



## Pain Cafes (Cornwall): Impact and Outcomes Report – early results January 2024



**Kevin Feaviour, January 2024**

(On behalf of Connected by Pain: Debs Onyons, Nikki Kelly, Libby Huddy, Sean Jennings, Vicky Taylor)

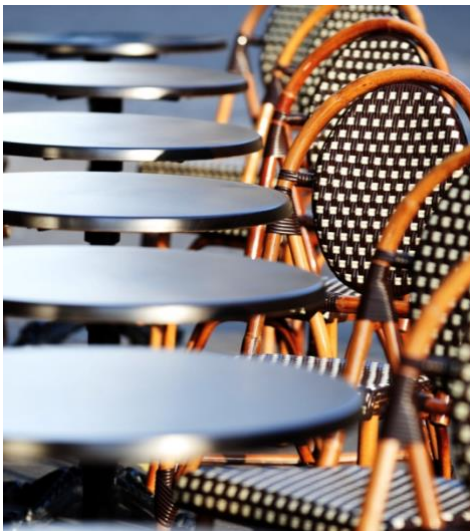


## 1.0 Introduction

Pain Cafes have been in development and delivery in Cornwall since 2020, starting during the COVID 19 pandemic. The aim of the Pain Café model is self-management - to help people feel more empowered to manage their pain, experience improved well-being through reduced isolation and psychological distress and greater social engagement. This will reduce their levels of medication, visits to a GP or health service and emergency admissions to hospital (people with chronic pain are hospitalised nearly three times as often as the general population). The Pain Cafe objectives are to provide informal, accessible, safe psychological spaces where people can develop confidence to talk openly about their health, feel supported by their peers and develop techniques to manage their pain and wellbeing and better respond to others. Our model is to reduce use of medication using a 'skills not pills' approach. There are now over 10 Cafes in Cornwall, over 50 trained baristas and a growing number of participants. The social and self-management elements have become key features with many groups creating their own activities and support through connections such as WhatsApp.

We have designed and developed online and face-to-face Pain Cafes, support other PCNs to run theirs, offer a Community of Practice and are collating data to promote a 'best practice' model including protocols for setting up and facilitating them, key interventions and materials that 'pain baristas' can use during sessions focused on an informal and less medical approach to managing pain. We have worked with Kernow Health, Queens Nursing Institute, RCHT Pain Clinic and University of Exeter and

- developed the Café approach
- created a digital platform Cornwall Connected by Pain: <https://pain.cafe>
- trained people in the Live Well with Pain 10 footsteps approach
- run a launch event at the Eden Project (Jan 2023)
- promoted the ideas at national events with College of Medicine and NHS England



Our work has developed across Cornwall and now reaching other areas of the country. Our research and development programme has worked with people living with pain, health professionals, pharmacists and community organisations to help develop a theory of change and codesign the cafes so that they are working as effectively as they can be. Previous research has taught us that more understanding is required in designing the most effective pain management strategies; 'lived experience' is central to shaping the research (see Davis et.al.2022). There is a societal and humanitarian need for pain management to support those in pain and distress (Faculty of Pain Management 2020). Sufferers and advocates refer to chronic pain as an 'invisible disability', a term which emphasises under-recognition, its impact on individuals and underinvestment in provision of appropriate, supportive, timely services. Our 'socialpsychobio' theory of change is based on a journey of achieving final outcomes e.g. reduced medication and GP visits through developing intermediate outcomes (social, psychological and health capabilities to change behaviour and mindset) that stem from successful outputs such participants enjoying cafes, feeling able to tell their story, be



heard, respected, and validated. Understanding this helps us focus on effective inputs and activities as catalysts for change. We work with the NICE Guidelines (2024) that state that people with chronic pain should

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

We are working with various partners to support the development including the College of Medicine, University of Exeter, Age UK and with groups to reach specific communities such as the Acute Hospital Pain Clinic and Help for Heroes (HfH). We have run an event for veterans which was very popular and have links to clinical team at HfH.

*“Whenever I feel I am struggling, I go to my folder of pain resources from the café and try to make an achievable action plan” (participant)*

The Cafes have received many testimonies. Using these and our delivery experience we have designed two surveys to develop our understanding of ‘what works’ and ‘what impact’ the Cafes are having enabling people to manage their pain more effectively. These surveys include validated tools e.g. WHO Wellbeing tool, Likert Scale and questions developed from participant feedback as patient reported outcome measure.

The Benchmark Survey ascertains peoples past and current experience of pain, levels of confidence and their goals etc. It is conducted within the first three sessions of a Café, normally not the first. The Review Survey is undertaken after 6 monthly sessions or more and seeks to identify any improvements in pain management, medication use, wellbeing, and the skills, knowledge, and support behind this. Both surveys are focused on helping the person understand and articulate their situation to consider what matters to them, what they want for the future and what will help them get there. It is about their future health and wellbeing as well as gathering data to help measure the impact of services and understand what difference they are making or not.

*“Being able to discuss at the pain café – to be listened to. Hearing people moan about pain must be very boring but to have someone listen and support is a great help”.*  
*(participant)*

## 2.0 Early Results Report January 2024

These results come from a sample of 48 people who have completed the benchmark and / or review surveys. These participants have attended cafes in Perranporth, Truro, Bodmin, Helston, Troon, Carnon Downs. These are early figures - more data is required to further our understanding of the impact the Pain Cafes can make to people's lives.

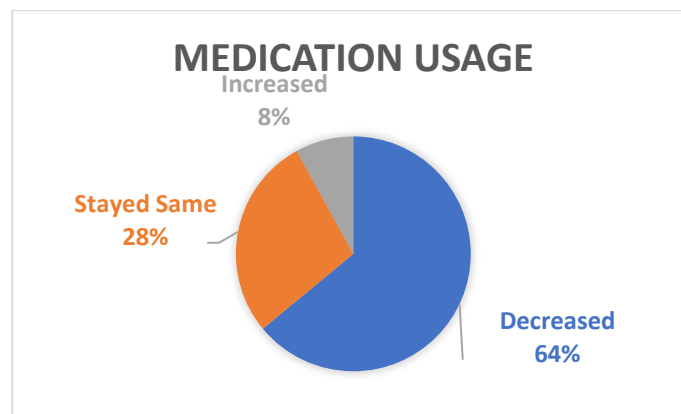
Cafes are attended by an **age group** of between **18 – 84**; **most participants** are aged between **55 and 74**. Most people are referred by GP surgeries or other health professionals: however there are several **self-referrals**; for a couple of the cafes this figure stands at around **50%**. The majority, **75% of participants are women** (see 5.0 Future Opportunities). Some **young people** have sought support and would like something focused on their age group (see 5.0 Future Opportunities).

### 2.1 Final Outcomes: Managing Pain and Lives

Our Pain Café theory of change identifies final outcomes as significant changes in behaviour and mindset that have led to increased health and wellbeing including reduction in the use of medication and visits to GPs, improved quality of life, more control over their lives and more able to manage their pain.

#### KeyNote: Reduction in the use of medication (opioids)

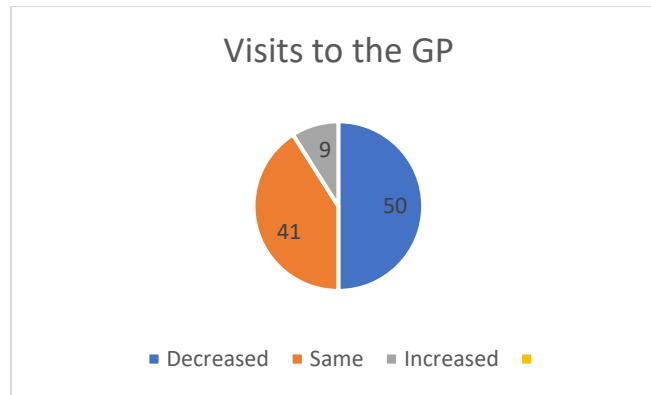
From the first sample **64%** had **decreased** their medication with **28%** **staying on the same levels**. Some people commented that staying on same level was better than increasing medication levels as might have happened previously.



#### KeyNote: Reduced visits to GPs

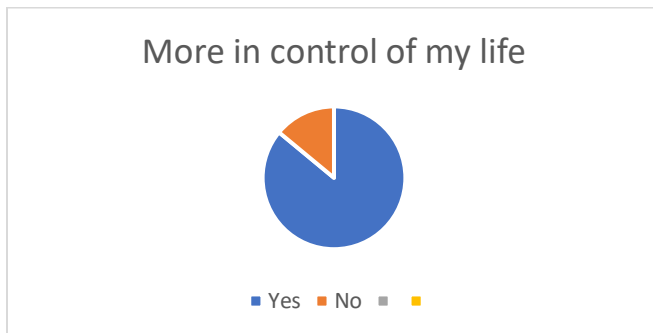
**50%** of respondents reported **seeing a GP less** and **41%** about the **same**. **31%** reported seeing a **pain clinic or other services less**, **46%** the same amount. It has been reported that people with chronic pain consult their GPs up to five times more frequently than other patients do translating to 4.6 million GP appointments per year. Pain Cafes could significantly reduce these.

22% respondents reported seeing pain clinics or related services more; this included some people taking up physio to compliment Pain Café activities. Participants suggested they had more control in connecting with services.



**KeyNote: Increased self-management and more control of pain and lives**

Participants reported on their pain management and feeling in control of their lives. **100%** felt more able to **manage pain** and **83%** felt more in **control of their lives**. In another area of the survey, **68%** reported being more able to cope and in control (self-efficacy). In addition, **64%** reported having an **improved quality of life**.



**Comments on managing pain included:**

*“I have several methods I am doing to manage my pain without medication like doing movement, meditation and breathing.”*

*“Techniques at the pain café have helped a lot”.*

*“It certainly helps to be in a like-minded group with peer support and suggestions - the mindfulness session is a great help.”*

**Feeling in control**

*“Yes, more control and more empowered – I don’t always reach for the tramadol or co-codamol... I reduce my pain by controlled breathing”.*

*“I can practice mindfulness change my environment”.*

## KeyNote: Reduction in the experience of pain

The sense of control and management of life seems to link to people’s experience of pain. In both surveys participants were asked about the level of pain they feel they experience on a scale of 1- 10 (with 0 being no pain/no distress and 10 being extreme pain/extremely distressing). In the Benchmark Survey, 56% rated themselves as 7 or 8 on the scale: 23% rated themselves between 4 and 6. In the review survey, 50% participants rating their pain as between 4 and 6 – **double from the benchmark survey**; 36% rated themselves as 7 or 8 – **a reduction of about a third**. These figures suggest that experience of pain had become less distressing. The scale reflects a person’s perception of their pain; discussion with participants suggested that their perception of pain had reduced but that pain levels remain significant and prominent in their lives. The Pain Café programme acknowledges that pain doesn’t go away but being able to manage it better helps reduce the psychological noise it creates.

*“This is a great service for me and the people of Cornwall - real ‘lived experiences’ are so helpful to us sharing our experiences”.*

## 2.2 Intermediate Outcomes

An aim of the Cafes is to increase participants personal **social, emotional** and **health** (bio) capabilities (skills, knowledge, confidence). Within the Pain Café theory of change these capabilities are intermediate outcomes - that lead to behaviour change and improved health and wellbeing outcomes.

### 2.2.1 Social Capability:

A key objective of the Pain Cafes is to increase in social connectedness; use of informed peer support; using new tools and techniques to manage their pain and social situations, higher aspirations for the future e.g. increased employment, confidence to influence change, increase in volunteering and social engagement.

## KeyNote: Increase in knowledge, skills, peer support, employment, and volunteering

**100% respondents** reported having an **improved knowledge** of self-management strategy ‘**skills and not pills**’, with **86%** using **new tools and techniques** to manage their pain. **64% respondents** reported using **new tools and techniques** to manage social situations; **79%** reported **increased use of informed peer support** and **64%** rated themselves as **more interdependent**. **8%** reported a change in their **employment** situation (gained or extended) and **21%** has **reduced the amount of sick leave** they had taken. **21%** described **improving their digital skills**. A few participants have started **volunteering** and supporting new members to the cafes and some are facilitating cafes – creating a sustainable self-managed resource which is part of our long-term plan.







### 2.2.2 Emotional (psychological) Capability:

A key objective the Pain Cafes is to build self-management of their pain through increased confidence, reduced fear and psychological distress, pain related interference e.g. catastrophizing and improved motivation.

**KeyNote:** Increased confidence, motivation, self-efficacy and reduced fear

83% participants reported having **increased confidence in new skills** and techniques and therefore more **motivated to manage** their pain and support others. **75%** felt **more confident** in managing their pain and **67%** felt more able to **cope and in control** (self-efficacy) and experienced **less fear** and pain related interference. Self-management demands levels of motivation and confidence, so it is crucial to build this capacity.

**KeyNote:** Increased confidence to live with pain and work

Participants were asked about their ‘confidence to live a normal lifestyle despite the pain’. They rated their confidence on a 1-7 scale from not confident (1) to completely confident (7).

#### Participants ‘confidence to live a normal lifestyle despite the pain’.

	Not Confident	-----	Completely Confident
Scale	1-3	4-5	6-7
Benchmark	54%	34%	12%
Review	39%	53%	8%

- In the Benchmark survey, 54% respondents recorded a score of 1-3 indicating that they were not confident to live a normal lifestyle; in the Review survey this had reduced to 39% - a 28% reduction.
- In the Benchmark Survey 34% rated themselves as having some confidence, scoring 4 or 5; in the Review survey this had increased to 53% - a 36% increase.
- In the Benchmark survey 12% indicated they had confidence, scoring 6 or 7; in the Review survey this has reduced to 8%.

This feedback indicates a **significant rise in confidence to live a normal lifestyle** after attending the cafes and supports previous data above in relation to confidence and self-management. We note a reduction in those feeling completely confident. This is partly related to individual differences in the cohorts and some people becoming more realistic and self-aware of their confidence and part of their learning journey.

Respondents were also asked about their ‘confidence to do some sort of work’ using the same scale. We note that many participants were not working - many had retired and so this question was less relevant to them. We will widen the scope of work to include volunteering, civic engagement, and support activity in the future.



**Participants ‘confidence to do some sort of work despite the pain’.**

	Not Confident -----		Completely Confident
Scale	1-3	4-5	6-7
<b>Benchmark</b>	57%	31%	12%
<b>Review</b>	30%	38%	31%

- In the Benchmark survey, over half (57%) of respondents recorded a score of 1-3 indicating that they were not confident to undertake some form of work; this had reduced to 30% in the Review survey – a reduction of 48%.
- In the Benchmark survey, 31% of participants rated themselves as having some confidence to work (4 or 5 on the scale); this had risen by a small increase to 38% in the review survey.
- In the Benchmark survey, 12% indicated they had confidence to work (rating 6 or 7); this had risen to 31% in the Review survey – a 62% increase.

This feedback indicates a **significant rise in confidence to work** after attending the cafes and supports the confidence data above. It suggests that Pain Cafes can have a significant role in building people’s belief and confidence in self managing their lives and being able to enter employment and other activities e.g. volunteering. These figures are supported by the fact that many participants have taken volunteering and facilitation roles within the cafes and are supporting other community groups e.g. Community Health Hubs.



Building skills and knowledge gives participants a new repertoire and sense of purpose which improves power.

**2.2.3 Health Capability:**

A key objective of the Pain Cafes is to increase participants ability to manage health and biological factors notably sleep, physical health including activity and movement and develop skills to reduce medication usage.

**KeyNote:** Increase in using new tools and techniques, improved sleep patterns

**86%** participants report **using new tools and techniques** to manage their pain rather than medication. Sleep and the lack of sleep was a major presenting issue in the Benchmark survey. Pain Cafes have focused on enabling participants to develop techniques to support improved sleep including mindfulness, breathing and yoga. **64%** respondents reported **improved sleep patterns**; however, **28%** felt there had been **no improvement**.

Another key presenting issue was participants wanting to be active and again. Pain Cafes support people with ideas to improve movement including ‘everyday activity’ and armchair exercises e.g. yoga. **30%**





participants felt their **physical strength and endurance** had **increased**; however, 62% felt it hadn't. This is an area that needs further review and focus, developing an activity and movement programme that can work with people struggling with pain that varies from day to day.

### 3.0 Wellbeing

**KeyNote:** Improved wellbeing

The aim of the Pain Cafes is to enable participants to improve their wellbeing - it is known that pain and wellbeing are very closely linked. Severe physical illness and chronic pain is associated with higher suicide risk Vahé Nafilyan et.al. (2022), Donaldson (2008), Tang and Crane (2006); having mental disorder is associated with experiencing fatal and non-fatal opioid overdose Draanen et al. (2021). This interaction emphasises the collaborative physical and mental health care for patients and hence a focus of Pain Cafes.

Participants were asked to rate themselves using the World Health Organisation wellbeing scale as shown below.

<i>Over the last two weeks:</i>	Better			//	Worse			<b>Mode/Mean</b>
	<i>All the time</i>	<i>Most of the time</i>	<i>More than half of the time</i>	<i>Less than half of the time</i>	<i>Some of the time</i>	<i>At no time</i>		
	5	4	3	2	1	0		
<b>1) I have felt cheerful and in good spirits.</b>								
Benchmark Survey	0%	9%	22%	41%	22%	6%	2 (2.0)	
Review Survey	0%	13%	57%	15%	15%	0%	3 (2.7)	
<b>2) I have felt calm and relaxed.</b>								
Benchmark Survey	3%	6%	25%	25%	23%	16%	2 (1.8)	
Review Survey	0%	21%	21%	36%	21%	0%	2 (2.4)	
<b>3) I have felt active and vigorous.</b>								
Benchmark Survey	3%	5%	8%	25%	37%	22%	1 (3.1)	
Review Survey	0%	8%	14%	36%	36%	7%	2 (1.69)	
<b>4) I woke up feeling fresh and rested.</b>								
Benchmark Survey	0%	0%	6%	31%	28%	35%	0 (1.0)	
Review Survey	0%	21%	14%	7%	14%	42%	0 (1.64)	
<b>5) My daily life has been filled with things that interest me.</b>								
Benchmark Survey	0%	18%	25%	25%	16%	16%	2 (2.1)	
Review Survey	0%	40%	41%	13%	17%	0%	3 (3.07)	

Results show an increase in all the five areas following participation in the Pain Cafes. There was a **significant increase** in participants **feeling more cheerful and good spirits**, from less than half the time to more than half the time; participants reported **feeling more active and vigorous**, moving up the scale from at no time or some of the time to half the time. More participants reported **feeling “fresh and rested” more than half the time** although a significant number reported not feeling that at any time. Over **80%** participants in the Review survey reported that their daily **lives had been filled with things that interest me** for over half the time or most of the time.

These results are limited by the small cohort(n=48) but offer an indication of potential impact of Pain Cafes on wellbeing. As more participants engage for 6 – 12 weeks or more we can continue to build the data and picture of Pain Café interventions. Pain is a complex issue – it is a variety of cycles and ups and downs



as physical issues interact with social and working lives and impact on the identity and wellbeing of the people involved.

- *“Depends on how much I do or my mental health if I am distressed its twice as bad, but it regulates between 3 and 7 most days”.*
- *“Dreadful getting worse but I am reducing my medication within the 6-week gap”.*

**KeyNote:** Value of shared experience and peer support

#### 4.0 What helped or hindered?

Participants were asked what had helped or hindered them in develop skills, knowledge, and confidence. **Peer support and shared ‘lived experience’** were most commented upon.

- *This is a great service for me and the people of Cornwall real ‘lived experience are so helpful to us sharing our experiences.*
- *Continued intentional and peer orientated reminders of context for struggles and challenges really helps.*
- *When I attend a session, I go home feeling more confident and my group has helped me accept my situation.*
- *Sense of community – its less lonely dealing with pain - just being able to meet those like you as you can’t really understand what it is like unless you’ve been through it*
- *It certainly helps to be in a like-minded group with peer support and suggestions the mindfulness session is a great help.*

Feedback from Veterans through the link with **Help for Heroes** was similar including *Peer Support, understanding I am not alone, lived experience stories, pain management, the relaxation techniques, alternative options other than medication.*

Peer support is one key feature of the Pain Cafes and shared experience can really help. The Cafes are about developing the patient voice and ensuring it is heard and more prominent. Peer conversations can build confidence and hone understanding.

**KeyNote:** Pain is a social issue

It is noted from all the feedback from participants that social activity is central. Pain restricts people’s ability to be with other people, social life and many of the daily activities that help define a person and their identity. Most participants want to be more socially active and consequently feel less isolated. They want to do the things they used to, including housework, and feel part of society. The social element of the Cafes appears to be a central feature to building confidence, realising identity, and supporting people to develop a new mindset and new behaviours to better manage pain, become more interdependent and more in control of their lives, reducing reliance on medication and health professionals.



## KeyNote: Importance of resources to support new skills and techniques

Many participants commented on the **importance of resources** in supporting them – tools, techniques and activities to help manage pain.

- *Whenever I feel I am struggling, I go to my folder of pain resources from the Café and pain clinics and try to make an achievable action plan*
- *Yes, more control and more empowered – I don't always reach for the tramadol or co-codamol - I reduce my pain by controlled breathing*
- *I can practice mindfulness and change my environment.*
- *Breathing exercises and pressure points and exercise from the yoga teacher - she is really great.*
- *Pain Café information techniques and exercise discussion etc along with interaction with the organisers and telling participants are all beneficial to some degree for me and hopefully I have given a few tips to others too.*

Other 'helps' included **making it manageable** and importance of **ongoing regularity**. Hinderances included people expecting too much of people in pain, struggle of everyday routines and 'normal' people not understanding pain.

- *And likewise, a huge thank you to the pain café teams this is a great service for us suffering with chronic pain and its complexities it is too complex to deal with in a one-off health professional appointment e.g. GP appt no offence to their skills this ongoing café is the right way to deal with it*
- *Example of positive outcome of a session we had retaking a list of outcomes you want from a GP from an appointment I wrote and took the list with me and felt that the appointment was far more successful.*
- *I know my limits now and I'm not so focused on being a burden and will actually try to look after myself and stop instead of pushing all of the time. I've accepted will deteriorate but on bad days I get frightened which just makes it worse.*

Other information that was gathered included the people who participants turned to most - friends and family and GP were most identified. This reiterates the importance of informal support of family and friends and it is important to consider how this can best be supported and utilised. Only 3 respondents reported regular medication checks, and none had personalised care plans.

## 5.0 Future Opportunities: Self-management

We are working with an increasing number of people who will contribute to future results. What we want to develop is a self-management approach that build peoples' social, psychological and health capabilities that could significantly reduce emergency admissions to hospital, suicide attempts, enable people to become more active and in more control of their lives. The Health Foundation (2022) study found that if the people who were least able to manage their conditions were supported and upskilled to the level that those who felt most able to, it could **prevent 436 000 emergency admissions to hospital and 690 000**



**attendances at A&E each year.** These are clearly national figures but suggest a significant impact on local hospitals and resources. We are also aware of mental health needs and the Café process could support a community-based approach protecting vital NHS provision.

Over the next year we want to

- **create pathways** into the Pain cafes as part of a wider **coordinated approach to pain** across the county including linking to MSK Clinical services and leads
- build a **holistic approach** by linking our work with **Public Health** on **activity and movement, suicide prevention**, preventable deaths, people with complex needs and Kernow Recovery Community and Fibromyalgia strategies
- offer a **structured pain management** programme.
- write a '**social model of health**' focused on community led, social enterprise and wider systemic funding model – "it takes a community to support people and their health"
- Tackle **health inequalities** through
  - **identifying specific support for women** – working with participants lived experience and Women's Health Hub in recognition that over half (56%) of UK women feel their pain is ignored or dismissed healthcare professionals, a third of women (31%) said they didn't want to waste their healthcare professional's time and 32% of women suffered from period pain as part of their daily lives (Gender Pain Gap Index Report 2022)
  - **Pilot a project for young people** experiencing chronic pain. Many young people have made contract saying that nothing is available for them. This again links to depression and anxiety in young people.
- Work with the **Patient Empowerment** (activation) measures to further define the shift to self-management of pain
- reach **key populations** such as **farming** communities through the Farming Health Hub and Veterans with **Help for Heroes**
- build on the model to identify **critical success factors**, develop more self and peer help resources and produce a **pack of materials** that people can use to design, develop and facilitate their own cafes, create local peer communities and become self-sustaining
- **widen the scope and reach** of the Pain Cafes to consider support for **carers, family members, friends** and other local people
- develop the **capacity of people to facilitate cafes**, other events and activities

*"Yes making more manageable goals and celebrating little victories as the big steps they are for me despite being mental to normal people"*

**Kevin Feaviour, January 2024**