

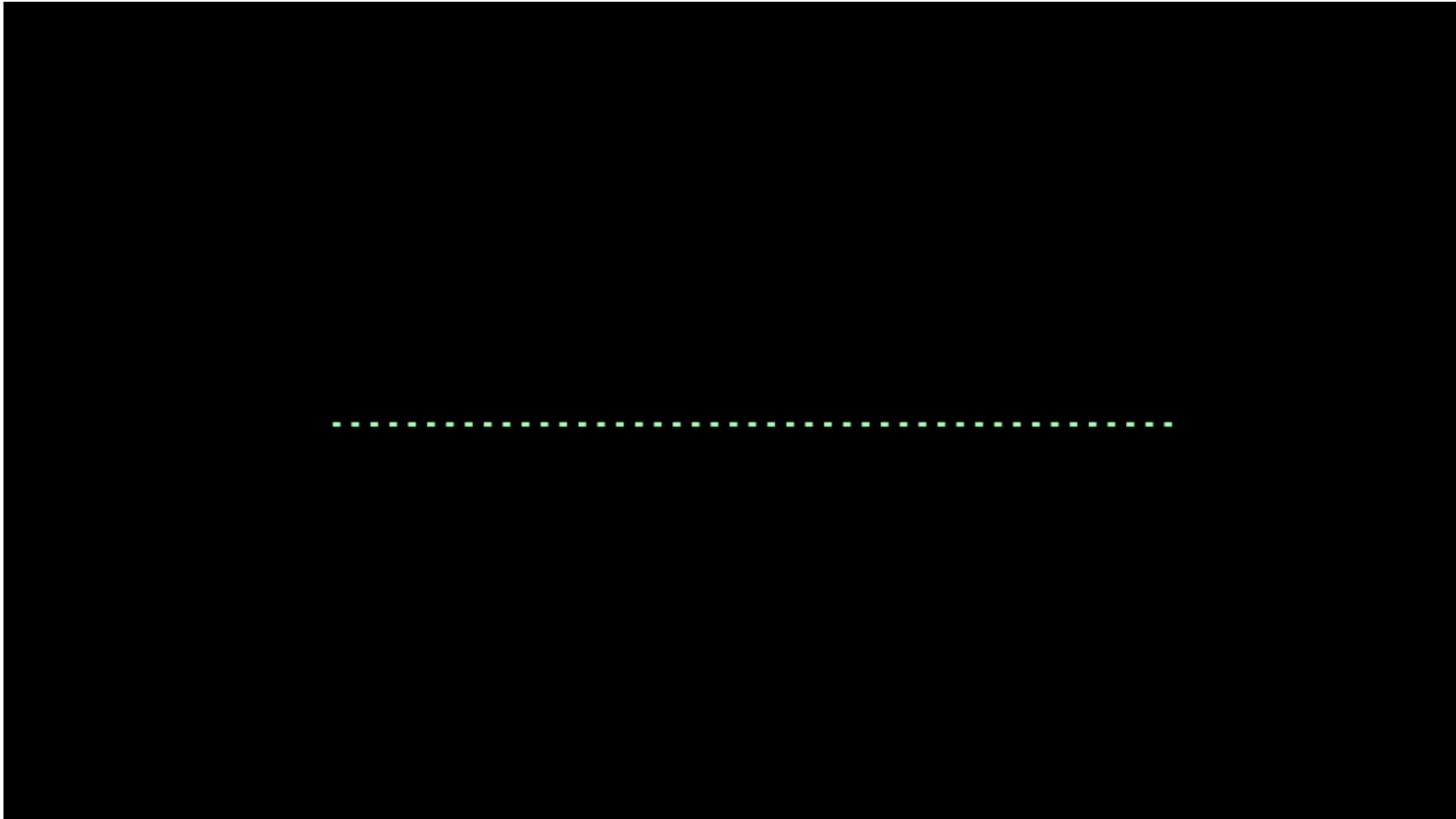
IMPROVING CO-PRODUCTION BETWEEN LIVED EXPERIENCE PARTNERS AND PROFESSIONALS

The LWWP Lived Experience Trainers

LIVED EXPERIENCE TRAINERS



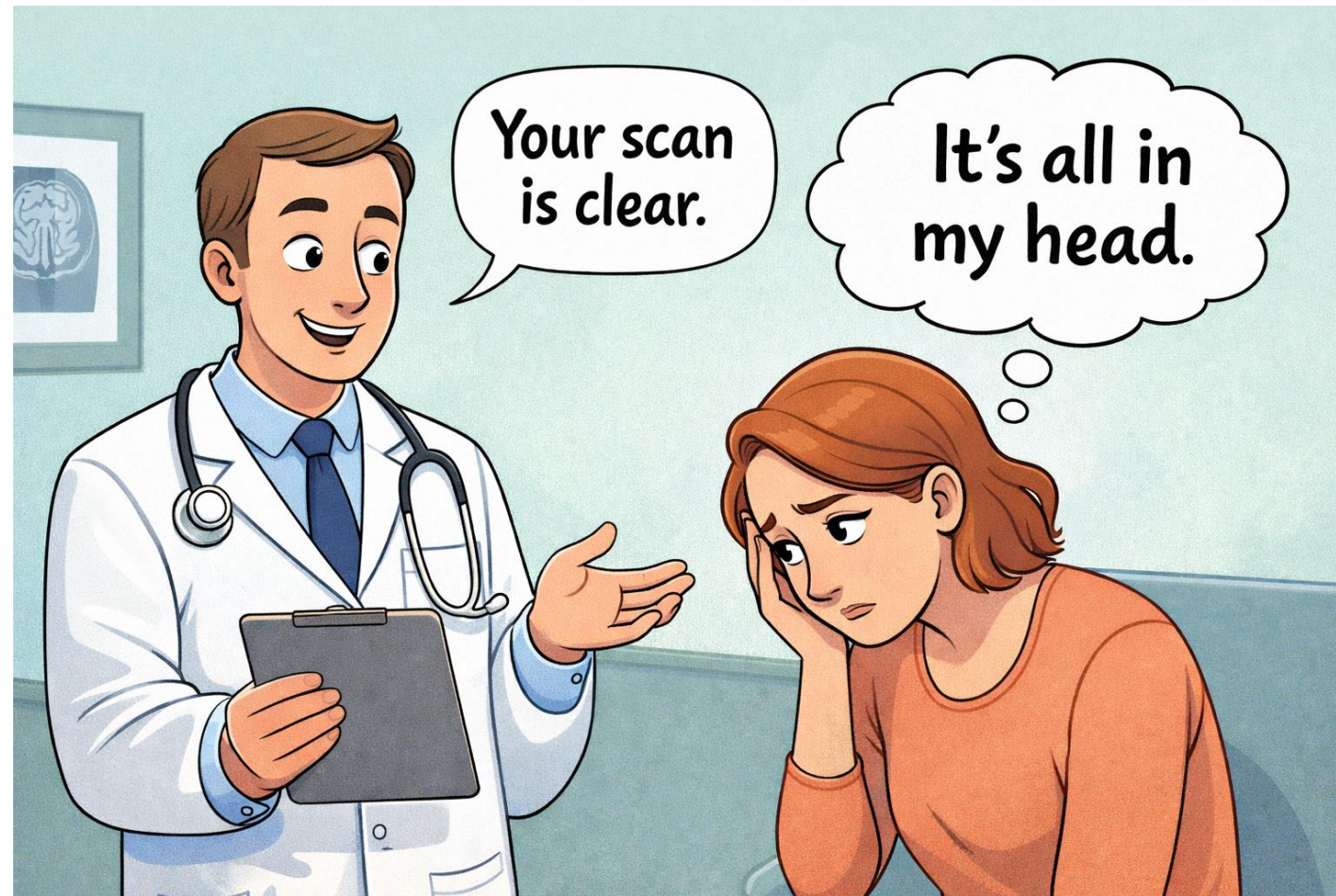
The problem...



A fish doesn't know it swims in water!



What you say and what we hear...



Co-production is...

- “Co-production is a way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation.”
- “Co-production acknowledges that people with ‘lived experience’ of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives. Done well, co-production helps to ground discussions in reality, and to maintain a person-centred perspective. Co-production is part of a range of approaches that includes citizen involvement, participation, engagement & consultation.”

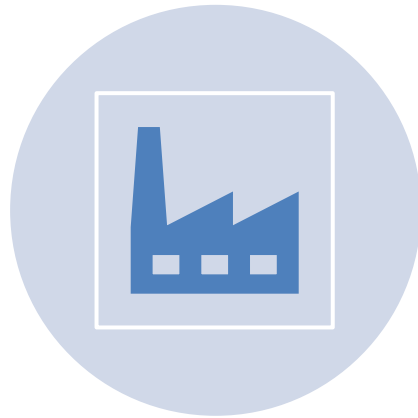
Co-production isn't...



Co-Production in Chronic Pain



THE NHS



VCFSE



RESEARCH

National (England)



Within NHS England GIRFT has a work stream dedicated to chronic pain.



Has a Clinical Lead and two clinical advisers but no listed LEPs



It replaced NHSE #BestMSK. This had LEPs but no chronic pain work stream.

National Strategy on Chronic Pain

NICE National Institute for Health and Care Excellence

Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain

NICE guideline | NG193 | Published: 07 April 2021



Lived experience input to both of these strategic overviews of chronic pain treatment.

The British Pain Society Patient Voice Committee assisted with Four Nations Strategy document.

Lived experience partners on the NICE Chronic Pain committee.

Regional

□ Pain Cafés in the South West



People with lived experience of persistent pain and the harm caused by long-term, high-dose opiate prescribing are driving the design and development of community 'Pain Cafés' in Plymouth, Devon, to support others living with chronic pain to use pain management techniques.

Integrated Care Systems/Boards

RETHINKING
PAIN

Rethinking Pain

A community-based service for people who live with long-term pain.



Rethinking Pain is a service led by [Keighley Healthy Living \(KHL\)](#)
In Partnership and collaboration with HALE, the Voluntary Community Sector,
Bradford District & Craven Health & Care Partnership and Primary Care Networks

OUR PARTNERS



NHS West Yorkshire
Integrated Care Board

Pain Services and Trusts



University College London Hospitals
NHS Foundation Trust



Whittington Health
NHS Trust

Pain Management Centre at NHNN

UCLH (NHNN) Pain Management Centre has a patient partner group

Whittington Hospital Pain Service is exploring setting up a Patient Advisory Group



The VCFSE



**THE BRITISH
PAIN SOCIETY**
EXPERTISE WHERE IT MATTERS

EXPERT PATIENT AND CARER COMMITTEE (EPCC)

- Chair and Vice Chair are both patients
- Runs programmes, i.e. Lived Experience Collective
- Represented across the organisation, including at ASM



TIM ATKINSON
VICE CHAIR

Live Well with Pain

AutoSave Co-production presentation – Saved to my Mac

Home Insert Draw Design Transitions Animations Slide Show Record Review View

Comments Record Share

You are screen sharing Stop share

Primary Care Networks (PCNs)

Youth & Community Worker since 1985 – roles mainly with young people and young adults, carer support with adults & community-facing social prescribing in 5 small rural communities in Somerset since 2019

Lived with Osteoarthritis since 2016 and Burning Mouth Syndrome since 2017 - BMS severely impacted mental health and wellbeing

2 years to diagnosis for BMS – felt unheard – told to ‘make friends with my pain’ – no support offered – I would have given anything to talk to someone else with BMS who understood the impact

2021 - Did LWWP training which transformed the way I understand and live with my pain day by day – wanted to develop support for others with chronic pain in my PCN

Tim Atkinson (ha/him)

Rachel Stovell

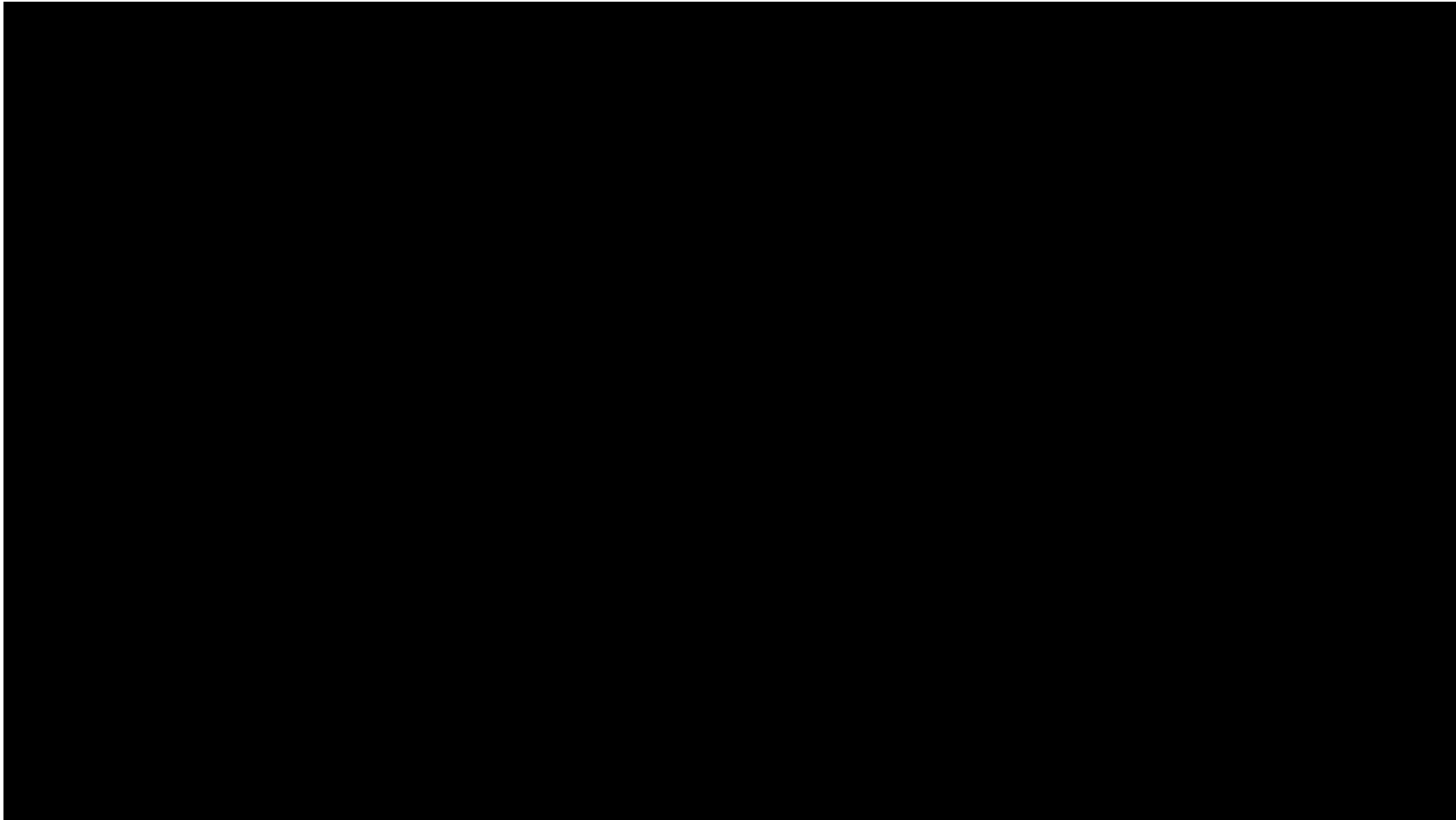
Sue Crisfield Lived Experience Trainer

Darrell Price

Mark Agathangelou

Slide 19 of 32 English (United States) Accessibility: Investigate

Su's story



The VCFSE, Patient-led Projects



Local Patient-led Support Groups



February 2026 edition at a glance:

[CamPain News](#)

[CHIPP Update](#)

[Mindfulness Course](#)

[Other Pain News and Opportunities](#)

[Community News](#)

[Pain Resources](#)

P.S. If these links don't seem to be working, try viewing this email in your browser using the link right at the top.

Hello Friends

We hope everyone has been coping with the cold, wet weather. This can be a difficult time of year for people with pain to deal with. We have some positive news and interesting opportunities to share which will hopefully bring some good cheer to early 2026 for you.

[CamPain News](#)

CHIPP Update

Join a workshop to help plan a new Camden pain project (with vouchers for your time)




Research

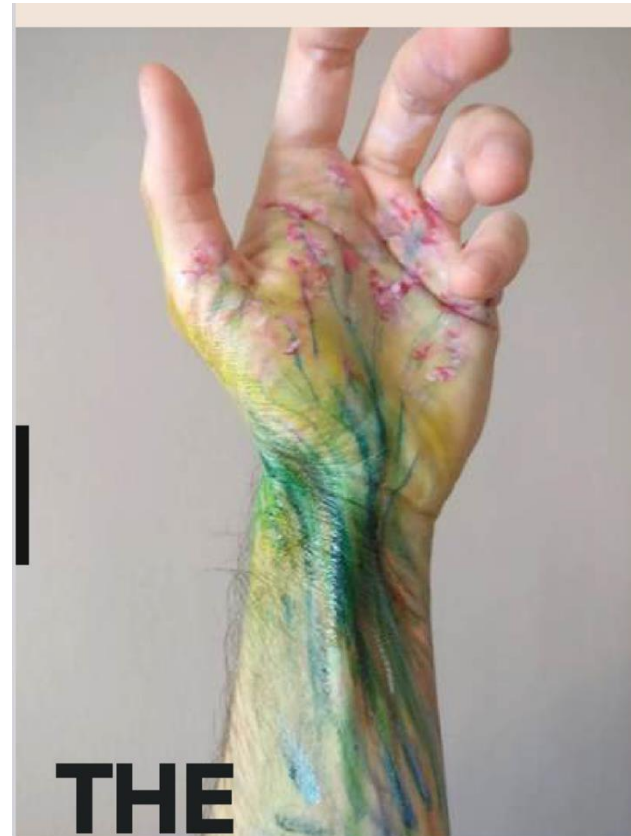


Identifying, Engaging and Involving People Living with Chronic High Impact Pain: A Study for Ambassadors

SARAH HARRISSON, LOUISE TREWERN, KRYSIA CANVIN, MEL HOOPER

Your Voice Matters
Living with Chronic Pain,
Shaping the Future of Research



THE LANGUAGE OF PAIN

PROJECT REPORT AUTUMN 2024



Do you have experience of living with chronic pain that has regularly affected your quality of life?

Do you care for, or regularly connect with someone whose pain had a high impact on their life for 3 months or longer?

Improving care for people living with pain

Have Your Say



YOUR VOICE MATTERS

To improve care for people living with pain, researchers at Keele University and patient **ambassadors** want to talk to *people like you*



YOUR WAY...

We want to talk to *you*. With the ambassador, you decide where and when to meet. You can make your meeting as informal as you like



RESEARCH MATTERS

Research with people with diverse experiences is more likely to result in better care for them and others. Unfortunately, we know that this does not always happen. We're hoping that ambassadors will make it easier for you to get involved and for you to have your say in research



YOUR VIEWS...

The ambassador will want to find out

- about *your* experience of living with pain
- what sort of help *you* want so that you can do the things that matter to you
- what you want to share with researchers



AMBASSADORS ARE...

- People with their own experience of living with pain
- You may already know them, sometimes quite well
- They are involved in activities, like research, in your community that aim to improve care for people like you



REIMBURSEMENT

All those who take part will be offered reimbursement for your time. You can choose to receive a voucher

- by post (choose between Love to Shop or Blackwell's Bookshops) or
- by email (Amazon.co.uk)



NIHR School for Primary Care Research

This project is led by Dr Sarah Harrison (researcher at Keele University and physiotherapist) and Louise Trewern (patient advocate)

Primary Care Networks (PCNs)

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Primary Care Networks (PCNs)

So, what changed?

There was nothing out there for me, so I developed & delivered something I had longed for!

Joined women's gym in 2021 which improved mobility and became stronger and fitter (& prevent osteoporosis) – still going now – 7.5% increase in spine bone density 5 years later.

Put Ten Footsteps into practice & stopped telling myself I couldn't do things – challenging negative thought patterns and developing new neural pathways, with more positive outlook – lots happening – enjoying life – lots of plans for retirement!

Primary Care Networks (PCNs)

Ten Footsteps groups & Pain Cafes

Pilot group with one practice of 12-week LWWP group – 2 hours per week. Led to pain café, then more 12-week groups around PCN. Now have 5 pain cafes, an online evening and young adult's group.

Used my lived experience in planning groups – what would have helped me? What support and information did I need?

Group sessions include movement, positive mindset work, LWWP input resources and info – lots of laughter, fun – PEER SUPPORT IS CENTRAL

Always listening – tweaking – adapting – building community

Neurodivergence & Pain – A Design Challenge



- ADHD and related traits are common in pain populations



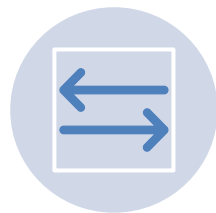
- Attention, energy, and regulation fluctuate



- Many pathways assume consistency and low cognitive load



- Disengagement is often a design issue, not a motivation issue



- Co-production reduces friction and improves usability

Complementary Therapies – A Co-Production Reality

- Many people with persistent pain already use complementary approaches
- This often happens without guidance or integration
- Services rarely acknowledge this wider landscape
- Co-production makes the landscape visible and discussable
- The focus is safe evaluation, pacing, and realistic expectations

Darrell Price: WHY?



Lack of support from GPs



Only offering to manage problem with pain meds & physio



No other types of support in my region, no groups or alternatives (that I could find)



Had to book a private consultation and private MRI Scan before GP referral for Emergency MRI where finally got diagnosed.

Darrell Price: HOW?



Social Prescriber helped me set up a Peer to Peer Pain Support Group in Chesterfield which very quickly grew to be largest in Derbyshire;



Visiting speakers talk about different ways to regard pain and holistic ways of managing it (e.g. sleep, nutrition, grief, activity, complementary therapy and Ten Footsteps Programme;



Successfully grown to include additional 8 week course on the Ten Footsteps which is immediately followed by a 4 week Sleep & Confidence course. Also weekly Chair Based exercise programme in collaboration with CFC Community Trust.

Aims

- Reduce reliance on pain medications - especially opioids
- Enable people to live a better quality of life
- Reduce loneliness and isolation.
- Peer to Peer Pain Support Group
- Fortnightly, Whittington Moor
- 908 attendances to date end of Sept 2025
- 25 average per session
- Approx 500 individual people through the door

Outcomes

Reducing reliance on prescription medications and associated risk of opioid addiction.

Reducing the need to access Mental Health and other NHS services.

Reducing number/cost of GP appointments.

£25k+ estimated savings for a my PCN over 2yr period group has been running

Based on:

- £50 per GP appointment
- 500 individuals through the door
- Each person having just one less GP appointment

Impact

On individuals:

- “Made new friends and gave me great strength.”
- “This group is a lifesaver for me. I don’t think I would be here if it wasn’t for this group.”
- “Great to be with people who really understand our pain.”

Wider impact:

- Reducing loneliness and isolation.
- Helping people implement small, self-led lifestyle adjustments with a big impact.
- Building individual confidence and contribution.

Summary: What does it mean?

Communication: thinking deeply about what's said and how;

Openness: not going in thinking you already know the problem and/or solution;

Equality: not consulting patients after things have already been decided;

Inclusivity: creating an environment that enables everyone to bring their best: not extending privileges but accommodating people whose views need to be heard;

There's good and bad at all levels, but what drives it and makes it successful is having people with pain involved.