Pain Café Implementation Toolkit

Learning from the implementation of pain cafés in the South West of England

June 2025

Health Innovation South West

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1. Introduction

About this document

This document sets out an approach to implementing pain cafés and aims to provide practical insights to systems and places wishing to implement pain cafés. Pain cafés are informal and non-medicalised sessions aiming to support people living with chronic pain, using non-medical pain management techniques in a supportive, non-judgemental peer group. It shares learning, insights and tips from those already implementing pain cafés as a new way of supporting people to manage their chronic pain in the South West of England, namely in Cornwall, Devon and Somerset. Pain cafés are a simple and inexpensive model that can be replicated in other areas.

The information is likely to be relevant to health and social care colleagues who support people living with chronic (non-cancer) pain in Integrated Care Boards (ICBs), primary, community, and secondary care, and to voluntary and charity sector organisations.

With thanks to Cornwall Connected by Pain and Imagine If, Cornwall and Isles of Scilly ICB, Chronic Pain Coaching CIC, Devon ICB, Somerset ICB and Rural Practice Network in Somerset, whose contributions and insights have informed this document.

Opioids deprescribing – the national context

NHS England's national Medicines Safety Improvement Programme[1], sets out the rationale for improving chronic non-cancer pain management by reducing harm from opioids:

> *Management of 'chronic non-cancer pain' requires personalised care and shared decision making at its core with patients requiring a mixture of biopsychosocial support so that they can live well with pain. Opioids are a highly effective class of analgesics and, when used judiciously, are of great benefit to many people living with pain. However, in the case of 'chronic non-cancer pain', when the source of long-term pain does not have a cause that can be treated, opioids can do more harm than good with 10% of drugs prescribed being unnecessary, inappropriate and could cause harm including premature death[2], particularly when used at higher doses.*

1. Further information can be accessed here with an NHS login: https://future.nhs.uk/MedicinesSafetyImprovement/view?objectID=29313040
2. Government 2021 National Overprescribing Review, https://www.gov.uk/government/publications/national-overprescribing-review-report

The Faculty of Pain Medicine has advised that increasing opioid load above ≥120mg/day morphine equivalent is unlikely to yield further benefits but exposes the patient to increased harm.[3] Despite this, PHE's review (2019)[4] showed that in 2017 to 2018, 540,000 adults in England were prescribed opioid pain medicines for 3 years or more. The effects of COVID-19 are anticipated to have exacerbated the use of opioids for chronic pain, which is linked to both deprivation (including homelessness[5]) and the prevalence of mental health conditions such as anxiety.

There is a growing number of people who are being supported to manage chronic pain and are awaiting diagnostics or surgery. Primary care prescribing data shows that since the beginning of the pandemic there has been a 27% increase in the number of patients who are prescribed opioid analgesics for longer than 3 months[6], the limit recommended by The Faculty of Pain Medicine. This increases the risk of long-term dependence which is strongly associated with increased mortality.

We estimate that for every 62 patients with chronic pain who can be supported with alternatives to long-term opioid analgesia, 1 life can be saved. Unchecked, it is predicted that around 6,000 people a year will be hospitalised with adverse events whilst taking opioids for extended periods.

Emerging evidence shows that biopsychosocial pain management initiatives such as pain cafés, can offer healthcare professionals and people living with chronic non-cancer pain a person-centred alternative to new opioids prescribing and may support deprescribing for patients already taking opioids.

People with chronic pain are hospitalised nearly three times as often as the general population[7], and the NICE Chronic Pain Clinical Knowledge Summary (2024)[8] states that people in chronic pain, defined as pain that persists or recurs for more than 3 months,

3. BMA [Online] Available at: https://www.bma.org.uk/media/2100/analgesics-chronic-pain.pdf
4. Prescribed medicines review: report - GOV.UK (www.gov.uk)
5. https://groundswell.org.uk/our-approach-to-research/peer-research/out-of-pain
6. Catalyst services NHSBSA Medicines Safety PAIN03
7. Fayaz A, Croft P, Langford RM, et al. Prevalence of chronic pain in the UK: a systematic review and meta-analysis of population studies. BMJ Open 2016; 6:e010364. doi:10.1136/bmjopen-2015-010364; https://bmjopen.bmj.com/content/bmjopen/6/6/e010364.full.pdf
8. https://cks.nice.org.uk/topics/chronic-pain

should be offered a biopsychosocial assessment, offered a supervised group exercise programme, encouraged to remain physically active for longer-term general health benefits, and offered self-management advice.

The biopsychosocial model is a general model positing that biological, psychological (which includes thoughts, emotions, and behaviours), and social (e.g., socioeconomical, socioenvironmental, and cultural) factors, all play a significant role in health and disease.[9]

What is a pain café?

In response to high levels of chronic pain in the rural and coastal communities of the South West of England, pain cafés have been co-created with people with lived experience of pain and implemented as a tool to support patients with effective pain management.

Pain cafés are a biopsychosocial self-management intervention that draws on evidence-based pain management approaches, often using resources developed by clinicians[10]. Pain cafés are informal sessions aiming to support people living with chronic pain, using non-medical pain management techniques in a supportive, non-judgemental peer group.

Pain cafés aim to provide an informal, accessible and safe psychological space, where people can develop confidence to talk openly about their health, be heard, respected and validated, feel supported by their peers and develop techniques to manage their pain and well-being. This helps people to develop the capabilities, opportunity and motivation to change behaviour, as well as improve their social engagement and psychological well-being. In turn, this has the potential to reduce levels of medication and visits to a GP, health services and emergency admissions to hospital.

Pain cafés provide support for both pain management and other aspects of people's lives, supporting people to feel more empowered to manage their own pain and experience. Sessions are run by people with pain management training and/or experience of chronic pain, including people with lived experience or social prescribers. Practitioners who introduced pain cafés in the South West place a strong emphasis on the social aspects of the model, preferring to speak of it as a "socialpsychobio" approach to highlight the peer and community-based aspects.

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9. Engel GL. The need for a new medical model: a challenge for biomedicine. Science. 1977 Apr 8;196(4286):129-36. doi: 10.1126/science.847460. PMID: 847460.
10. Resources include: Live Well With Pain's Ten Footsteps programme, developed in partnership with Durham University (https://www.durham.ac.uk/research/institutes-and-centres/wolfson/research/challenge-academies/pain-academy); Back Skills Training Implementation (iBeST) — Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (https://www.ndorms.ox.ac.uk/rrio/ibest);

Pain cafés can be accessed by anyone living with a chronic pain condition at any point in their pain journey, and irrespective of a diagnosis. They are not suitable for people living with acute pain and who are expected to get better in the short term (3-6 months), nor for those with complex and chaotic lives, or who may need more clinical advice and guidance. Where people in these circumstances self-refer, links to clinical services can facilitate access to appropriate care.

Pain cafés in the South West of England

Health Innovation South West's Medicines Safety Improvement Programme is focused on improving the care of people living with non-cancer chronic pain by reducing the prescribing of high-risk opioids. We are supporting systems to adopt a whole-system approach to reduce harm from opioids by bringing together networks, partners, social prescribers and the voluntary sector to leverage opportunities in the system that can facilitate a cultural change around the safer prescribing of opioids.

In Cornwall, 20 Primary Care Networks now either run pain cafés or are planning to. In Devon, 10 pain cafés are running in and around Plymouth with several others emerging across the county including in Dawlish. In Somerset, a system-wide approach is being taken by Somerset ICB, building on individual examples of pain cafés in Somerset.

Emerging insight from the South West of England shows that this has been shown to lead to improved well-being through reduced pain scores, isolation and psychological distress, a reduction in pain medication, along with a greater social engagement. Initial figures highlight the potential positive impact of pain cafés on individuals' pain management and overall well-being. However, more data is needed to fully understand the long-term effects. For more information see the Impact and Data section on page 18.

2. Setting up a pain café

Top tips/lessons learnt

From ICB perspective:

- It's key to have someone providing leadership in order to bring different areas on board with the approach.
- COPD was being under-diagnosed due to a lack of spirometry testing.

From social prescriber perspective:

- Use community venues to ensure a non-medical, "skills not pills" approach. Medical settings can sometimes put people off.
- Peer support is the overwhelmingly important factor in pain cafés – a nurturing, safe space for people to share.
- Ensure that focus in the sessions is positive - not focussing on how much pain people are in. Group facilitation skills can help to keep individuals and the group in a positive space

From Voluntary, Community and Social Enterprise perspective:

- Set up clear links to Primary Care Network and surgeries to support referrals and collaboration.
- Build links to other VCSE groups and forums such as your local voluntary sector forum.
- Use social media to publicise your pain cafes and reach people who can self-refer.

Introduction

To set up a pain café you will want to shape the offer to suit your context and the people who will participate. Depending on the type of organisation you represent, you may also need to develop a business case or project proposal. The following sections will introduce you to a range of factors to consider as you set out what you're trying to achieve, and to get your pain café up and running.

Assess local need

Understanding your local context, including your population and their needs will help you to shape your pain café. Local data and insights, as well as your Integrated Care Board (ICB) ambitions and projects, will help you to ensure that your Pain Café is based on the need of the communities your service/practice/Primary Care Network serves.

Sources of information:

- Patient and Public Involvement and Engagement (PPIE) groups or Voluntary, Community and Social Enterprise (VCSE) organisations operating in the area, or PPIE insight documents to understand barriers and opportunities around accessing pain management support
- Integrated Care Board priorities
- Local knowledge of your area and characteristics of your patient population
- Availability and waiting times for pain management clinics or other local pain management services
- Potential data sources and tools to access this information include:
  - Epact2
  - Catalyst Medicines Safety Dashboard (PAIN03)
  - Open Prescribing
  - NHSBSA Opioid Prescribing Comparators dashboard
  - PrescQIPP
  - English Indices of Deprivation
  - SHAPE Place Atlas and Evidence Hub

What to look for:

- Size of population and expected prevalences of chronic pain. How many people in your population have chronic pain or associated diagnoses such as fibromyalgia?
- Are there high levels of opioids prescribing, in number of prescriptions, length of prescription, and high-dose prescribing?
- Consider local variation – are there certain areas (e.g. in the Integrated Care System) with particularly high opioid prescribing? Does geography or poverty mean that certain areas are underserved or have greater need?

- Can you identify any distinguishing features about the cohort? Are there patients who should be prioritised for support?
- Are there unusual or unexpected figures or trends, compared to neighbouring practices/Primary Care Networks or nationally, relating to:
  - Referrals for pain/functional neurological disorder(s)
  - Referrals to social prescribing or health and well-being teams for pain or related conditions
- Can you identify any health inequalities, such as disparities in prevalence, access, outcomes or healthcare usage related to certain populations? If so, which barriers to accessing pain management support could be contributing to these health inequalities?
- Are you aware of existing services in your community, including VCSE services, that serve people with chronic pain?

Outputs from this work:

- Summary of key insights/data about your population and those you are seeking to reach.
- Identification of potential cohort(s) of patients for whom a pain café could be beneficial.
- The challenges for people with chronic non-cancer pain in the area.
- What are you trying to achieve? For who, why?
- How a pain café can make a positive difference to the community you serve.
- How a pain café could help people overcome barriers to healthcare.
- How the proposed pain management approach relates to relevant ICB priorities and activities, as well as national, local, and your community's priorities?
- Health inequalities relating to patients with chronic non-cancer pain and patient identified barriers to pain management offers.
- Where a pain café would be best located.

System collaboration

Cross-system collaboration brings together stakeholders for mutual benefit and to facilitate a more joined-up service. Pain cafés have the potential to not only enable people to manage their pain more effectively, but also positively impact capacity in local GP surgeries, services delivering functional neurological disorder services, and pain management courses/clinics, as well as to deliver on ICB and national medicines optimisation opportunities on opioids deprescribing. Collaboration can be facilitated by sharing both up to date information about how a non-medical model can benefit patients and the insights you have developed when assessing local need.

Particularly for ICBs working to improve non-cancer pain management by reducing harm from opioids, the 7 Phase Whole System Approach Framework (Future NHS requires an NHS account to access) developed by the national Medicines Safety Improvement Programme may be useful. Although not specific to pain cafés, systems collaborating to set up pain cafés may benefit from the approach and tools made available.

The following sets out elements to consider for anyone considering how to work collaboratively in their place:

1) Identify people and organisations to involve. This could include:

- GP practices and Primary Care Networks: GPs, Nurses, Social prescribers, Health and Wellbeing coaches, Care Coordinators, Pharmacists, Practice/PCN Managers.
- Secondary care: Psychiatrists, Psychologists, Service leads for pain/functional neurological disorder services,
- Integrated Care Boards: Leads for supported self-management, personalised care, pharmacy, medicines safety/optimisation, voluntary sector partnerships, long term conditions, aging, self-enablement, health coaching,
- Community-based organisations: Charities, community interest companies and voluntary sector organisations, such as those already running wellbeing or health offers in the community, or with an organisational focus on a particular community of interest or geography you wish to engage.
- Regional organisations, such as your local GP Training Hub or Local Medical Committee or Local Pharmaceutical Committee.
- Data experts, who can help with data gathering and analysis.

2) Understand where pain cafés fit into the patient journey or pain pathway to facilitate collaboration and target resources. Pain cafés have the potential to support people

throughout their pain journey alongside referrals to e.g. pain management clinics and following any specialist intervention. Working together across the system can facilitate referrals, enable data sharing to demonstrate impact, and it could release pain specialists to deliver care to people with more complex needs. Social prescribers and health coaches may also be able to work with up to 20 people in the time otherwise spent seeing 2-3 people.

3) Set out a collaborative vision and shared purpose for what the project will achieve. Some places have found logic models and/or driver diagrams useful to create a shared visual understanding. View an example logic model in the Impact and Data section below.

- System mapping: Who has an interest or is delivering work in pain management locally and possibly nationally? Who is willing to share their experience and develop the approach?

- Identifying assets, skills, relationships, and resources you and system stakeholders can draw on for the delivery of this work. This could include protected time to develop the approach, staffing resource, expertise and knowledge, relationships with community organisations or other healthcare providers, funding, etc.

- Collaborative meetings: Bringing together healthcare system stakeholders in your place can shape and position the pain café in a way that meets local need and can ensure people are aware of the pain café, understand the potential benefits to their patients and how to refer to it. Collaborative meetings can also agree the model of pain cafés that will be used, how people will be trained, and identify impact metrics to collect as a system.

- Community of Practice: A recurring series of collaborative meetings for those managing and delivering pain cafés to share knowledge, best practice, experiences, peer support, troubleshoot challenges. ICBs are often well placed to run a Community of Practice.

- Pathway map: You can together create a visual map of a person's pain journey showing touchpoints with the healthcare system, and perhaps also community offers. When in that journey will the pain café be of benefit? When and how do people move between which healthcare offers and pain cafés? Can you improve coordination?

- Evidence base: Both sharing evidence of the impact of pain cafés and collaboratively gathering evidence can facilitate joint understanding and ability to demonstrate impact of your work to others. Evidence could for example include patient impacts (self-management) and GP/healthcare usage. See the Impact and

Data section below for more information about evaluation and existing evaluation resources.

- Business case: Securing funding for a pain café is key, and some organisations will need to produce a business case. Any business case should provide as strong an evidence base and rationale as possible, including insights developed through the above section on assessing local need and any positive outcomes including reductions in prescribing of e.g. opioids. A business case can secure longer-term funding for delivery and for collaboration through for example pain café champions and communities of practice.

CASE STUDY #1

In the South West of England, development of pain cafés has mainly been led by **voluntary and community and social enterprise** (VCSE) organisations or **primary care staff upskilling with pain management skills**, some working in partnership with secondary care partners. We have also seen psychological services in secondary care work to set up pain cafés by utilising existing staff resource in community-facing roles. These pain cafés benefit from the close links and understanding that the people in these roles have into the communities they serve and deeper expertise in delivering psychological interventions. **Social prescribers and health and well-being coaches** are well placed from within primary care to bridge clinical care into the community via pain cafés. **Integrated Care Boards** have collaborated with and learnt from these initiatives to develop ICS-wide system integration, ways of working, and resources, strengthening impact and system collaboration.

Cornwall

Applying a "skills not pills" approach, pain cafés were developed in Cornwall through a cross-sector partnership, Cornwall Connected by Pain, between community interest companies Imagine If and Kernow Health, Cornwall and Isles of Scilly ICB, Royal Cornwall Hospital Trust Pain Clinic. Through a strategic collaborative group, they bring together the organisations' priorities and insights of local need, the team designed and developed online and face-to-face pain cafés, supported Primary Care Networks to run their own pain cafés, and currently offer a Community of Practice to facilitate shared learning.

Funding

When setting up a pain café, we recommend you consider the funding required for:

- Development work: This could include the time and resource needed to project manage, develop skills and train facilitators, build links and collaborations, review data to identify those who will benefit as part of assessing local need, develop a model that works for the relevant population, and many of the other elements in this guide. Depending on your type of organisation, this could be on a very local level for one pain café, for a cluster of pain cafés in a Primary Care Network, or across a whole ICB, and could be simply to develop the model, or for larger projects, involve ongoing collaboration and development.

- Operational costs: Staffing to manage and deliver the pain cafés including paid external partners who contribute to delivery e.g., movement sessions, room hire, refreshments, printing and any other resources required.

It's advisable to consider whether your pain café is a time limited offer, and how ongoing sustainability could be secured. This could be through upskilling staff in existing roles that are funded, such as social prescribers or health coaches. If you intend to test the approach with a view to developing a business case for longer term funding, then be clear on what you want to achieve. This can help you to set the pilot's parameters and requirements to ensure you gather any impact data and evidence you might need to make the case for future funding.

Funding sources for pain cafés vary. In the South West, a lot of the initial funding for pain cafés has been one-off grants to VCSE organisations. Organisations making grants have been ICBs, Primary Care Networks, charitable trusts including national (such as the National Lottery Community Fund and Queen's Nursing Institute), local, and thematic (such as agriculture focused for farming communities).

In some instances, funding can come from a Directed Enhanced Services (DES) contract with Primary Care Networks if reducing health inequalities is identified within it, through for example a social prescribing role or other mechanism to fund the pain café.

Many external partners who contribute movement-based activities, such as chair-based yoga or tai chi, are volunteers in the local community, but some receive payment.

Some pain cafés ask for a nominal contribution such as £0.50 for refreshments or voluntary donations of £2.50.

Ways of delivering pain cafés

The logistics

Many pain cafés run monthly, although some of those delivering pain cafés would like to deliver them more regularly to meet need and facilitate peer support longer term. Suggested number of pain café attendees is between 8-20 to facilitate quality conversations.

Pain cafés are mainly run in person in community (non-medical) settings such as community halls, village halls, or health hubs. Some pain cafés have been run online to provide access for patients who are unable to attend in person due to rurality, timings, or mental or physical barriers. These are delivered using online meeting tools like Zoom or Teams.

The social nature of pain cafés is important to their success. Setting up the venue to be welcoming and ensuring someone is on hand to provide a friendly welcome to each participant can ease people into the pain café. Providing tea, coffee and biscuits gives the sense of a social experience, and providing a comfortable temperature of the room, comfortable chairs, and a café-style setup of the venue further sets people at ease.

Knowing your local health inequalities and the barriers people have to accessing healthcare can support people to attend. For example, considering the time of day you deliver the pain café, venue location, bus routes, and the need for community transport. A separate and sound insulated room can help people to hear better and also allows people to share confidential matters. Also pay particular attention to patients who do not traditionally access healthcare and whether they might benefit from this offer and how.

Targeted pain cafés. Pain cafés tend to be delivered to anyone who signs up. Some pain cafés have successfully been set up for veterans, often in partnership with VCSE organisations who provide wider support to veterans. Pain cafés generally cater to mixed gender groups, but some people setting up pain cafés have considered whether females or males might feel more comfortable sharing with others of same gender.

There are a number of referral routes for people to attend pain cafés, with some pain cafés seeing only self-referrals and others a mix of professional referrals and self-referrals. Making sure that relevant organisations are aware of the benefits of the pain cafés and how to refer to them is crucial.

Promotion of pain cafés helps spread the word. **Self-referral** can be based on promotion on social media and posters in local community venues (e.g. where delivery takes place), and in GP surgery waiting rooms – as well as word of mouth. Cross-sector relationships can facilitate self-referrals, for example **community organisations** sharing information with

their mailing lists or through referrals, and in some places the Department for Work and Pension are also engaged to make referrals.

In **primary care** some pain cafés are built into referral pathways, with for example GPs making referrals to a social prescriber or directly to the pain café. Other referrals in primary care come from nurses, social prescribers, and health and well-being coaches. In Glastonbury, Somerset health coaches and health connectors work in surgeries 2.5 days a week and have a close relationship with reception staff who support 80% of their referrals. Some Primary Care Networks send invite texts to patients, which could be done using bulk texting systems such as Accurx.

In **secondary care** referrals are seen from colleagues in functional pain, pain clinic teams, community nurses, psychologists, psychiatrists, pain management clinicians, and MSK teams.

Consider organisational health and safety procedures and approaches, as well as those relating to the venue hosting the pain café. You may want to consider whether there is life-saving equipment such as a resuscitation device at the venue.

Workforce and skills for delivery

Pain cafés have been set up and delivered by social prescribers, health and well-being coaches, people with lived experience of pain, as well as secondary care staff coordinating care flow and delivering pain management support in the community. The majority of pain cafés are delivered by paid members of staff as part of their role in the NHS or with the community interest company or the charity they work for, although some pain cafés are facilitated by volunteers.

Lived experience of pain Some pain cafés receive volunteer input, alongside paid members of staff, from people with lived experience or ex-NHS nurses, for example. Some volunteers are previous pain café attendees who have been upskilled to facilitate or contribute to the sessions. Learning experience, non-didactic, peer connection.

Facilitators should have pain management knowledge based on clinically evidence-based training or resources. This includes goalsetting, acceptance, movement and other approaches and tools. This knowledge could be gained from their local pain clinic or from online resources; see Resources section towards the end of the document.

Facilitators do not need to have clinical or medicines knowledge, but some pain cafés based in a Primary Care Network or Secondary Care can access and update patient records and have **access to clinical guidance from a GP** during setup and oversight or support for specific issues if needed. Access to a pharmacist can also support people with

a medicines review. Pain cafés run by the voluntary sector have built links with local GPs and Primary Care Networks and can make referrals to a GP or other roles.

Group facilitation skills can support those running pain cafés to have the confidence to run a pain café and deliver their knowledge to a group.

Accessing training and skills development

Currently in the South West, the models for training are to upskill staff in pain management and group facilitation through either a) training individual staff or b) through a train the trainer approach commissioned by the ICB. Several organisations deliver training and/or make resources. You can access more information about this in the Resources section.

Things to think about:

- Which organisation and which staff roles would be best suited to developing and delivering pain cafés?
- What skills development model would suit your area or across your ICB?
- How many staff need to be upskilled to make this a sustainable service – and how will you retain the knowledge in the system over time?

CASE STUDY #2

Somerset ICB initially funded social prescribers and staff in Somerset Activity & Sports Partnership (SASP) to access pain management knowledge through Live Well With Pain's (LWWP) Ten Footsteps course to facilitate delivery of pain cafés. They also worked with a social prescriber already delivering pain cafés to set up a Community of Practice. Working to create a sustainable model and with aims to have a pain café in each of Somerset's Primary Care Networks, the ICB engaged SASP to engage the system to learn from experience and need, leading to the development of a Train The Trainer course and ICB-wide impact metrics. In 2025/26, the ICB is offering this course to staff across Somerset, leading to accreditation with LWWP and creating a resource of staff with skills to train future pain café facilitators.

Content and facilitation

Pain cafés are social. Pain cafés should be designed and structured to support people with chronic pain to engage. Pain can be isolating for those experiencing it and some feel that they are the only one who knows what it's like. Therefore, making it a welcoming

experience is important, and providing a strong social aspect supports people to attend, engage, and to speak about their experiences. This can create the opportunity for people to feel understood and heard by others who may be experiencing something similar.

Information for patients before they attend. It is important to be clear on the potential benefits and expectations of people attending. This helps people to understand what they are taking part in and to feel more comfortable to attend. Patients may be sceptical of the benefits of attending pain cafés or be nervous about how it all works. Some pain cafés offer a conversation in advance of attending to give more information and help overcome these barriers, others send materials digitally, and some may allow participants a carer or friend to join them for their first visit.

Pain cafés are often 2 hours long and tend to be structured to include:

- 30 minutes of socialising to introduce and connect those attending, supporting them to feel comfortable in the café environment

- 30 minutes of seated movement. This often is delivered by an external organisation and could be chair-based yoga, tai chi, physiotherapist, or other movement. Some avoid calling this exercise as the phrase can be off-putting to attendees.

- 60 minutes of learning and discussion around a pain management topic. Some pain cafés have a set series of discussion topics that they run in succession (e.g. 10 or 12 weekly rolling themes), others are more responsive to the needs arising in each group. Most pain cafés have a set of resources they use to guide this section of the sessions, with many including both pain management content and local information.

This model of delivery works for most, but it is important to be responsive to group needs and wants. Some variation is possible, and pain café facilitators can vary the balance of these elements. For example, some pain cafés find that participants with CFS/fibromyalgia don't wish to participate in movement activities.

Pain cafés can include speakers from local services to facilitate access to support such as the local Citizens Advice for legal and financial matters, movement-based charities, nutrition. mindfulness or independent living advice through for example Independent Living Centres (example: https://www.somerset.gov.uk/housing-support/help-to-live-independently) or other organisations providing advice and guidance.

Some pain cafés share **hardcopy materials** to enhance what people learn in the pain café, such as self-management materials, goal setting or personal pain management plan templates. Information sheets about local offers can connect people with local organisations who often also provide speakers for pain cafés. It is important to consider

literacy levels and language skills to make sure that materials are accessible to people who attend. Some Primary Care Networks have developed their own resources incorporating the above into one document.

Pain cafés can make referrals. This could be to a pharmacist for a medications review, social prescribers for social support, local Department for Work and Pensions staff for benefits support, to a foodbank, local gyms, social groups, etc.

In addition to self-management approaches, other psychological and therapeutical approaches can enhance the delivery of pain cafés, such as:

Trauma-informed: Recognising the role of trauma in chronic pain is foundational for empathetic and effective support. Understanding a person's past experiences can improve their care and outcomes.

Facilitating with a positive mindset is key to guiding conversation to focus on positive experiences and appreciative elements. This can avoid groups delving into negative conversations that bring the mood of the group down and put people off attending. It is important to acknowledge the negative thoughts and feelings – this is people's experience. It is also important to shift the focus onto things that can help people move on – exploring what people can do rather than can't do, what support might be around, what actions they can take, what conversations they need to have. This is about turning a downward spiral of thinking into an upward spiral,

Impact and data

Impact that pain cafés can deliver for patients

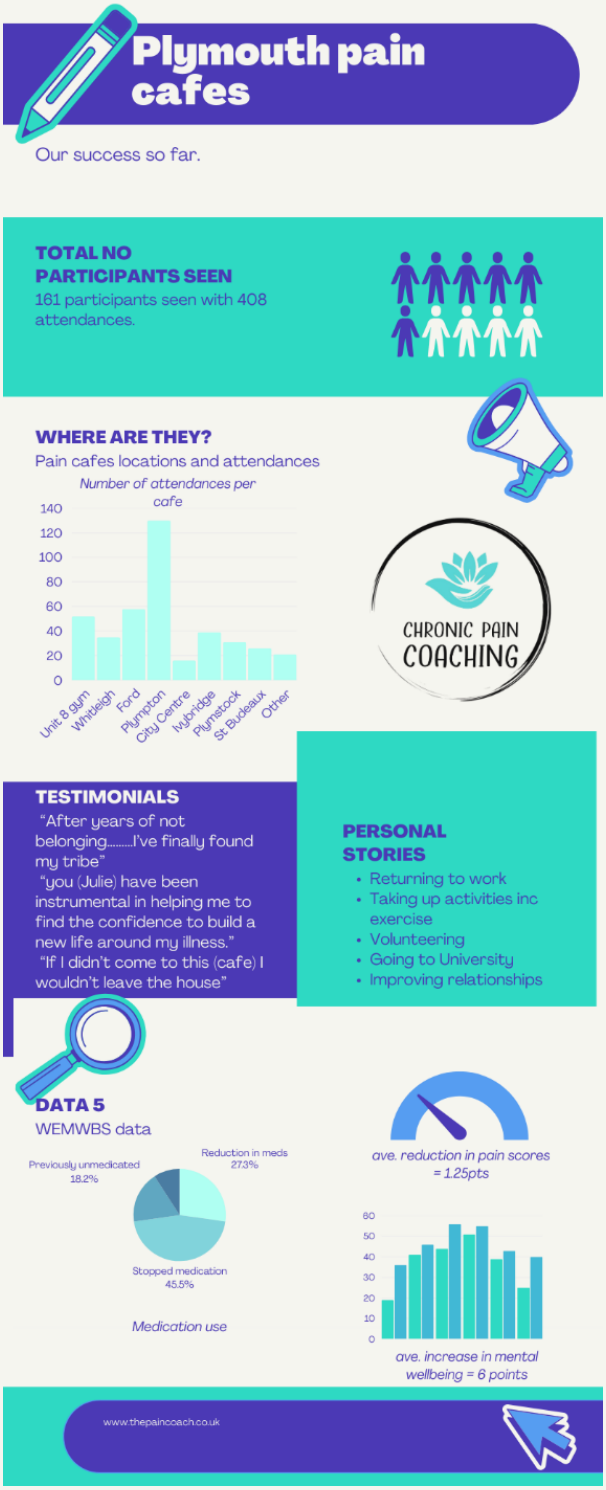
Recent evaluations demonstrated that patients in Cornwall, Devon and Somerset were better able to manage their pain after accessing pain cafés.

An early impact report on the Pain Cafés (see link in Resources below), based on a sample of 48 participants from Cornwall Pain Cafés who were given a benchmarking and 6+ month review survey, reveals promising results:

- Opioid Use: 64% of patients decreased opioids use
- GP Visits: 50% of patients decreased number of GP visits
- Pain Clinic Use: 31% decreased pain clinic use
- Self-Management and Control:
  - 100% of participants feel more able to manage their pain
  - 83% feel more in control of their lives

- 64% report an improved quality of life

- Social and Psychological Benefits:
  - 75% reported reduced isolation
  - 70% experienced reduced psychological distress
  - 80% engaged more socially



In Plymouth, Devon, Chronic Pain Coaching followed 11 people attending pain cafés over a period of 6-12 months and found:

- 100% of those on pain medications (n=10) had either reduced or stopped their medications.
- Average 1.25 pain score decrease, whilst reducing/stopping medication.
- 82% have positively increased their mental wellbeing by an average 6.7 points.
- Average 6-point increase in self-reported mental wellbeing score (on the 14-point Warwick-Edinburgh Mental Wellbeing Scale)
- Participants reporting that they were returning to work, taking up activities such as exercise, volunteering, going to university and improving relationships.

Figure 1: *Insights from Chronic Pain Coaching in Plymouth, Nov 2024-Feb 2025*

In Somerset, 33 patients in the Rural Practice Network (PCN) accessed both a 12-week course based on Live Well with Pain's Ten Footsteps and 1-hour pain cafés during Sep 2022-Dec 2024. 22 patients took up an offer of medication review with a pharmacist, and there was a notable increase in patients' perception of their ability to understand their pain:

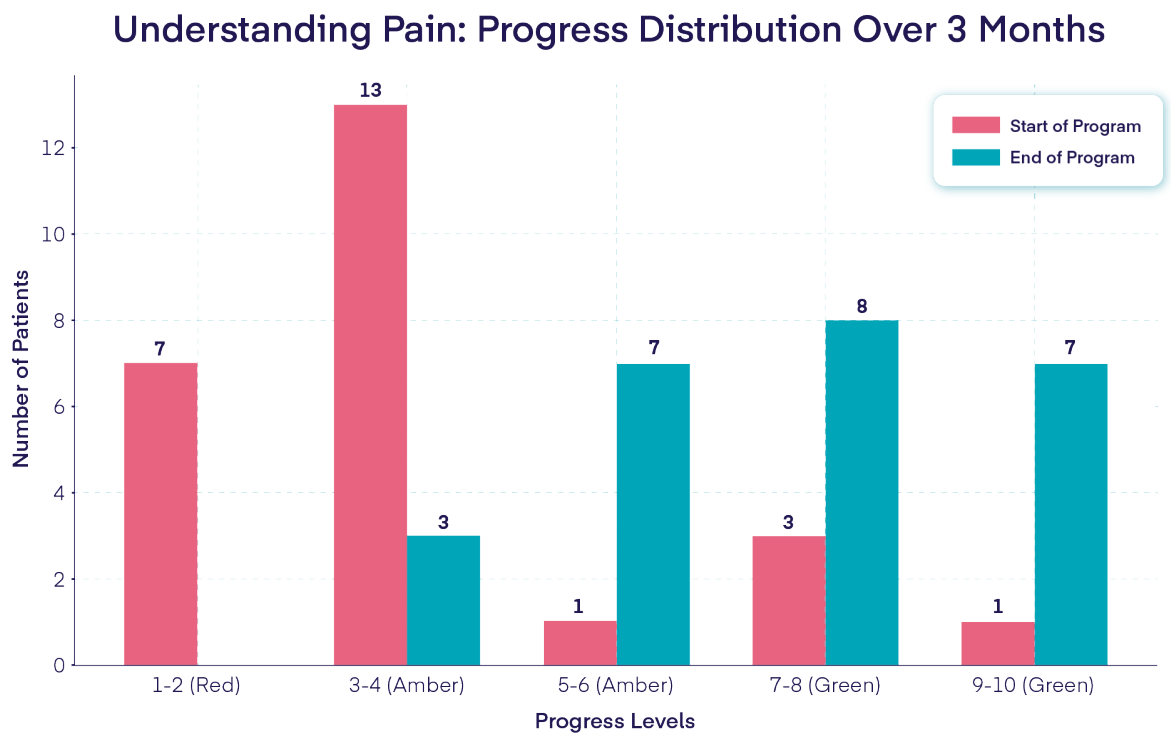


Figure 2: *Data from Rural Practice Network in Somerset showing an increase in patients' ability to understand their pain using the Live Well With Pain's Health & Wellbeing Check tool using self-reported data collected between* Sep 2022-Dec 2024

Impact that the pain café approach can deliver for health systems

As an example of the potential for pain cafés to ease pressure on local pain services, in the South West one hospital annually offers approximately 50 places on their pain management course, whereas the pain cafés in Plymouth had 300+ attendances in their first year.

Below is an example of a simple logic model, a tool that can support organisations and/or systems to clarify their problem, work, and outcomes sought.

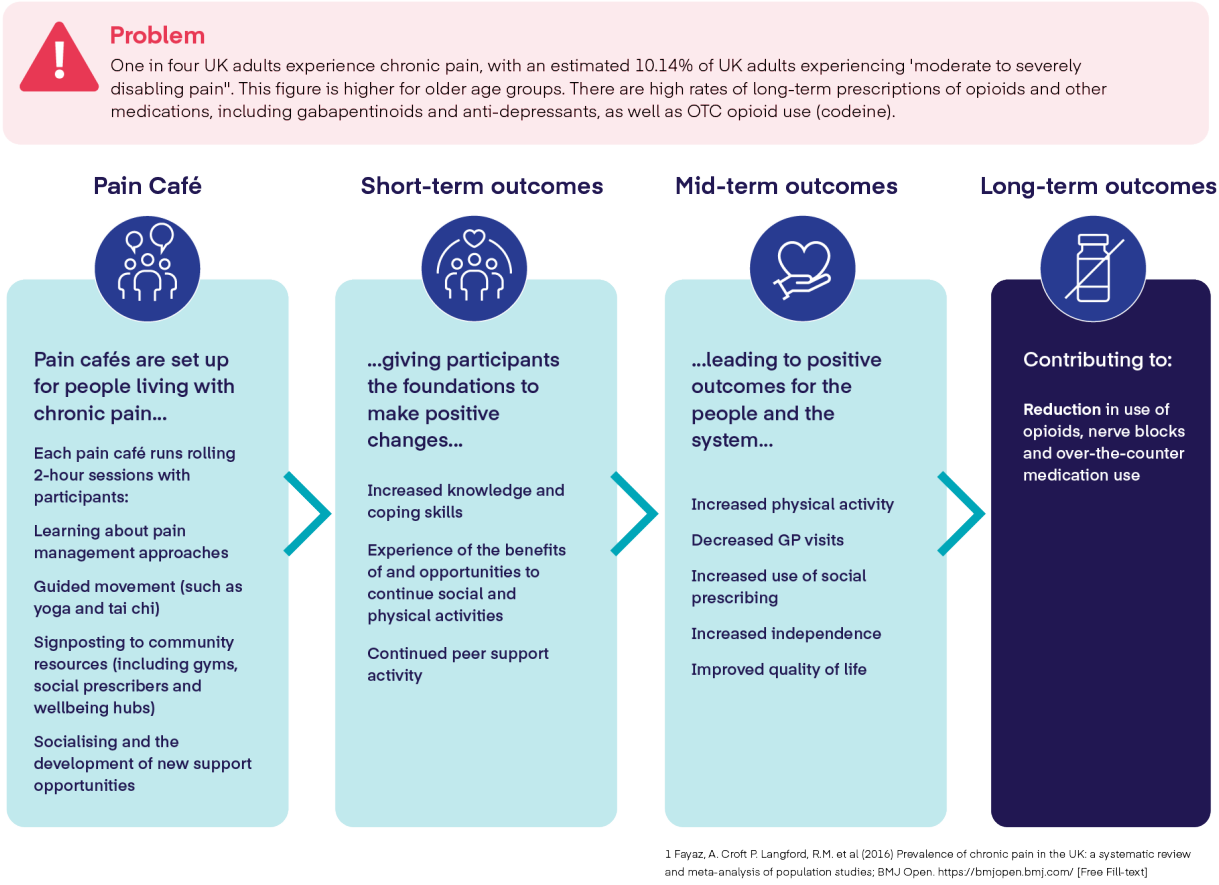


Figure 3: *An example Logic Model developed by Health Innovation South West.*

Tools are available or being used to measure impact

You can use a range of tools to measure impact from bespoke surveys and validated questionnaires to local GP records or medications data. The tools you need depend upon the questions you want to answer and who the information is for.

When to collect impact data

The timeframe for when you collect data will depend on the question you want answered. If you want to know if something has changed because of the pain café then you will need to look at that measure either before and then after the pain café or with a group of people who have attended the pain café versus a similar group of people who have not. It is very important that the comparison group are similar (in demographics, diagnosis and symptoms) to the pain café group so that you can be sure that any changes you see will be a result of the pain café.

Who collects data

Data should be collected at the end of a pain café sessions by the organisation running the café in alignment with their policies and procedures, including GDPR. This could be a Primary Care Network or VCSE organisation. In Cornwall, the VCSE organisation Imagine If collates data from across the county, although local cafés in Primary Care Networks also collect and consider their own data to improve their delivery.

To be able to demonstrate change in people accessing pain cafés you need to collect data over a period. You would expect to initially see a change in beliefs (such as self-efficacy in managing pain), then shifts in behaviour, and finally in self-reported pain. Ideally, you want your data collection period to be as long as possible to be able to include as many people as possible in your evaluation. This will probably mean collecting data over at least 6-12 months. In Plymouth and Cornwall, data is collected when people initially join (at first or second visit) and again at intervals of 3, 6, 9, and 12 months.

How to collect data

Pain Cafés are deliberately social, informal and aimed at supporting participants feeling it is easier to talk about their pain and health. Asking people to complete questionnaires can be at odds with the experience of this de-medicalised approach.

When measurement/feedback tools are used it is important to make the experience as easy and informal as possible. Focus on the impact you are trying to show to make sure you get the balance right between providing thorough insights and asking a lot of questions, which may make participants feel uncomfortable and more like the current medical model. It is advised to keep any questionnaires short, simple, and to consider the literacy levels of participants. Where people feel they have to do something, or the ask feels complicated, they may be less engaged and more likely to complete without properly thinking it through, which in turn makes the data less reliable.

When asking for feedback it can be helpful to frame the data collection in how it benefits the person (understanding their experience over time) and capturing the benefits of the pain café in general for those running the pain café, e.g. to secure future funding.

You may consider asking participants to provide subjective feedback through case studies or similar. Experience has shown that participants are generally happy to share about the experience and impact that cafés have had on their lives but can find the measurement instruments difficult.

Cornwall pain cafes have taken parts of different measurement instruments and included them as part of a participant survey that explores where a person wants to be – an action plan for pain. The aim is to make the survey useful for the participant and not just research.

The following table gives examples of the types of questions you may want to answer and the data you will need to collect to answer them:

Question	Why is this question useful?	Measures and Data source	Timeframe
Who is being supported by the pain café?	To ensure you are reaching certain geographies or groups of people in the community. It is also useful to be able to describe the sample of people you have supported to better demonstrate impact	**Demographics** (age group, ethnicity, post code, gender) **Clinical details** (diagnosis/injury, baseline pain levels, baseline movement levels etc) The easiest place to get this is from the service users themselves through a survey. If you intend to use this information for evaluation purposes, you will need to clearly state this when you ask for it.	Before people start on the pain café
How many people are attending the pain café?	To understand individuals' attendance. This can demonstrate use of the pain café, and alongside other data on impact can help you to show the difference the pain café is making to individuals.	**Number** and **name** of individual participants at each pain café.	At each pain café session
What are the service users' experiences of the pain café?	To know what people think of the service to help you to improve the café or to help you market the service to others who may benefit.	Self-reported: **Usefulness** of different aspects of the pain café How well the service **met their needs** What **worked well** What **worked less well (EBI even better if)** How people found out about the pain café **Satisfaction** with the venue, pace of the sessions, content of the sessions etc People's **experience** of attending (travel, sitting during session, location of setting, etc) This kind of information can be easily asked in a survey	After people have attended the pain café sessions, this can be directly after the café or at a follow up time point.

What is the impact of the pain café on service users' wellbeing?	To know the impact you are having on service users' well-being to allow you to better support them and to market the service to others.	**Self-reported quality of life or well-being measures** These can be measured either through a validated questionnaire like the Warwick Edinburgh Mental Wellbeing Scale, the WHO-5 or the EQ5D. OR you could ask some directed and specific questions within a bespoke survey. Validated measures may be more useful if you plan to use findings to support commissioning as they can be compared across services. They are also proven to accurately measure (in this case) quality of life or well-being, meaning you can have more confidence you are measuring what you intend. Do check it is a freely available tool before using it. Other tools are also available to support the practical monitoring of pain and well-being over time, such as these: Professional tools - Live Well with Pain. These tools can be used as measures over time, although not all will be academically verified.	Before AND after the pain café to demonstrate change over time (preferably at a follow up point, weeks later)
What is the impact of the pain café on service users pain levels?	As above. It may also be useful to understand how effective the pain café is on people's actual experience of pain.	**Self-reported levels of pain, over time** This is a useful reference when considering how you might measure pain over time: British Pain Society Outcome Measures	Before AND after the pain café to demonstrate change over time (preferably at a follow up point, weeks later)
What is the impact of the pain café on service users' behaviour?	As above. This is also a good question to balance a question about pain levels over time. Think if it would be a good outcome if pain levels were maintained BUT people were	**Self-reported medication taking behaviour** (type, dose, frequency), over time. You can ask this is a survey OR	Before AND after the pain café to demonstrate change over time

	taking less opioids. Or had seen reductions in pain but there had not been a reduction in medication usage.	You may be able to get hold of medication data from primary care if you are working within a specific Primary Care Network footprint to support this question. **Self-reported knowledge, confidence and understanding** of how to live well with pain **Self-reported changes in behaviour** since starting the pain café These measures would be best ascertained within a survey or interview.	(preferably at a follow up time point weeks later) Reported changes in behaviour should be gathered after the pain café (possibly at a follow up point)
What is the impact of the pain café on system resource?	This might be useful information to support commissioning decisions and the sustainability of the model in your area.	**# of interactions with general practice** **# of attendances at A and E** **# of admissions to hospital** **Length of stay in hospital** **Changes in medications** etc You may be able to get hold of this data through GP records, otherwise you could ask people how many appointments etc they have had in the last 2 or 3 months before and after their interactions with the pain café.	Retrospective look at GP records following engagement with the pain café OR before AND after the pain café to demonstrate change over time

CASE STUDY #3

Cornwall has developed a progress tool to capture data from pain café participants, which involves a benchmark survey completed within 2-3 sessions of attending and a progress survey completed after ca. 8 months. These surveys have been developed using a mixture of research tools including Warwick Edinburgh, World Health Organisation, McGill Pain Questionnaire and Pain Self Efficacy questionnaire. A visual scale is used although many participants feel that scaling is overused. The tool has to date only been used in Cornwall. Contact **Imagine If** to learn more

3. Resources

A range of resources shared in the event and others are shared below to support you in your work to improve medicines safety, deprescribe opioids, and implement pain cafés.

Evaluations

- Cornwall pain café evaluations from Imagine If: https://www.imagineif.net/pain-cafes-in-cornwall
- Pain cafe and pain management course impact documents from Rural Practice Network PCN, Somerset: RPN LWWP two year report December 2024 v2 – Medicines Safety Improvement Programme – FutureNHS Collaboration Platform

Forthcoming research insights

- Imagine if have applied for a National Institute for Health and Care Research (NIHR) grant with Plymouth University to assess the critical success factors of pain cafés and a tool to measure pain from a person-centred approach.
- Chronic Pain Coaching in Plymouth have applied for research grants through Plymouth University to explore the impact of pain cafés to inform a best practice model, and Virtual reality studies on lower back pain.

Locality-based pain management/pain café information

- **Cornwall. Imagine If** (Community Interested Company, www.imagineif.net) runs:
  - **Cornwall Connected by Pain**, a collaborative movement delivering pain cafés across Cornwall: https://pain.cafe
  - **Cornwall Pain Café Community of Practice**
  - **Imagine If evaluations: Webinar**: Cornwall Pain Café Outcomes and Shared learning, 16/10/2024 https://vimeo.com/1023960420
- Somerset:
  - **Somerset ICB webpages** with resources on pain management and overview of pain cafés: https://oursomerset.org.uk/pain-management-somerset
  - **Somerset Pain Café Community of Practice**, run by Somerset ICB
- Devon
  - **Chronic Pain Coaching**, delivers pain cafés in and around Plymouth, Devon: www.thepaincoach.co.uk

- **Devon Pain Café Community of Practice**, run by Imagine If and Chronic Pain Coaching

- **South West Pain Café Event** sharing learning from Cornwall, Devon and Somerset, write-up and recording

Pain management information and training offers

- Practical advice on running a pain café, Sue Crisfield, Rural Practice Network. Page 3-4 of Live Well with Pain Newsletter Jan 2024

- Live Well with Pain, range of resources, including course 10 Footsteps and a self-assessment tool for people accessing pain cafés, used by some pain cafés to capture impact

- Let's Live Well With Pain – Facilitator's guide - a resource developed by Health Innovation East Midlands for facilitators planning and delivering the Let's Live Well With Pain (LLWWP) Programme. It may also be useful for peer support groups such as Pain Cafes.

- Flippin' Pain, range of resources for professionals and patients

- Making decisions to help you live well with chronic primary pain - NHS document aimed at patients to support decision making

- ReConnect2Life, an interactive programme to help you look at your pain and how it affects you. ReConnect2Life - Torbay and South Devon NHS Foundation Trust

- Plymouth Hospitals Pain Management Links: https://www.plymouthhospitals.nhs.uk/pain-management-links

Book recommendations to support learning around the impact of trauma on pain

- 'The Body Keeps the Score' by Bessel Van Der Kolk

- 'When the Body says No' by Gabor Mate

- 'The way out' by Alan Gordon

Medicines safety

- Primary Care Networks are required to identify patients who would benefit from a Structured Medication Reviews and to deliver them. In a Structured Medication Review clinicians and patients work as equal partners in a shared decision-making conversation to understand the balance between the benefits and risks of and

alternatives of taking medicines. More information here: https://www.england.nhs.uk/primary-care/pharmacy/smr

- NHS England: Opioid prescribing for chronic pain

Materials on Health Innovation South West's website

- Medicine Safety - Health Innovation South West
- 'Rethinking pain management: How Pain Cafes are reducing opioid use' video
- https://healthinnovationsouthwest.com/blog/2024/12/19/south-west-pain-café-event-shares-learning-on-national-level
- Piloting Pain Cafés in Plymouth to reduce opioid prescribing - Health Innovation South West
- https://healthinnovationsouthwest.com/blog/2024/03/14/plymouth-pain-cafés-to-benefit-from-national-lottery-funding-to-help-people-in-chronic-pain

This document was prepared by Maja Jorgensen, Programme Manager