



**Health
Innovation**
East Midlands

Let's Live Well With Pain Programme

Implementation Guide



LiveWell
with pain

Contents

3 Introduction

- 3 Purpose of this guide
- 3 Background
- 4 How to implement the Let's Live Well With Pain Programme

6 The Let's Live Well With Pain Programme

- 7 Pre-course
- 8 Six-week course
- 9 Post course
- 9 Useful implementation documentation

10 Resources

- 10 Useful websites
- 11 Information for patients
- 11 Videos and webinars
- 12 Apps for smartphones
- 12 Further reading

13 Appendices

- 13 Appendix 1: Email invitation for patients
- 14 Appendix 2: Health and Well Being Check Tool
- 17 Appendix 3: Let's Live Well With Pain Programme information leaflet
- 18 Appendix 4: Patient feedback survey form

We thank Lister House Surgery, Joined Up Care Derbyshire and Live Well with Pain for working in collaboration with Health Innovation East Midlands to develop, promote and support this pain management programme.

Introduction

PURPOSE OF THIS GUIDE

This toolkit is designed to support healthcare providers to create a local pain management programme (the Let's Live Well With Pain Programme) that supports individuals living with chronic non-cancer pain. The programme supports a self-management approach and advocates active participation. This toolkit aims to provide tested tools and resources to support practices and Primary Care Networks to implement the programme in a way that meets their local needs.

Background

Ongoing (or chronic) non-cancer pain is usually described as pain that lasts over 3 months that is not related to a cancer diagnosis. At this stage, it is unlikely that there is any tissue damage causing the pain, though patients still experience severe pain that can affect their daily activities and overall quality of life.

The National Institute for Health and Care Excellence (NICE) **guidance** (www.nice.org.uk/guidance/NG193) states that opioids should not be offered as an option to patients with chronic pain, as the harm outweighs the benefits. Despite this, according to national prescribing data from NHS Business Service Authority, in January 2021, over one million people in England were prescribed opioids for more than three months.

The Let's Live Well With Pain (LLWWP) Programme is a six-week pain management programme designed to help and support people to:

- Learn effective skills and methods that support the self-management of their pain, allowing them to live better despite experiencing ongoing pain.
- Increase their confidence and knowledge to take control of their own pain management and improve overall well being.

- Learn from and share experiences with other people who are living with ongoing pain.
- Consider how well their pain medication is working for them and access support to review their medication.

The programme has pre and post support to the patient that includes a clinical review of their pain and screening to ensure the person is suitable for the programme.

The Let's Live Well With Pain (LLWWP) Programme was developed by Health and Wellbeing Coaches from Lister House Surgery in Derby following the ten footsteps approach which recognises self-management as key to living well with pain and improving quality of life. The programme is intended to be adapted to suit local capacity and needs, but to support planning, the method used by Lister House is also provided in italics and clearly marked as the *LH model*.

We recommend that anyone wishing to implement this programme and approach should make themselves familiar with the resources available on the [Live Well with Pain website](https://livewellwithpain.co.uk) (<https://livewellwithpain.co.uk>).

How to implement the Let's Live Well With Pain Programme

There are a number of things to consider before implementing the programme and we have listed these below to help you plan your own programme.



Identify the need

As a practice or Primary Care Network, consider the regular challenges faced when supporting patients living with chronic pain. Listen to your patients. Do they want peer groups and do not currently have access, or cannot travel to them? Have a look at some data for the practice e.g. pain medication prescribing, number of people with certain conditions. Are certain populations more in need of support? Be clear about the benefits that the course could bring to your patient population and healthcare team.



Identify your support and skill set

The programme requires people to fill vital roles, with the capacity and skill set to support including a:

- Lead GP to provide clinical support and direction to the programme.
- Facilitator (preferably more than one person who can undertake this role).
- Clinician to undertake post course medication reviews.
- Clinician to screen people for suitability for the programme.
- Social prescriber and health and wellbeing coaches.
- Administration.

Live Well with Pain provide an excellent [short course \(https://livewellwithpain.co.uk/dashboard/training-zone\)](https://livewellwithpain.co.uk/dashboard/training-zone) that supports people to practitioner level on the ten footsteps approach and can be useful, especially for facilitators.



Identify your location

Find a room that will be able to hold the number of people you wish to attend (perhaps 10 or 12, plus family or carers, plus facilitators) with enough room and facilities for some light activities. Are there facilities to make a drink? Is it available at the same time each week?

Avoid rooms that require attendees to climb stairs if possible and the layout should be wheelchair accessible.

One of the positives about this course is that it aims to be run in the community where the person lives, making travel easier. Public transport, travel and parking should all be considered in deciding the venue.

If your practice does not have a suitable room consider approaching the local authority for support as well as local leisure centres and libraries.



Timing of the meeting

It is useful to keep the same timing and day each week. Try and avoid early mornings and running over lunchtime. You can consider changing the day and time for different courses to accommodate preferences.



Involve everyone

To make the course a success all practice staff should be aware of the course, its aims, content, and how to refer people into it. Consider advertising the course in practices and with patient groups.



Measure your progress

Think early about what success would look like for the programme and how that can be measured. Try and use data that you are already collecting. The Pain Health Check survey, suggested in the programme, and taken at the beginning and end of the programme can provide useful data. Data can include:

- Quantitative data (i.e. numbers) such as:
 - Number of patients attended/on the waiting list
 - Change in opioid dosage before and 6 months after the course
 - Change in scoring for mood or activity
- Qualitative data (i.e. descriptive) such as:
 - Case studies
 - Free-text feedback on the course

Measuring helps you to understand how to improve the course, evidence the value of the course, and allows you to celebrate your success.

The Let's Live Well With Pain Programme

THE PROGRAMME HAS THREE DEFINED PERIODS:

- Pre-course
- Six-week course
- Post course

These periods are detailed in the sections below and summarised in Figure 1

Let's Live Well With Pain Programme Outline

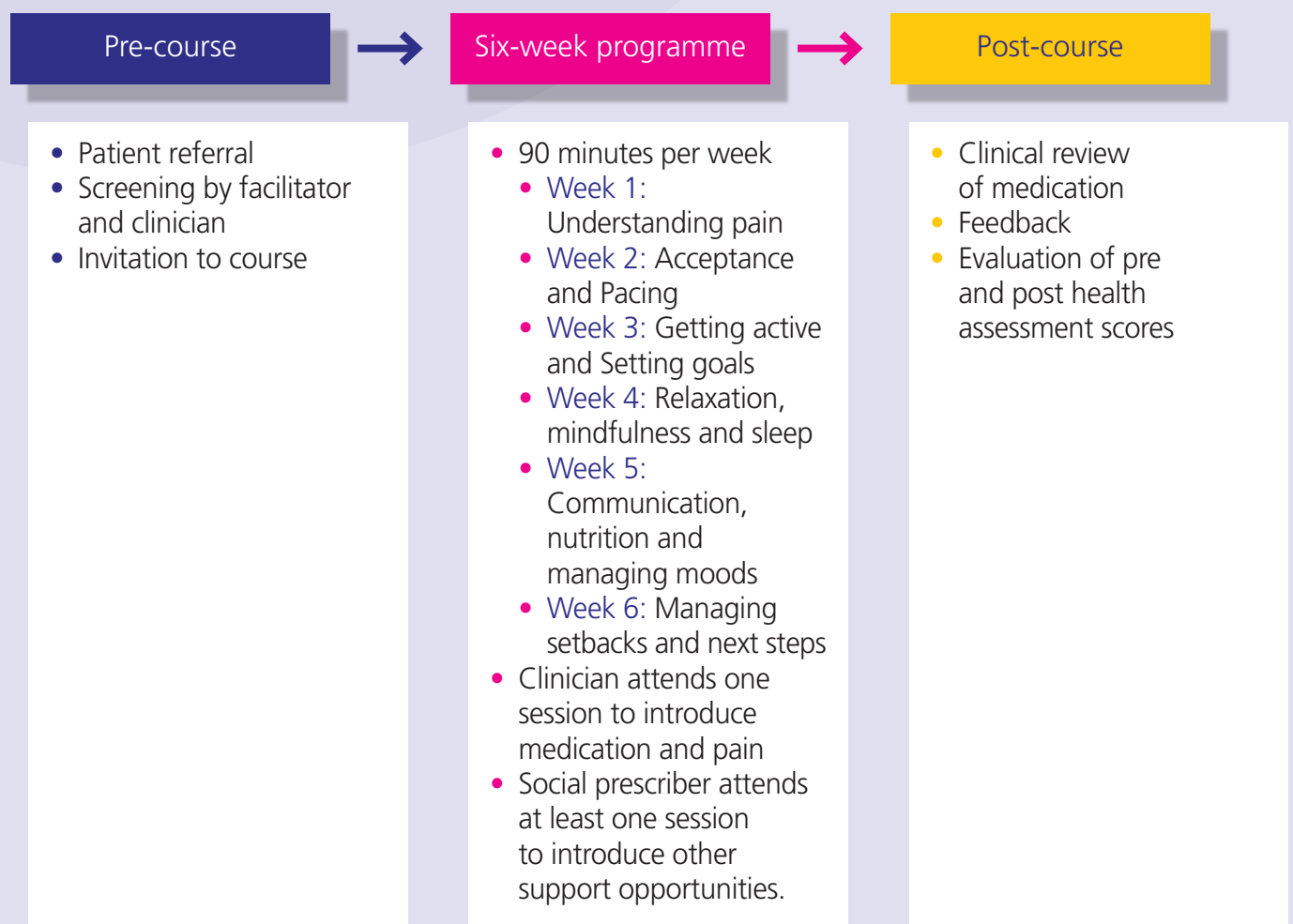


Figure 1: Outline of the Let's Live Well With Pain Programme

Pre-course

1. The patient is referred to the programme in line with the agreed criteria (*LH model: Referral can be made by anyone in the practice, clinician or non-clinician. Criteria for inclusion were:*

 - a. Any patient that is living with chronic pain such as Fibromyalgia, Chronic fatigue syndrome, Osteoarthritis etc.*
 - b. Patients within the associated practice/PCN.*
 - c. Patients who can commit to attending a six-week programme).*
2. A facilitator screens the referral. The patient is contacted by the facilitator to understand their pain journey, to check suitability, explain the course, and confirm how they would like to be contacted about the course. (*LH model: The facilitator is a health and wellbeing coach*)
3. Patients are added to the waiting list to be screened by a clinician to ensure suitability and a diagnosis of chronic (ongoing) pain which cannot be treated by medical intervention. (*LH model: The clinician is a physiotherapist with referral to a GP if needed*).
4. Once a patient is suitable they are placed on a waiting list for the course. Participants are contacted by their preferred route to invite them to an appropriate cohort and the date and location are confirmed. Accurx can be a useful tool for sending out invitations. An email invitation is also sent out that includes a Let's Live Well With Pain Programme information leaflet and Health and Well Being Check Tool (see appendices).

TOP TIPS



- Invite many more patients than there are places.
- Experience would suggest 10 or 12 people is the maximum that an experienced single facilitator can manage on a course, but they may need assistance when people arrive.
- When introducing the course to patients, it can be useful to be clear that the course does not focus on medication and that reducing medication is not the aim of the course but learning to live well with pain is.

Six-week course

The Let's Live Well With Pain Programme is designed to run over six weeks, with patients attending for 90 minutes, once a week. Each session contains:

- A 30–45 minutes discussion focused on the ten footsteps of living well with pain to support self-management.
- 30-45 minutes of low/moderate physical activity, a creative activity, or relaxation activity.

Patients are encouraged to share their own skills/methods with the group. The sessions are led by a facilitator that has been trained and understands the ten footsteps approach and has ideally completed the practitioner training offered by Live Well with Pain. *(LH model: The facilitators were Health and Well Being Coaches and the sessions were run face to face in a venue in the local community).*

Each week has a different focus:

Week 1: Understanding pain (footstep 1)

Week 2: Acceptance and pacing (footsteps 2 and 3)

Week 3: Getting active and setting goals (footstep 4)

Week 4: Relaxation, mindfulness and sleep (footstep 5 and 6)

Week 5: Communication, nutrition and managing moods (footsteps 7, 8 and 9)

Week 6: Managing setbacks and next steps (footstep 10)

- Family members/carers are welcome to attend any of the sessions, but it is most useful in week six when considering the next steps and further support needs.
- Patients are provided with resources/information on community groups/exercise/activity that is available in the area, especially at the last session when the social prescriber supports discussion about next steps and any further support needed is planned.
- Midway through the course, begin planning and assisting in the formulation of peer groups. Offer peer support training to those who want it. The creation of these peer groups supports the group after the completion of the programme. *(LH model: These discussions were supported by a social prescriber.)*
- It is useful to introduce the practice pharmacist or other clinician that will be offering the post course medication review in week 3 or 4. The topic of medication in chronic pain should be introduced and the offer of a medication review mentioned. This allows the attendees to meet the clinician ahead of the consultation.

TOP TIPS



- Providing hot drinks and a biscuit at the beginning of the session helps informal conversations and cohesion in the group.
- At the end of each session the plan and topic for the next session is shared with the attendees.
- During the course you may be able to identify attendees that would be willing to support future courses.

Post course

1. If not completed at week 6, participants are asked to complete the [Live Well with Pain Health and Well Being Check tool](#) (Appendix two) (paper version or digitally if available) which can be compared to the one completed prior to starting the six-week course.
2. Within one month of the course completing, the attendees are invited to attend an appointment with a clinician (*LH model: This was a clinical pharmacist*) about their medications, to have a Structured Medication Review, and have a conversation about their opioid medication if appropriate. Ideally this should be the clinician they met during the programme.
3. Patients are asked if they wish to provide feedback for future programmes.
4. The facilitator will contact attendees to follow up on any outstanding care needs if required.

USEFUL IMPLEMENTATION DOCUMENTATION



As part of the Let's Live Well With Pain programme a suite of resources has been developed. These are provided in the appendices and are summarised in Figure 2. The delivery booklet is a separate document that is intended to support facilitators.

Resources available in appendices



Figure 2: Summary of resources in the appendix

Resources

This section provides information on additional resources, support groups, and services available to individuals managing chronic non-cancer pain. This list is not exhaustive and should be used as a guide.

Useful websites



Explaining pain – why things hurt, pain management advice and support.

- www.tamethebeast.org
- www.knowpain.co.uk – click on resources tab, booklets and open the Tazzy Persistent Pain Booklet
- www.livewellwithpain.co.uk
- www.retrainpain.org
- www.action-on-pain.co.uk

Explaining CFS/ME – causes, diagnosis, management and support for those living with the CFS/ME

- www.nhs.uk/video/Pages/CFSexpert.aspx
- www.actionforme.org.uk
- www.meassociation.org.uk
- www.fmauk.org

Mental Health Support

- www.mind.org.uk
- www.mentalhealth.org.uk
- <https://insighttimer.com>

Medication Support

- www.nottsapc.nhs.uk/de-prescribing

Mindfulness – A range of information and mindful practices to try.

- www.franticworld.com
- www.ummhealth.org/center-mindfulness
- www.stressreductiontapes.com
- www.wildmind.org

Guided videos to help stay active or increase activity levels.

- www.nhs.uk/conditions/nhs-fitness-studio – a range of movement options to explore
- www.nhs.uk/live-well/exercise/10-minute-workouts
- www.nice.org.uk/guidance/NG193

Information for patients



- **Explaining Pain**
Available at: <https://livewellwithpain.co.uk/wp-content/uploads/2022/09/explaining-pain.pdf>
- **Pain Concern: Self-Management Navigator Tool**
Available at: <https://painconcern.org.uk/the-navigator-tool>
- **Risks of Opioid Medications**
Available at: <https://livewellwithpain.co.uk/wp-content/uploads/2022/09/Risks-of-Opioid-Medications.pdf>
- **The Pain and Self-Care Cycles**
Available at: <https://livewellwithpain.co.uk/wp-content/uploads/2022/09/the-pain-cycle-v02.pdf>
- **The Pain Toolkit videos**
Available at: www.paintoolkit.org/pain-tools
- **Tame the Beast**
Available at: www.youtube.com/watch?v=ikUzvSph7Z4
- **The 10 Footsteps**
Available at: <https://livewellwithpain.co.uk/ten-footsteps-programme/managing-setbacks>

Videos and webinars



- [Life After Opioids](#) from [Live Well with Pain](#). After more than a decade and a half of trying – unsuccessfully – to deal with her fibromyalgia through opioids, Louise finally decided that one way or another, she was going to have to manage her pain another way ... In Louise's words: "I got my life back – I'm living proof that there really is life after opioids!"
[A Live Well with Pain production \(duration: 23 minutes\)](#)
- East Midlands Academic Health Science Network. Implementing a realistic approach to pain management part 1, Dr Cathy Stannard. [Available here](#).
- East Midlands Academic Health Science Network. Implementing a realistic approach to pain management part 2, Dr Francis Cole. [Available here](#).
- North Shields PCN, North Tyneside. Persistent Pain Management. Dr Dave Thomson (GP and Clinical Director). [Available here](#).
- North West London Integrated Care System. Chronic Pain Management webinars (2022-2023). [Available here](#).
- PrescQIPP Clinical Masterclass – May 2022 Dr Cathy Stannard who spoke about the NICE guideline on Medicines associated with dependence or withdrawal symptoms: safe prescribing and withdrawal management for adults. [Available here](#).
- West of England Patient Safety Collaborative. Improving chronic pain management: reducing harm from opioids (Aug 2022). [Available here](#).
- Yorkshire and Humber Academic Health Science Network. Reducing harm from opioids in chronic non-cancer pain management (Jan 2023). [Available here](#).



Resources

Apps for smartphones

- Insight meditation - free
- Headspace - free introductory period of 10 days



Further reading

- **Explain Pain**
By: David Butler & G. Lorimer Moseley
- **Living well with pain and illness, using mindfulness to free yourself from suffering.**
By: Vidyamala Burch
- **Painful Yarns**
By: G. Lorimer Moseley
- **Mindfulness for Health, a practical guide to relieving pain, reducing stress and restoring wellbeing.**
By Vidyamala Burch and Danny Penman
- **The Happiness Trap and The Reality Slap**
By Russ Harris.
- **The mindful guide to self – compassion.**
By Christopher K. Germer.
- **Self-Compassion, Stop beating yourself up and leave insecurity behind**
By Kristen Neff.
- **The mindful way through depression.**
John Teasdale and others (has CD with it).
- **Journey into Mindfulness. Gentle ways to let go of stress and live in the moment**
Dr Patrizia Collard
- **Mindfulness: a practical guide to finding peace in a frantic world**
By Mark Williams and Danny Penman (CD comes with the book)



Appendices

Appendix 1: Email invitation for patients

To be sent after the facilitator has confirmed with the patient that they are able to attend the course. The email should be sent with the Let's Live Well With Pain Programme information leaflet and Live Well with Pain Health and Well Being Check tool.

Welcome to the Let's Live Well With Pain Programme!

We are pleased you will be joining us on this programme to help you self-manage and live your life well despite the pain you are experiencing. Please read this email carefully as it contains important details of the programme, as well as what you should do **before** arriving at the first class.

Details of your first class:

Location:	
Date:	
Time:	

Note: there will be one class per week for six weeks.

What you should do before/during your first class:

To make sure the programme continues to be successful; you'll be asked to complete a **Live Well with Pain Health Check form** (attached) about how your pain affects your life. You'll also be asked to complete the assessment again at the end of the **6-week** programme. This information is useful to see **how much progress you have made** and to keep track of how the programme is helping people.

What to bring to your first class:

Please wear some loose-fitting clothing, comfortable shoes, and bring a water bottle.

If you have any questions, please contact me.

I look forward to welcoming you soon.

Appendix 2: Live Well with Pain Health and Well Being Check tool

The resources from the Live Well with Pain programme are reviewed and updated on their website. Please check www.livewellwithpain.co.uk for the latest versions.



Live Well with Pain Health and Well Being Check

Exploring how pain affects your health and life

Please help us understand about your health and the main obstacles to improving your quality of life and self managing with confidence.

There are **four steps** to completing this Health and Well Being Check. Please complete all four steps – tick or circle all the answers that apply to you.

STEP 1 How do you feel?

For each statement please circle which is closest to how you have been feeling over the past two weeks

	all of the time	most of the time	more than half the time	less than half the time	some of the time	at no time
I have felt cheerful and in good spirits	5	4	3	2	1	0
I have felt calm and relaxed	5	4	3	2	1	0
I have felt active and vigorous	5	4	3	2	1	0
I woke up feeling fresh and rested	5	4	3	2	1	0
My daily life has been filled with things that interest me	5	4	3	2	1	0

STEP 2**Tell us a bit about your pain****Your current level of pain**

Circle one of the numbers on the scale to rate your pain level at present.

0 = 'No pain' 10 = 'Worst/extreme pain'

0 1 2 3 4 5 6 7 8 9 10

Your pain over the last seven days

Circle the number on the scale to rate **how distressing** the pain was on average over the last seven days.

0 = 'No distress' 10 = 'Extremely distressing'

0 1 2 3 4 5 6 7 8 9 10

Managing your pain

Please rate **how confident you are** that you can do the following things at present, despite the pain. Circle one of the numbers on each of the scales.

0 = 'Not at all confident' 6 = 'Completely confident'

"I can live a normal lifestyle, despite the pain"

0 1 2 3 4 5 6

"I can do some form of work, despite the pain"

0 1 2 3 4 5 6

(work includes housework, paid and unpaid work)

STEP 3**Do you have any problems or difficulties with:**

- 1 Walking or moving about, lack of fitness and stamina
- 2 Balance or recurrent falls
- 3 Side effects or problems with current pain medication e.g. tablets etc.
- 4 Pain relief
- 5 Understanding why persistent pain occurs
- 6 An unhelpful pattern of activity of doing too much, getting more pain, then doing too little
- 7 Eating the right sort of foods, weight changes
- 8 Disturbed sleep, tiredness or lack of energy
- 9 Managing mood changes of depression, anger, anxiety or worry
- 10 Relationship difficulties: with partner, family etc, or sex life concerns
- 11 Remaining in work or returning to work and/or training
- 12 Financial or money difficulties
- 13 Other difficulties (for example, concerns about housing, leisure or social events, drinking, gambling or drug use). Please describe here:

STEP 4

If you ticked more than three boxes above, please circle the three most important ones to change.

Have you completed all four steps?

Please have the completed form with you at your **pain management and medicines review**. We will look at it together to help explore your concerns, issues and problems linked to your pain. Thank you for helping us understand how your pain is affecting your health and life.

Your name

Your date of birth

Date filled in

Appendix 3: Let's Live Well With Pain Programme information leaflet

Testimonials



"Knowing that I've got somewhere to come where I can say what has happened this week and get people's ideas of how to cope with that. But also gaining all the knowledge and the exercises are really good."

"Coming to the group has helped me quite a lot with my confidence, it's got a lot better. There are times where I do struggle and normally if I was struggling I wouldn't come out, I'd stay in. But I feel comfortable in this group and everybody is friendly and everybody understands."

"I just like being around other people who have the same sort of problems as me. It's nice to get out and be together with other people."

"I find it really good and I enjoy seeing other people when I'm here, it's social as well as good for me."



Contact Us



Do you live with ongoing pain?

Let's Live Well With Pain Programme

An opportunity for enabling self-management and coping for people living with ongoing pain.



What is the Let's Live Well With Pain Programme?

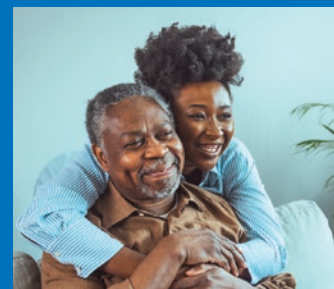
The Let's Live Well With Pain Programme is designed to support people living with ongoing pain. Over six weeks attendees will learn techniques to improve their quality of life, despite the pain they are experiencing.

What will I get from attending a class?

- Information, advice and support to help you better manage ongoing pain and lead an improved quality of life
- Exercises tailored to individual needs
- A chance to socialise with and learn from other people living with ongoing pain
- An opportunity to try new skills and activities

Next available class

Contact us to find out when our next available programme is.



How to sign up



You are able to join the group by doing a self-referral through your GP surgery.

Ask your GP for a referral to the Let's Live Well With Pain Programme. The Health and Wellbeing Team will then contact you to book you on to the programme.



Appendix 4: Patient feedback survey form

Let's Live Well with Pain Programme Satisfaction Survey

Please tell us about your experience of the course to help us to improve.
Please use the box below to describe your ongoing pain

Please tick or circle a star rating of between ☆ and ☆☆☆☆☆ for each question

How appropriate was the course to support you to Live Well with Pain?	☆	☆☆	☆☆ ☆	☆☆ ☆☆	☆☆☆☆☆
How accessible was the venue?	☆	☆☆	☆☆ ☆	☆☆ ☆☆	☆☆☆☆☆
How convenient was the time of the sessions?	☆	☆☆	☆☆ ☆	☆☆ ☆☆	☆☆☆☆☆
How helpful was the sharing/discussion?	☆	☆☆	☆☆ ☆	☆☆ ☆☆	☆☆☆☆☆
How helpful was the section for physical activity?	☆	☆☆	☆☆ ☆	☆☆ ☆☆	☆☆☆☆☆
How helpful was the section for creative activities?	☆	☆☆	☆☆ ☆	☆☆ ☆☆	☆☆☆☆☆

Please write any comments about the venue, times, content of the course in the box below

Please tell us about your experience of the course in the box below.

Are there any things you would add or change to the course content that you think would be helpful to you?

Yes No If yes, please can you tell us about them below:

Please use the box below for any other comments about the course

Would you recommend this course to other people living with pain?

Yes No

Please give reasons for your answer in the box below

Many thanks for filling out this satisfaction survey.



Contact us

Health Innovation East Midlands
Sir Colin Campbell Building
University of Nottingham Innovation Park
Triumph Road
Nottingham
NG7 2TU

 healthinnovation-em@nottingham.ac.uk

 www.healthinnovation-em.org.uk

Follow us on X (formerly twitter): @healthinn_em

For updates, sign up to our newsletters at: www.healthinnovation-em.org.uk/updates