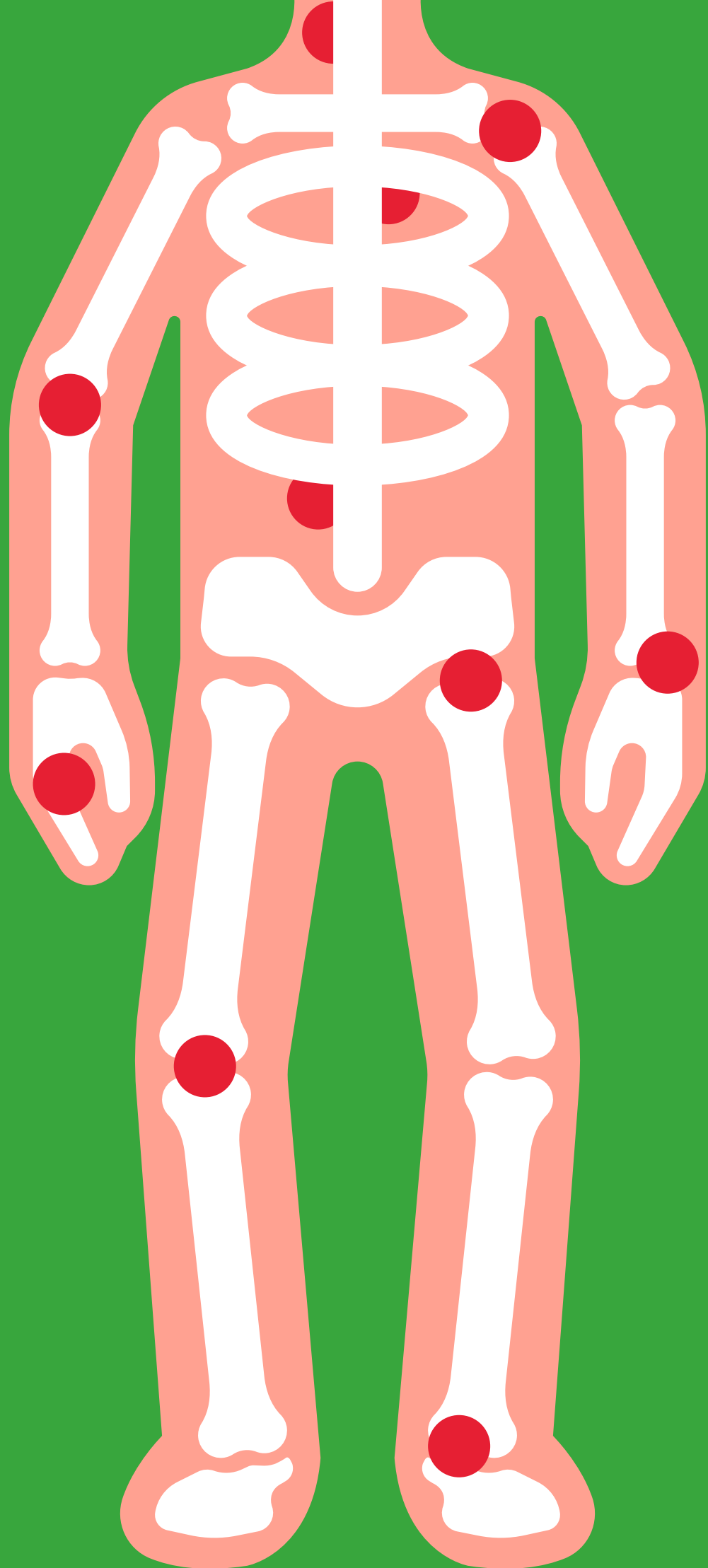


MENTAL HEALTH



In the focus groups, participants were asked the question, **'What does pain mean to you?'** Initially people would offer words like **"discomfort"** or **"frustrating"**, but as time went on other expressions emerged which articulated more fully their experience:

ALWAYS THERE
UNFAIR
RELENTLESS
WORRY
ANGRY
EXHAUSTING
POISON
NEVER ENDING



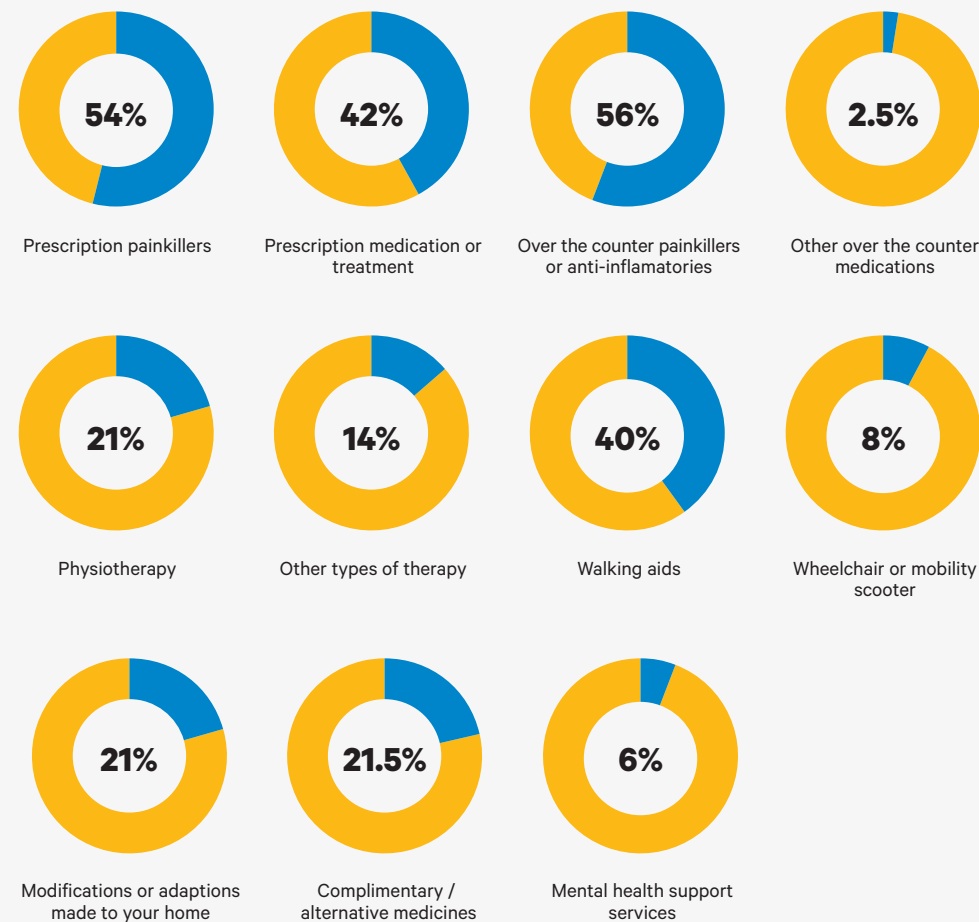
MANAGING PAIN

9 out of 10 people experienced pain every day or most days, but most had very little or no confidence in taking practical steps to reduce the impact of their pain on their daily life. This included managing pain, fatigue, dexterity, mobility, low mood, and anxiety.

Reliance on medication was very high with most survey respondents taking prescribed medication including opioids, disease modifying medicines, or over the counter medication. **34%** used complementary therapies, including massage and acupuncture.

Most respondents (78%) regarded keeping moving/staying active as key to managing their joint pain, with **56%** using low impact exercise, and **54%** 'maintaining a healthy diet'.

Which, if any, of the following kinds of medication, treatments and support do you use to manage your joint pain?

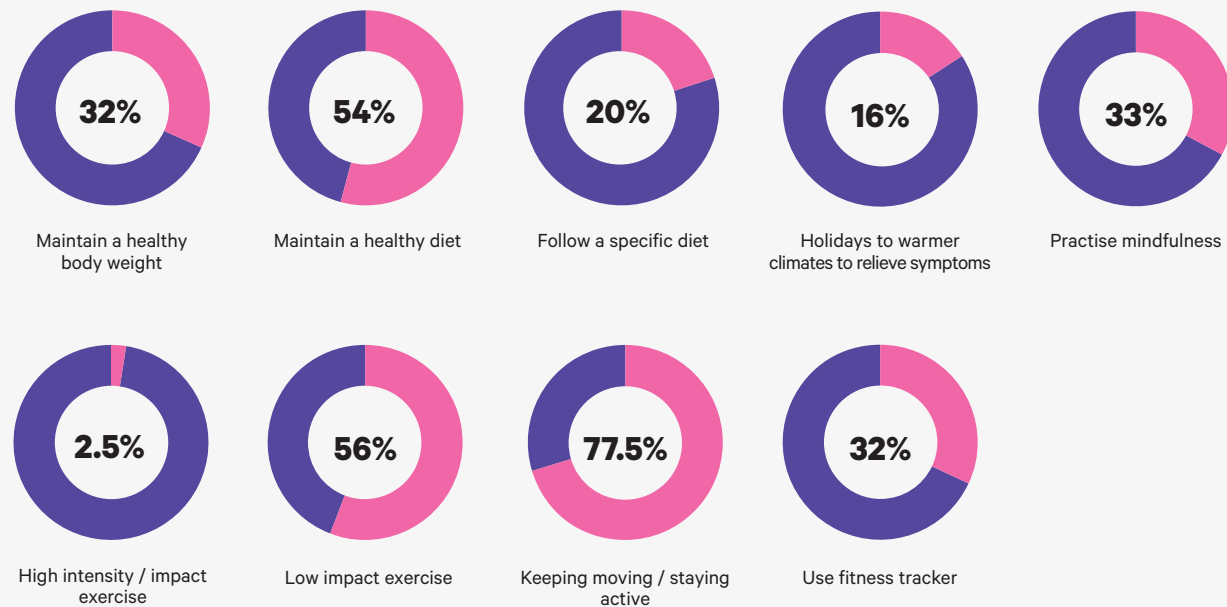


SELF-MANAGEMENT APPROACHES

Some self-management resources had been suspended due to the pandemic, e.g., one interviewee talked about the weekly balance and movement class run by the Cowal Befrienders, which was no longer running. Other options had opened in the past few years, e.g., the same person downloaded the Let's Move with Leon resources from Versus Arthritis, although they found it difficult to physically engage. Walking was a significant part of many people's self-management with the caveat that **"it is so hilly everywhere!"**.



Besides more formal treatments, medications and support, do you do any of the following to try to help manage your joint pain?

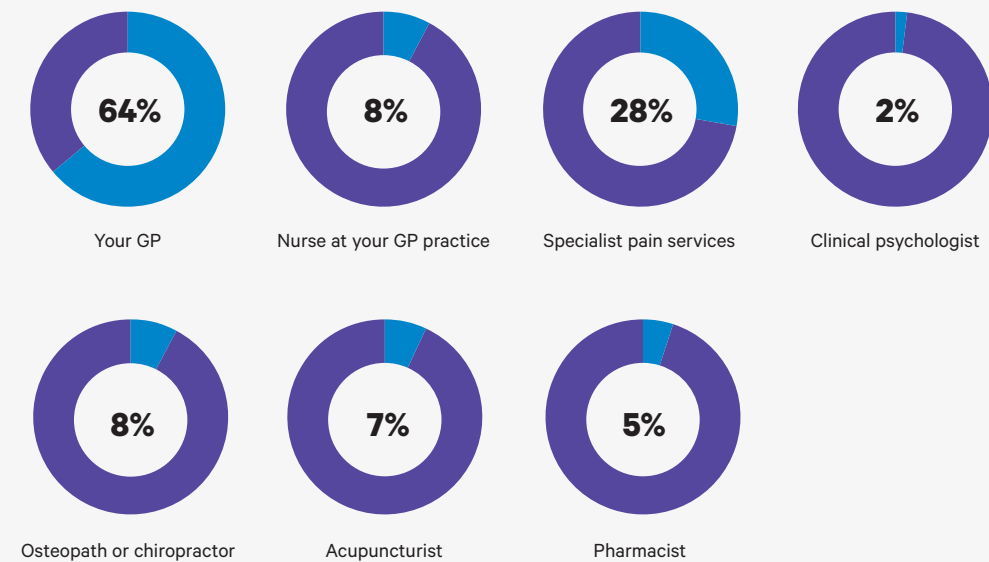


INFORMATION AND SUPPORT

In the survey, people identified healthcare professionals – GPs, Rheumatologists, Physios – as the key sources of information, although many accessed information from other people with arthritis.

The GP was the main source of formal support and information, although a significant number of survey respondents (27%) were seeing a Rheumatologist and 28% attended a specialist pain service. People wanted to know more about their condition, medicines/treatments, and where to get help/support.

Have you seen any of the following professionals or advisors about support or help to manage your pain?



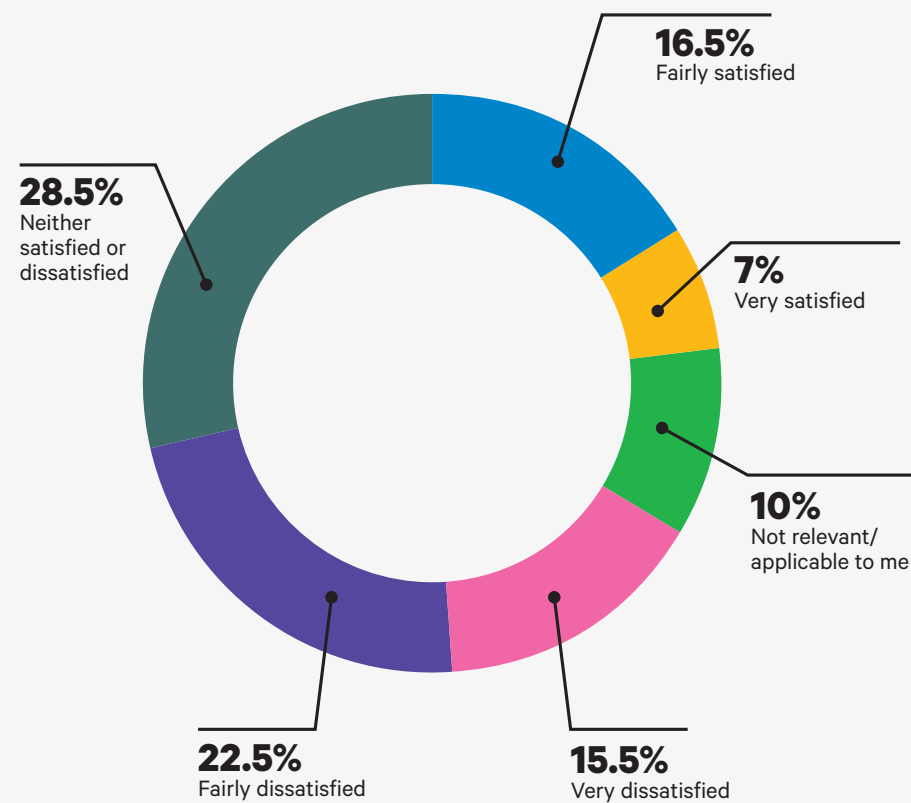
Satisfaction levels

38% of respondents were dissatisfied with their current treatment. Although the majority of survey respondents felt that they were to some extent involved as much as they wanted to be in decisions about their care and treatment, 1 in 5 respondents felt otherwise.

For some focus group participants, the absence of a diagnosis was a barrier. As one woman said, **"without a diagnosis it's hard to get access to information and to get taken seriously."**

"I FEEL THAT GPs, NURSES, ETC DON'T REALISE HOW MUCH PAIN YOU'RE IN WITH ARTHRITIS AND HOW MUCH IT AFFECTS YOUR LIFE."

Generally, how satisfied are you with the level of support you receive from the health and social care professionals you interact with?



The focus groups elaborated more of the complexity of the experience of information and support services. Although the role of the GP was often seen as helpful, there was concern expressed that GPs could also be a barrier to accessing support. For example, one parent carer (of a child with Junior Idiopathic Arthritis) talked about the local nursery as the key support, taking time to understand their child's condition and putting in place personalised support, including a GIRFEC child plan, and trained nursery workers. Paediatric nursing support was also key but, in this case, the GP's approach was seen as more cursory and one-sided.

Participants talked about needing help to find information and services. People we spoke to understood that information itself is not enough - it needs to be understood in relation to their own circumstances and how it can support them to engage with change. As one man said, **"it would be good if I had someone I could contact to ask about my health and how to manage my conditions."** Link Workers were mentioned as a vital connection to support. Peer support through local support groups was raised by some.

Over half of respondents wanted information about how their condition would impact their future. **44%** wanted to know about medicines/therapies, and around a third wanted self-help related information, e.g., on diet and exercise.



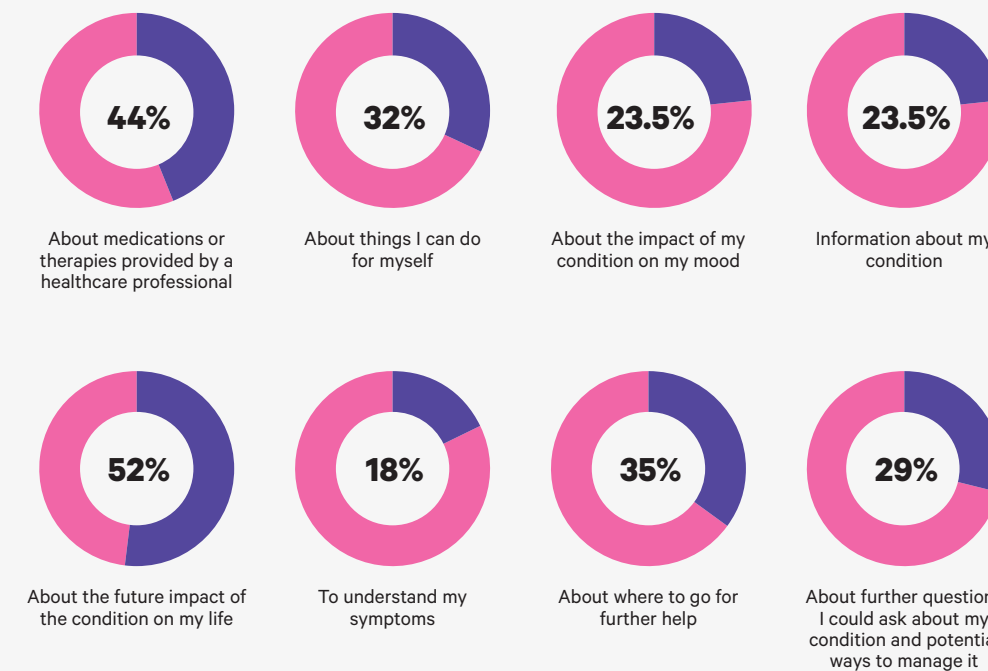
"BUSES (ARE) LIMITED AND DON'T JOIN UP WITH PEOPLE'S NEEDS LOCALLY".

In the focus groups, when participants talked about access to support, they would often frame it around transport issues quoting **"long travel times"**, **"limited public transport"**, and the need to **"improve the infrastructure"** as **"buses (are) limited and don't join up with people's needs locally"**. For many communities in Argyll, ferries are an essential part of travel, including to and from appointments. This was described as **"challenging"**, especially for non-drivers. Some thought that having personal transport was essential to accessing services. Also, worth noting that, apart from Oban-Glasgow, there is no train network in Argyll.

In this rural context, online access was considered important, but not everyone can readily access online options and there were differing views on the digital trend. The switch to digital-only access to services was an issue for some focus group participants, but for others it meant less travel for appointments and increased accessibility. They also mentioned the ability to email their GP for any queries they had as particularly helpful.

Online searches were used by **60%** of survey respondents and the NHS Inform website was used by just under half of respondents. The third sector accounted for around a third of information sources.

Thinking about your joint pain right now, which of the following types of information would you say you have the greatest personal need for / interest in at the moment?



DISCUSSION

Living with pain had an impact on people's confidence, with 70% of survey respondents saying they lacked confidence in their daily life due to pain. This, in turn, may have undermined their ability and willingness to share and articulate how they were feeling, with comments like, **“you just learn to live with it”**, and **“there are people worse off than me”** suggesting a capacity for self-censorship. Both the survey and the face-to-face work indicate that many are living with pain which they feel very little influence over. One person commented, **“They throw painkillers at you”**, while another had been told, **“there is nothing else we can do for you.”** However, this capacity for disengagement was reversed when there was confidence that, when they did share their concerns, they would be heard. As one of the respondents said, **“When people believe me, it really helps”**.

The need for mental health support came up frequently as people described the impact of living with long-term pain. For some, being able to see beyond the present moment was difficult: **“I am terrified what the future holds for me.”** A quarter of those who completed the survey said they wanted to understand more about the effect of chronic pain on mood. In the focus groups, participants talked about isolation and loneliness, particularly when shielding, and the impact on their mental health. Some experienced a loss of social and peer support. **64%** said they felt unable to change their experience of pain. That lack of agency can have a real impact on mental health.

**“YOU JUST
LEARN TO
LIVE WITH IT”**

**“I AM TERRIFIED
WHAT THE FUTURE
HOLDS FOR ME.”**



“THE PANDEMIC HAS MADE ALL OF THIS MUCH WORSE. I'M IMMUNO-COMPROMISED, BUT EVEN THE DOCTORS THINK I'M USING A MASK BECAUSE I'M 'ANXIOUS'. MORE AND MORE PLACES REMOVE PROTECTIONS, LESS AND LESS PLACES I CAN GO TO SAFELY. UNTIL WE CHANGE ANY OF THAT AND MAKE IT SAFER AND EASIER FOR PEOPLE LIKE ME TO EVEN EXIST AND THRIVE, NOTHING WILL CHANGE. I WON'T HOLD MY BREATH...”



On self-management, the key concern that emerges is that living with pain has undermined people's confidence to self-manage, and that the basics of self-management – staying active, community connectedness, and being able to access resources for daily living – are absent or limited in many cases. Addressing this confidence gap and supporting people emotionally as well as linking them to information and resources is fundamental to the development of services and support in Argyll.



There were specific concerns around support for weight management, which was seen by several respondents as a negative experience – **“I have done more damage trying to starve myself down to a weight where doctors felt I was worthy to treat”**. In the context of **three quarters** of respondents feeling challenged in trying to do low impact exercises, and the overall lack of confidence in dealing with pain, this is an issue that needs particular attention, especially for those who are waiting for joint replacement surgery.

A free text section in the public survey was particularly helpful in highlighting the impact of the pandemic, and foregrounding themes of recovery – access to services, loss of self-confidence, fitness, and wellbeing. For some this related to the loss of face-to-face services and having to negotiate their way through the virtual alternatives. For others, it was their continued vulnerability in a ‘post-Covid’ society. Some had just had a diagnosis and the pandemic disrupted access to professional support.

BUILDING BLOCKS FOR IMPROVEMENT



Self-Management

What people say they need:

- Increased access to activity-based support, including walking groups and access to local pools
- Improved support for weight management
- Peer and group support to build confidence and improve self-management

How to get there:

- Chronic Pain services and support to be part of the Argyll & Bute Living Well Strategy
- Identify cross-sectoral opportunities to supporting people with chronic pain through the Argyll & Bute Healthy Living Partnership

Work

What people say they need:

- Support to work and support at work.
- Pain services should include employment support

How to get there:

- The Living Well strategy partnership should consider developing a 'working well' strategy, which would incorporate key information and best practice to support people dealing with the challenges of chronic pain at work.

Travel & Transport

What people say they need:

- Services need to recognise that:
- Access to services is often dependent on access to transport.
 - Travel to and from an appointment can take a full day, or more.
 - Public transport can be unreliable.
 - Fuel costs are going up.

How to get there:

- Consolidating or establishing links between chronic pain services and patient transport, community transport and volunteer car schemes will help to support people access services and support
- Digital pathways to support access to primary and secondary care-based pain services.

Services & Support

What people say they need:

- More holistic approach by GPs and improved continuity of care
- Continue with blended ways of working, including phone and email access to GPs
- Joined up services

How to get there:

- Healthcare Professionals (HCPs) to develop pain-informed practice through use of the Pain Informed Toolkit being introduced as part of the Framework for Pain Services
- HCPs in Argyll to contribute to the development of the new Knowledge Hub on Chronic Pain
- Embed the Knowledge Hub in healthcare practice across Argyll
- Ensure that healthcare professionals have access to information on community resources for appropriate referrals
- Commitment to partnership through the Living Well strategy steering group and the healthy living partnership

Mental Health

What people say they need:

- People need to be able to connect to third sector and community resources, which can support their mental and emotional health
- Focus on building self-confidence and support for emotional wellbeing

How to get there:

- Strengthening community-focused approaches, including third sector and community-based services, will help to support the mental health and wellbeing of people living with chronic pain in Argyll. The Living Well Strategy is key to this and the forthcoming Mental Health & Wellbeing Strategy, due to be published by the Scottish Government in Winter 2022, offers an additional impetus to making improvements in Argyll.

COVID recovery

What people say they need:

- For some, the feeling of being vulnerable continues. For others, a lot of ground still needs to be made up - fitness, mental health, confidence, etc.
- Services need to take all of this into account

How to get there:

- Recovery is a key theme for services and for people and should be reflected in planning and provision of chronic pain services. This means a focus on pre/rehabilitation and access to mental and emotional support, including peer-led support.

CONCLUSION

At the heart of what people told us is that they lacked confidence to manage their pain effectively, and they lacked confidence because of their pain. Their capacity to engage in daily activities, including using public transport and remaining physically active was, for many, seriously diminished by their experience of pain, reinforcing a sense that there was little they could do to change things. Breaking that circle of negative reinforcement is key to improvement.

The Scottish Government's Framework for Pain Management Service Delivery is a stimulus for improvement and innovation across Scotland and should be a focal point for generating new approaches in Argyll & Bute. However, the strength of partnership work in Argyll & Bute through, for example, the Healthy Living Partnership is the main building block to sustained improvement, rooted in an understanding of communities and the role of the third and community sectors. Ensuring that clinical pathways support self-management; that social prescribing is front and centre of health and social care; understanding the balance of local/regional/national and the reality of how people access services and support; growing capacity, based on shared commitment. It needs partnership to drive these.

Versus Arthritis was and remains a key partner in the development of the HSCP Living Well Strategy and its implementation in Argyll and Bute. We located one of our UK Touchpoint/Together Versus Arthritis sites in Argyll & Bute because of the strength of our presence. For the same reason, the Pain People Place project chose to focus on Argyll, as we know that the work here can have an impact. Building on the insights from this report, and to ensure that lived experience helps to drive positive change, we will work with the Health & Social Care Partnership, the Healthy Living Partnership, and others to develop information and support for people living with chronic pain. This will include our own commitment to chronic pain events, self-management programmes, and support for physical activity. We will continue to campaign on the issues that matter to people living with arthritis-related pain to ensure that they have access to the services and resources they need. This means investment in and enabling of communities to have the building blocks and local assets to thrive, leading to accessible and sustainable services, which address the issues of health inequalities across remote, rural and island communities.

We conclude this report with a story of a toddler living with chronic pain as the result of Juvenile Idiopathic Arthritis. It's told by his mother, Lauren, in a conversation with our project consultant, Audrey Birt.

The story isn't illustrative of all the issues highlighted in the report; it connects with many of them, but it's a personal story, providing insight into the experience of pain in a family in Argyll.



LAUREN'S STORY

'HE HAD TO LEARN THE LANGUAGE OF PAIN.'



Lauren is the mother of two four-year-old twin boys who were keen to play a walk-in part on our session together. Her patience and firm kindness gave a glimpse of her skilled parenting. A mother of twins must have stamina, creativity, and endless patience to survive each day. In Lauren there is a deep wisdom too, some of which it seems likely has been gained in recent years when she's had to learn to be not only a parent to one of her sons, but to have so many other roles too. She and her husband have had to be advocates, nurses, therapists and even negotiators whilst watching their child suffer pain, something no parent ever wants to do. Lauren has even had to teach her sons to describe pain as well as other emotions. This was really driven by their intuition as parents. They looked out a body book and spent lots of time talking about different body parts and different feelings, both physical and emotional, to give Roghan and his twin, the tools to tell them what was going on for them.

I have a grandson of a similar age and had to swallow hard as she described introducing her twin boys to the book called Ouchie so her boy, who was so clearly struggling, could find new words to tell her of his pain.

I needed to understand where this all started. There will be tears, she warned. She spoke of how her two boys changed from very active participants in long walks around their locality; a locality, as is much of Argyll, whose beautiful landscapes invite exploration and fun. It was the start of lockdown and like so many they were at home, without work or income. So, they were out together as a family. Even at such a young age, the boys could cover many miles. But then one day, Roghan couldn't manage. He was struggling to keep up and then the next day started to limp.

Perhaps they'd just gone too far that day? It was when they noticed some knee swelling that they took him to the GP. They were initially reassured but went back shortly afterwards as his knee had ballooned. Eventually they were sent to A&E in Glasgow, 90 miles away, and a more than two-hour journey over a mountain pass. They will be waiting for you, they were advised. They weren't. It's maybe a toddler fracture they were told. It wasn't. Cue much anxious googling on their part and finally they saw a rheumatologist.

Roghan was admitted to hospital, at the peak of the pandemic, so only Lauren was allowed to visit and stay. Her husband and her other son waited outside. He finally got a diagnosis of polyarticular juvenile idiopathic arthritis. A powerful combination of steroids and methotrexate (a drug also used in chemotherapy for cancer) was prescribed as many of his joints were affected by then. It took time to see any improvement. In fact, it was only after a series of steroid injections were given into the joints that the swelling started to reduce. They were still being told he could grow out of it, something they could hardly hope for as they had witnessed his sudden decline and dreadful pain and fatigue.

It was such a difficult time. Their son was so unwell, immunocompromised during a Covid-19 pandemic, which could have devastated him further. It was a time when death tolls were rising and any vaccines or treatments far from certain. Hospitals were a place of great risk and yet for Roghan, a necessity. The deep worry about his condition was made worse by concern about the cost of overnight stays, transport, and keeping a household together while unemployed. It was a time of deep uncertainty about the future and how all of them would cope.

A couple of years has now passed and some of the rawness has healed, but the sense of distress still permeates throughout the telling of the story.

Interestingly the one thing Lauren found so unhelpful was being told to remember to have hope that there would be a full recovery. It was so very hard to be hopeful in the face of such pain and trauma. The more she read up on the condition the less she believed in the full recovery. Experience of others suggested he was more likely to be looking at a long-term condition. Comments such as *'But he's so much better'* by health professionals were out of step to parents still mourning their healthy active boy and grieving about an uncertain future. Their home wasn't suitable and so they moved to a bungalow. While a positive move, it was also isolating. Transport is irregular and unreliable for such communities, so reaching out for support and being able to work is difficult. The boys by this time were in nursery, but for Roghan the need for rest and recovery meant frequent requests for Lauren to collect him and take him home. His dad's work was too far away, although he had the car, which meant Lauren had to get there and home by public transport.

Lauren talked a lot about fatigue, which is common to many people living with persistent pain. She cautioned, however, that this is about more than the impact of a lack of sleep. Fatigue is mentally draining and can embed itself in the day to day; catching up with sleep won't shift the longer term impact.

Lauren was open about the role that professionals have played in her family's life since her son's diagnosis. The GP practice was not particularly helpful. In small communities, the options are generally, 'take it or leave it' and unlike in a city or town there are no real alternatives. However, others were helpful. The Occupational

Therapist (OT) helped so much in day-to-day life. She even lay on the floor with the boys while role playing, helping them make sense of their new reality. The speech therapist was involved but the physiotherapist helped them understand the needs of the children. The parents especially appreciated the holistic approach, organising with the OT for Roghan to access to a Theraplay trike, which is designed to enable all children to be able to cycle and which made such a difference for Roghan.

The Health Visitor was *"a star who really listened"*, who held them through it all and who coordinated so much of their support as well practically helping them to get Disability Living Allowance and Carers Allowance (although it took a year).

As any parent of a disabled child will testify, there are many professionals involved in their support and care. With every trip to specialist services meaning a round trip of six hours with a child in pain, a locally organised GIRFEC* approach, which the health visitor worked hard to establish, has become a huge support. So many people involved can result in confusion, contradiction and can be overwhelming. GIRFEC ensures team-based support, and there is now a coordinated approach with the Roghan and his family at the centre.

And at the heart of this coordinated approach is, according to Lauren, listening. Saying, *"keep positive"* and, *"but he's so much better"* isn't helpful when his pain remains poorly controlled; listen and help the family set realistic expectations. The family needs realism not blind optimism. But most of all, they need to be heard. Even with the complexity of the situation she's been dealing with, Lauren's main message is deceptively simple, "please listen".

***Getting It Right For Every Child**

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