PAIN ASSOCIATION SCOTLAND

Self-Management Courses for Chronic Pain

Overall outcomes for all Courses delivered Scotland-wide 2024-25

Contents

This report provides evaluation results from 16 self-management courses for people with chronic pain delivered during the 2024/25 financial year.

This report gives a description, background and rationale of the service followed by combined results from the courses. Conclusions and a summary are provided at the end of the report. Thereafter there is a discussion on the trajectory needed for future of pain services in Scotland.

Overview of work

Pain Association Scotland provides specialist education, training and support in the self-management of chronic pain. The organisation has developed expertise in an effective interactive person-centred approach which helps to engage people in the principles of self-management and motivates them to adopt new ways of thinking based on a better understanding of their health and themselves.

Self-management is a core driver of reform in health and social care in Scotland, including the National Clinical Strategy, the Chief Medical Officer's report on Realistic Medicine and Making It Easier, the National Health Literacy Action Plan.

In general terms, self-management can be described as a set of approaches which aim to enable people to feel able to live well on their terms with a long term condition. It includes a spectrum of support that help someone to learn about their condition, acknowledge the impact it has on their life, make changes and identify areas where they require support. A simple definition that we sometimes use is: self-management simply means anything that you can do to improve the quality of your life. We sometimes add: There are lots of things that make pain worse that you're in charge of, that your doctor can't affect much: like stress, anxiety, communication, confidence, sleep, pacing, understanding pain, attitudes and your relationship with pain.

In the UK, defining chronic pain requires a careful, multidisciplinary approach that encompasses medical, psychological, and sociocultural factors. Chronic pain is typically understood within the framework of the International Association for the Study of Pain (IASP), which defines it as pain persisting for more than three months. This duration-based definition recognizes that pain which extends beyond the normal healing time becomes distinct from acute pain, transitioning into a complex condition often independent of the original injury or pathology.

In the UK, academic and clinical definitions of chronic pain increasingly acknowledge its biopsychosocial dimensions. Chronic pain is not merely a symptom but a condition that can result in significant disability, affecting an individual's quality of life, mental health, and social functioning. As noted in UK healthcare policy, chronic pain management includes not only medical interventions but also the integration of psychological therapies and social support systems, underscoring the importance of viewing chronic pain within a holistic care model.

Moreover, recent discourse in the UK highlights the tension between biomedical definitions of chronic pain and the lived experiences of patients. This is particularly evident in debates surrounding invisible illnesses, such as fibromyalgia, where pain is often subjective and lacks clear physiological markers. Academically, there is a push towards embracing patient-reported outcomes and moving beyond a purely biomedical approach towards more inclusive definitions that validate subjective experiences of pain.

Understanding chronic pain

Chronic pain is a major personal, social and economic issue. For the majority of those suffering from chronic pain, it is not about the length of time they have had the pain, it's about the loss of function, loss of identity, loss of mental health and indeed for many, a loss of hope. (*Eccleston, 2011, 2016*). [1]

The bigger economic and societal impacts of chronic pain are often overlooked. There are significant direct costs associated with chronic pain, these include: hospitalisation and outpatient care, medication and equipment to improve activities of daily living. Indirect societal costs are dominated by social benefits, unemployment benefits, sick leave, productivity losses, absenteeism and early disability retirement – quite often for those who are to become carers too. (*Nielsen, 2013; Valentin et al, 2016*).[2]

Chronic pain is a significant public health issue in Scotland, affecting individuals' quality of life and the healthcare system. It is estimated that 1 in 5 people in Scotland suffer from chronic pain, with a higher prevalence in older adults and those in socioeconomically disadvantaged areas.

During this period (2024/25) the courses were delivered with collaboration from Angus Health and Social Care Partnership, NHS Tayside, NHS Western Isles and NHS Dumfries and Galloway.

16 Intensive Self-Management Courses were delivered for **206** referrals with a **97%** completion rate for all those who started the courses. The majority of referrals were from the Pain Clinic, closely followed by self-referrals from GP Primary Care. One will appreciate that this can often be challenging as in effect, any referrals from the GP or community mean that a patient hasn't necessarily been medically triaged in order to ascertain their engagement with self-management so often such patients can be harder to help.

Looking forward, we need to be mindful that the effects of COVID will be felt for a long time in the pain world. Increased demand will meet with limited capacity – lengthy waiting lists are inevitable. We have therefore done a lot of work over the last 12 months to provide initial first appointment introductory sessions as well as introductory videos so that people would be able to have an understanding of what the course is about as well as self-management. The important message here is that people know that they are not alone and that self-management doesn't mean going it alone.

There is an urgent need to sustain and increase our capacity and address the demands of clinicians and patients who wish to see our services as an integral part of their local provision. This need is made all the more pressing by the implementation of the Scottish Government's directive to all Health Boards and Councils to roll out a combined/ integrated Health and Social Care Service.

Our unique model of community based education and support programmes, delivered in collaboration with referring Health and Social Care professionals has been developed to improve quality of life and well-being. Key features are:

- ✓ *Person–centred and outcomes focused*
- ✓ *Enables people to live independently in the community by improving quality of life for people with chronic pain and their carers*
- ✓ *Collaboration and joint working amongst and within agencies and organisations to improve outcomes for service users*
- ✓ *Co-operation with service users and carers in assessment and support as well as in the planning, development and delivery of services.*

Improved collaboration and referral processes enable better patient access to courses (speed and location) enabling them to utilise this vital paradigm of care. The service provides part of a viable exit strategy for people who have reached the end of their clinical pathway and as such helps to break 'revolving door' cycle that many patients get stuck in.

There are some key points to note regarding a public health significance:

Prevalence and Burden:

- Chronic pain affects around 38% of the Scottish population. However, one could argue that the code of chronic pain (1M52) is currently inadequate and the reporting of chronic pain wait times is irregular due to the capacity and

facility present within different health boards. This coding is also only used if chronic pain is the only presenting condition. However, if chronic pain is the result of a primary condition, then it is this condition which is coded and not the chronic pain. This includes conditions like arthritis, back pain, and neuropathic pain. It often leads to disability, limiting people's ability to work, socialize, and engage in daily activities. This contributes to economic burdens, both personal and societal.

Impact on Healthcare System:

- Chronic pain is a leading cause of GP consultations in Scotland, contributing to high healthcare costs. Patients with chronic pain often require multidisciplinary care involving general practitioners, physiotherapists, psychologists, and pain specialists.

Increased demand for pain management services, including medication, physiotherapy, and psychological support, has stretched the healthcare system.

Mental Health Implications:

- Chronic pain is closely associated with mental health conditions, particularly depression and anxiety. In Scotland, those with chronic pain are significantly more likely to experience these mental health issues often compounded with those living in high areas of deprivation. Managing chronic pain often requires addressing both physical and mental aspects, increasing the need for integrated care approaches.

Socioeconomic Inequalities:

- Chronic pain disproportionately affects people in deprived areas in Scotland, where access to healthcare and support services may be more limited. Individuals in lower socioeconomic groups report higher levels of pain, more severe pain, and worse outcomes, exacerbating health inequalities.

Workplace Absenteeism and Disability:

- Chronic pain is a leading cause of long-term sick leave and workplace absenteeism in Scotland. It is also a major reason for individuals seeking certain disability benefits, thus placing a financial strain on social welfare systems.

Public Health Initiatives:

- Scotland has recognized the need for better management of chronic pain. The Scottish Government’s Chronic Pain Improvement Plan (updated 2019) aims to:

- Improve access to pain management services.

- Provide self-management support to help individuals cope with pain.

- Promote early intervention and preventative measures to reduce the long-term impact of chronic pain.

- Initiatives to raise awareness, improve pain education among healthcare professionals, and invest in mental health support are critical components of addressing this public health challenge.

In summary, chronic pain in Scotland is a significant public health concern due to its high prevalence, impact on mental health, contribution to healthcare demand, and exacerbation of social inequalities. Effective public health strategies are needed to manage and mitigate its effects on individuals and society.

Overall service, style and rationale

Our service delivery is person-centred and based on Engel's bio-psycho-social model, which is the gold standard model to understand chronic pain and challenges the concept of mind-body dualism (which has the potential for stigmatisation of Secondary pain experiences). [3,4] This means that the work is not just about pain, but rather deals with pain in the wider context of life, health and well-being. We provide a combination of education, training and support in a group setting that encourages peer support and thereby engenders normalisation. Working with people in this group context means that they can hear from others in a similar situation, discuss ideas, benefit from mutual support and thereby integrate self-management into everyday life.

From a cost perspective, poorly controlled chronic pain often results in less productivity, hospitalisations and use of other healthcare resources. Self-management education and learning programmes help people to become more independent and ultimately less reliant on costly external resources.

In addition to the courses provided during this period, the Association have also provided monthly staff led groups within various health board areas throughout Scotland (funding permitting). These groups provide vital on-going education and peer support and are delivered using a blended model. This network enables people attending the courses to maintain their skills, understanding and motivation. The groups also offer the areas in which they run, early access to self-management. The combination of self- management courses backed up by an ongoing monthly groups is a very effective way to create positive change and then keep it going throughout the year. Participants on the courses often comment that they are very impressed and comforted by the opportunity for on-going support after the course has finished. Some comment that the benefit of other courses they have attended faded quickly without ongoing maintenance.

Pain Association Scotland's Self-Management Course for Chronic Pain

Pain Association Scotland is keen to encourage all interventions for chronic pain and sees the self-management course as sitting alongside other more specialist treatments and interventions.

Scotland's health reform heavily involves third-sector organizations who provide resources and support for self-management. If the value of self-management and reducing people's long-term reliance on specialist services and treatments which demonstrate low clinical efficacy is clear, then patients need help to be better engaged with the concept of self-management. It is appreciated that time is maybe limited to explain self-management and it is also recognise that many people might not absorb all the details during a GP appointment, but this is maybe an example of the type of action needed within future framework around pathways, language and a more holistic modelling approach – a further rationale for this paper.
In terms of Data as a Primary Driver, it would be welcomed for agreed key measured outcomes (not necessarily outputs) to be recognised for the effectiveness of third sector provision.

Chronic pain care faces several significant gaps that affect both patients and healthcare systems worldwide, including in Scotland. These gaps limit the effectiveness of chronic pain management, contributing to reduced quality of life, increased healthcare costs, and poor long-term outcomes. Below we discuss some of key care gaps in chronic pain management:

Delayed Diagnosis and Access to Care - long waiting times for pain clinic appointments and specialist care are common. In many cases, patients wait months or even years to access pain specialists, leaving them without appropriate treatment for prolonged periods. Primary care providers often struggle to diagnose chronic pain conditions early due to the complexity of symptoms, leading to delays in treatment and worsening of symptoms over time. To further compound this, limited availability of specialized pain services, particularly in rural areas, exacerbates access issues, with disparities in care between urban and rural populations.

Insufficient Multidisciplinary Care - chronic pain requires a multidisciplinary approach, involving doctors, physiotherapists, psychologists, and other specialists. However, many healthcare systems lack integrated, team-based approaches to pain management, leading to fragmented care. Many simply do not have the budgets or resources for this. Therefore, access to multimodal therapies —combining physical therapy, psychological interventions, and medication—is often limited. Patients may receive one type of treatment, such as medication, but miss out on other important therapies like cognitive behavioural therapy (CBT) or physical rehabilitation.

Overreliance on Medications, Especially Opioids - one of the most critical care gaps in chronic pain management is the overreliance on pharmacological treatments, particularly opioids. Opioids are commonly prescribed due to the lack of immediate

alternatives, but long-term use can lead to dependence, tolerance, and even overdose. Many papers report the issue of there being a lack of access to non-pharmacological treatments such as physical therapy, psychological support, and alternative therapies, forcing healthcare providers to rely on medications as a first-line treatment. However, one could argue that some healthcare professionals prefer to explore the more "evidenced-based" medicines before exploring a more holistic approach. A study of disability in relation to a range of physical and medical conditions showed that chronic pain was the single condition which contributed the most to disability measures in all European regions (*Barbaglia et al, 2017*) [(5)]. We know that there are many variations within chronic pain prescribing and there is much debate around addiction and misuse of chronic pain medications. In most countries of the world, self-management with little clinical intervention is actually the first and most widely used approach for the management of pain by patients. So, the question is why, in the UK, are we getting it so wrong?
Additionally, many patients face difficulties in managing medication side effects, especially from opioids, which can lead to further health complications.

Limited Mental Health Support - chronic pain is frequently associated with mental health conditions like depression, anxiety, and stress, but there is often insufficient integration of mental health services into pain management, often due to complex pathways. Many patients report a lack of psychological support within their pain journey, even though evidence suggests that addressing the emotional and psychological aspects of chronic pain can improve outcomes. Stigma surrounding mental health and chronic pain often discourages patients from seeking psychological care, even when they experience emotional distress related to their condition.

Inadequate Patient Education and Self-Management Support - patients often report that they are not adequately informed about their condition or the available treatment options, leading to frustration and a sense of helplessness. There is a significant gap in providing self-management resources and education, which could empower patients to manage their condition more effectively between healthcare visits. One could argue that access to digital tools for pain tracking, education, and self-management is improving but remains inconsistent, with some populations lacking access to these resources due to socioeconomic or geographic barriers.

Health Inequalities and Socioeconomic Barriers - chronic pain care gaps are more pronounced in socioeconomically disadvantaged populations, where individuals often face higher rates of pain but have limited access to care. Disparities exist based on geography, income level, and education, with individuals in rural or underserved communities having more difficulty accessing specialists and comprehensive pain care. Costs related to chronic pain treatments, particularly for services not covered by public health systems (like physical therapy, psychological support, or alternative treatments), can further limit access for those from lower-income backgrounds.

Lack of Personalized Care Plans - many chronic pain patients do not receive personalized treatment plans tailored to their specific needs, symptoms, and life circumstances. Instead, care is often generalized, focusing on short-term symptom relief rather than long-term management. Patients with complex, overlapping health issues (e.g., chronic pain and mental health conditions) often fall through the cracks due to poor coordination and navigation between different parts of the healthcare system.

Undertraining of Healthcare Providers - Primary care providers, who are often the first point of contact for patients with chronic pain, may receive insufficient training in pain management, leading to underdiagnosis or inappropriate treatment. Pain education among clinicians needs to be drastically improved and healthcare professionals' experience inadequate pain education as undergraduates (*Briggs et al, 2011*) [6]. Anaesthesia is the only medical speciality that has recognised postgraduate pain training in medicine, although palliative care medicine does include pain management training as a core activity. Therefore, considering the above, when one looks at the possible opportunities, there is certainly much more to do within Scotland in terms of statutory pain education. The messages given by referring clinicians can make a huge difference, but unfortunately there is wide. Some people are well briefed whilst others say that they were just told to attend without explanation. We seek to fill this gap in the pre-course information and when people join the course, but what clinicians say always carries a great deal of weight.

Lack of Long-Term Follow-Up and Monitoring - many patients with chronic pain do not receive regular long-term follow-up care, leading to inconsistent treatment and poor management of their condition. Without consistent follow-up, healthcare providers may miss opportunities to adjust treatment plans according to need or intervene when pain becomes more severe or impacts other areas of life. The lack of chronic disease monitoring systems for pain conditions is a significant barrier to providing continuous and adaptive care.

Social Stigma and Lack of Recognition - there is still significant stigma surrounding chronic pain, often due to the invisible nature of the condition. Patients may face scepticism from healthcare providers, family, or employers, which can lead to underreporting of symptoms and reluctance to seek help. Chronic pain is not always recognized as a serious condition, especially when there is no clear physical cause (e.g., neuropathic pain), leading to gaps in both diagnosis and care.

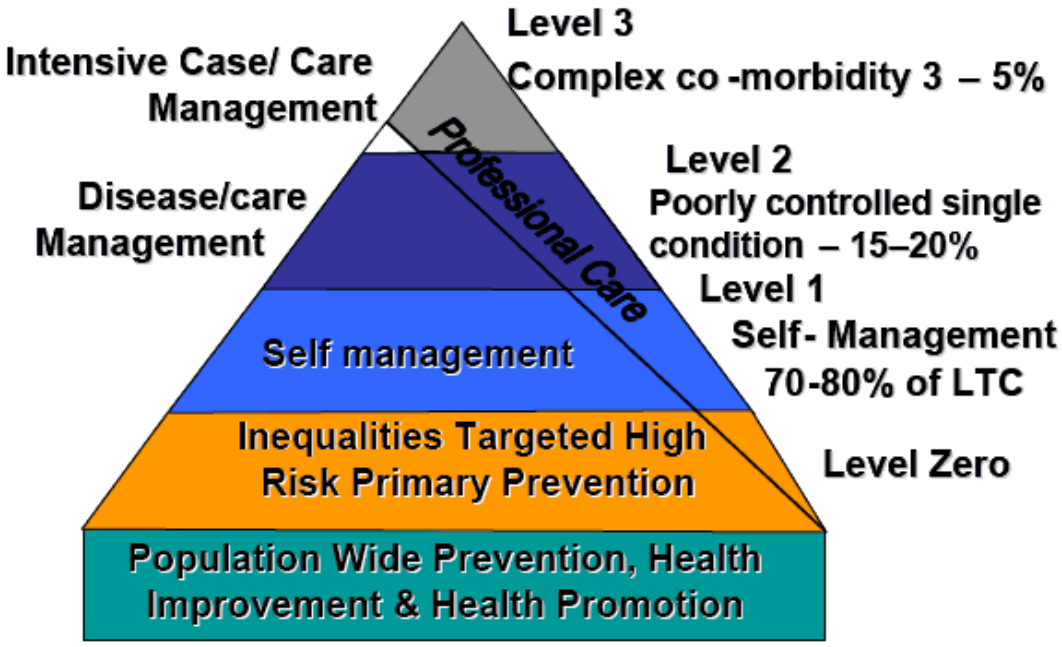
Challenges in Policy and Research - chronic pain often does not receive the same policy attention as other long-term conditions, leading to insufficient funding for pain services, research, and public health initiatives. Lack of research into chronic pain mechanisms and treatments contributes to these care gaps, as there is still much to learn about how best to manage chronic pain in different populations. Many national policies often fail to fully address the comprehensive needs of chronic pain patients, including the integration of physical, psychological, and social care.

Often, they do not know where chronic pain "fits" due to the wide-ranging nature and severity which therefore inhibits robust funding strategies.

In summary, the care gaps in chronic pain management highlight the need for more integrated, patient-centered approaches that address the multifaceted nature of chronic pain. To improve outcomes, healthcare systems must enhance access to multidisciplinary care, promote mental health support, improve patient education, and invest in non-pharmacological treatments, while addressing health inequalities and the stigma surrounding chronic pain. Filling these gaps requires a coordinated effort between policymakers, healthcare providers, and patient advocacy groups.

The key features of Pain Association's Course for Chronic Pain (SMC) are:

High level of access – ties in with the stratified model of care
The Pain Association self-management course (SMC) has less stringent referral guidelines than highly specialist PMP's. This means that many people can access the course who simply wouldn't be able to access a PMP either because they weren't considered suitable following triage process or that places weren't available due to lengthier waiting times. This higher level of access means that the self-management course is relevant and available for people in level 1 and 2 of the Stratified model below:-



(ref: Improving the Health and Well-being for People with Long Term Condition: A National Action Plan -http://www.gov.scot/Publications/2009/12/03112054/4)

In reality people attend the course on the 'way up' and on the 'way down' the stratified model. This is because even if someone has benefitted from a PMP they are rarely 'fixed'. Unlike an acute model of care, chronic conditions often need constant input. For example, some people have attended our courses who

previously attended residential Pain Management Courses in Bath or Glasgow; they have said that the self-management course is similar to the PMP they attended, but less formal and more understandable.

Wide variation in needs & motivation

Participants attending the course will be at different 'stages of change' with a wide variation of needs and motivations. It is also likely that many people have significant levels of co-morbidity. It requires skill to deal with such a mixed group of people.

To encourage and enable people to make an informed decision regarding attendance on the course a new information leaflet highlighting the benefits of the course has been produced. Delivering courses online has meant that we have been able to develop other resources to encourage attendance and make sure that people understand what exactly is on offer – we have sent more detailed welcome e mails and recorded an introductory film to explain what is involved.

Whilst we do everything we can, it is inevitable in this kind of work that some people may not be sufficiently motivated to attend. This is often because they misunderstand what is on offer. In the past people have told us that they thought: *"I thought it would be about just getting a grip; all about how it's just in your head, it would be mainly P.E; just a lot of theory; all that mindfulness stuff that I can't do; just telling me to stop my meds; a lot of old waffle; just other people moaning…."*

The messages given by referring clinicians can make a huge difference, but unfortunately there is wide variation. Some people are well briefed whilst others say that they were just told to attend without explanation. We therefore ultimately seek to fill this gap in the pre-course information and when people join the course, but we need to be mindful that what clinicians say always carries a great deal of weight. Like all pain management work, the idea of a non-medical paradigm is not always popular at the outset.

Aims

Overall the aims of the self-management courses are similar to many PMPs. The course seeks to improve the individual's relationship with their condition and themselves. Part of the change in this relationship is recognising that there are things that can be done to improve the 'bigger picture' and reduce suffering so that people can live a better life, despite pain.

The self-management course does not claim to change pain levels but rather aims to reduce the suffering component and change maladaptive habits. As a result of understanding more and changing behaviours, some people do report a change in their pain levels or fewer flare-ups or reliance on medication, but most report a change in how they feel about their condition and their life. For many this is a shift away from being a 'victim'; this is often characterised by the move from focusing on what they can't do to what they can. Others talk about feeling less isolated and more in control. These are significant issues that herald an improvement in health and well-being.

Delivered by an experienced member of staff with considerable experience in self-management (a safe pair of hands)
The self-management course is delivered by the Lead Health and Wellbeing coach from Pain Association Scotland, who has delivered 800+ courses and has industry-leading levels of experience. He has subsequently written a book on chronic pain based on his experience working in pain management for 25 years. This all means that the course is highly credible to patients many of whom are suspicious of a non-medical model. It also means that the self-management course isn't just defined by theory, it is delivered by someone who is known to the professional pain community throughout the UK and is able to bring subjects alive, drawing on practical experience that enables him to tell stories and explain ideas with confidence using new ideas and metaphors. This all means a 'safe pair of hands' delivering a long-term evaluated model that can be trusted.

Non-medical
Our self-management course for chronic pain (SMC) is expressly non-medical and non-clinical. This means that there is a total and whole-hearted focus on what the individual can realistically for themselves under their own steam. This approach is consistent with the spirit of self-management, which is by definition a non-medical paradigm.

Participants comment that the quality of the interaction is different (respectful but often less deferential) to clinical relationships. It also means that the course is delivered in a realistic way that reflects the essence of self-management i.e. what a normal person can do and is willing to do.

Communication style
The style of communication on the course is effective and down to earth. Complex ideas are explained in easy to understand ways that people can relate to.
Stories, metaphors and drawings help to get concepts across effectively, but above all, we have been told repeatedly that participants benefit greatly from the open and interactive style in which people are welcome to ask questions and express honesty how they are feeling.

The story element can enable a form of 'bench marking' where people say that they have changed their thinking based on hearing about another's story. Bench marking within the group is also important whereby participants learn from each other's example. It can be a case of – *if they can do it, so can I*.

The drawings are a central part of the approach - they are simple bad drawings that people can connect with. They also 'go in' – at the end of a course people often comment on how the 'pants model', 'fuel tank' and the 'badly drawn camel', really made the point and would be remembered for a long time.

The combination of these approaches means that the course is a lively energizing experience that responds to everyone's situation and learning style.

Working online this year has meant that we have been able to play videos and send audio files which have enriched the learning experience.

We are acutely aware that people may have had bad experiences. Some complain that have felt patronised and misunderstood and 'fobbed off'. We are keen to meet participants on their own terms and help them to explore what works for them. We use a variety of approaches that are based on practical experience rather than just theory. The aim is to present participants with a new perspective on their situation and the tools and mind-set to find their own solutions and way forward. It is an approach in which we work to engender self-efficacy and resilience.

Handouts
All sessions are backed up by handouts that have been written by the Lead Health and Wellbeing coach. These help with additional home learning because a great deal is being packed in to 5 weeks. As mentioned above, audio files and links to recordings help to enrich the 'notes'. It is often commented that the audio recordings of relaxations are particularly helpful, especially with sleep issues.

Therapeutic alliance
The self-management course is delivered in a way that creates a powerful therapeutic alliance, or rapport which is essential to all good therapeutic work. Features of this approach are: honesty, empathy, knowledge, credibility and the drawing out of the ability of the group to share experiences and support each other.

Models
The course is based on a Bio-Psycho-Social model of health which explores the impacts of a change in health and seeks ways to address any mal-adaptations that can often easily develop.

The core idea of the course is that pain affects life and life affects pain – if we are able to improve either, we improve both.

During the course all the key ideas of self-management are explored, alongside topics that are particular to chronic pain. Key topics include: understanding pain, stress awareness, cycles and management; pacing and the boom-bust cycle; improving sleep; dealing with change, understanding emotions, relaxation skills, goal setting, communication, confidence.

The course draws upon a number of therapeutic traditions, but we do not seek to impose any particular model apart from a person-centered, bio-psycho-social, solution focused general approach. These ideas are generally welcomed because they give a useful human perspective. The only people who struggle are those who are still seeking a purely medical solution.

Discussion and explanation are used to help people to make their own connections and bring previously unconscious items in to conscious awareness. This is especially

important when habits are examined. The approach is broadly based on the principles of CBT, ACT and motivational coaching work but a significant number of new ideas are developed through discussion and drawing on the Trainer's experience. Raising levels of emotional intelligence is important especially around social interaction and relationships.

Interactive
Every session is flexible and interactive in which the session is run in a way that responds to the needs of the group. This is a significant point of departure from many self-management approaches which, people tell us, are often 'more rigid' and 'teachy'.

Maintenance (integrated model)
Pain Association Scotland provides a unique service in which the self-management course is supported by local, staff led, monthly self-management community-based groups - which participants are encouraged to attend. No other organisation in Scotland delivers this two-tier system (course and groups). The groups provide vital on-going learning, peer support, and maintenance of the skills and insights gained during the 5-week self-management courses.

There are qualitative differences between online and face to face sessions, but with experience, we feel that we have overcome the limitations of online work and developed it in to a viable alternative to face-to-face work. Some of the issues are explored below:

- **Interaction -** Rapport is central to all therapeutic work and personal interaction is central to this. This involves the use of and ability to read body language quickly. Working online makes this harder since it is difficult to pick up on the nuances of feeling based solely on head and shoulders. It is also hard to scan a group online in the same way that a live group can be scanned. This has meant that staff have had to learn some subtle but important new skills so that online working is as natural and effective as possible.

- **Live work -** means that it is possible to pick up on the feeling in a room – a kind of intuited extra sense which harder to feel online. But again, experience working has meant that the gap between online and face- to -face has narrowed somewhat. Having said that, people remain split on what they prefer, online or face to face. That preference is based on a number of important factors. Sometimes it is literally a preference of one form of interaction to another, for others there are practical logistical issues (time and distance).

- **Online benefits -** working online has brought some advantages. And some of those benefits are significant. We have been able to work with people who wouldn't normally access live events, either because of distance or work commitments. Online means that the problems of geography melt away. That has meant that people who wouldn't normally be able to attend face-to-

face events, due to cost, time or distance, have been able to access the courses. We have also been able to provide a number of courses nationwide.

- **Richer** - one of the benefits of online working is that it is possible to deliver sessions that are richer in content. In the absence of 'live people' there is less of an issue with 'crowd control' – this is especially the case with relaxation and visualisation work where everyone can be muted. Notes and handouts can be sent via e-mail which means that there is less chance of them being folded up and lost in a back pocket or handbag. With live ebvents there can be a lot of toing and froing and comfort breaks tend to be longer, whereas online work allows for more focus on content and discussion.

- **Preference -** One of the challenging aspects of online working is that some people adopt it whilst others didn't. Some of this was surprising because Online offers significant advantages. There is no need to travel and the service can be accessed from the comfort of home. There are distinct advantages in terms of time and convenience. A positive result of this is that we have helped more of the people who wouldn't normally be able to come due to time or logistics. This includes hard to reach groups including young mothers and working people. Social anxiety is a major issue in chronic pain. Sometimes people don't come to courses because they are socially anxious. We felt that online work would help with this because people are in the comfort of home and have the advantage of an off button. We also have some people who keep their cameras off until they are confident to join. There were some who maybe attended because online gave an opportunity to be partly dissociated and feel safer, but we also found that others said that they were too anxious to join online and would prefer face to face, which was puzzling. We can only conjecture that maybe the technology added to their anxiety or that they preferred a format that they were familiar with i.e. a live group.

- **The only available access** - The other glaring advantage of online was that during COVID online was the only way of accessing pain management. We did find that those who accessed online were on the whole more motivated to learn. Perhaps this was because it required an extra effort to use online and maybe this meant people came who were more motivated to learn rather than thinking (mistakenly) that a group would be a social experience. Having said that, live groups do tend to be more social, but that is not the main focus.

- **Demographics -** There is a demographic issue which means that online working can be more appealing to younger people who are more familiar with technology. Or perhaps the demographic is simply those who are comfortable with technology. Some people said that they were angry about lack of services and yet were not prepared to use an online service and only wanted face-to-face sessions. During lockdown there wasn't a choice, there

were no face-to-face sessions being provided anywhere. We have been puzzled by this, because it would seem that the need for pain management 'should' outweigh reservations about online work, but perhaps it doesn't for some. Or perhaps there are some perceived problems that did not in fact exist.

It is difficult to know exactly what all of the issues were, because some people simply didn't communicate. Others said that they didn't like technology. We feel that some of this is an inevitable resistance to change and perhaps a fear of the unknown and unfamiliar. It may also have been one barrier too many for those who were equivocal about attending, which is why being able to deliver such a blended model is ideal and potentially reaches everyone suitable.

Course evaluations 2024-2025

Information and evaluation results presented in this section consist of:

- Referrals
- Completion rate
- Evaluation results from questionnaires administered at the beginning and end of the course, these were:
  Depression, Anxiety and Positive Outlook Scale (DAPOS)
  Pain Self Efficacy Questionnaire (PSEQ)
  Pain Association's 'Skills and Strategies' Chart
- Anecdotal comments

Referrals

There were a total of 206 referrals from healthcare professionals to the intensive self-management with a **97%** completion rate. All those who were UTA's or DNA's were given the opportunity to attend the next available courses.

Completion rate

The average completion rate for the 16 courses was 97%.

Evaluation tools

The evaluation tools used to assess progress on the course are recognised measures that capture information about progress in areas that the Course seeks to improve. These areas include: function/self-efficacy despite pain (PSEQ); Depression, Anxiety & Outlook (DAPOS); the acquisition of skills, strategies and understanding (Spider/Radar Graph). We also ask for written feedback because this often gives insights that number based reporting cannot.

During the period of this report, we used an online set of evaluations. This was used to avoid the inconvenience of paper based questionnaires and thereby improve compliance. It was also a way of generating cleaner, anonymous data.

An unforeseen issue with this approach has been a relative lack of participation. Despite assurances, it seems that there is a reluctance to complete evaluation forms, especially when completed out with a normal live group environment. One issue that might explain this is that some people have said that they are concerned that their progress on the courses may 'go on their record' and some have explained that they are concerned about potential impacts on state benefits. Despite assurances about anonymity and GDPR, compliance under this system has been relatively disappointing. Where we have received a full set of results ie pre and post course, data has continued to show that the course has a statistically significant positive impact on health and well-being.

Pain Self-Efficacy Questionnaire (PSEQ) [7]

The PSEQ measures people's beliefs that they can continue to perform important activities despite the presence of pain. It consists of ten items, such as "I can still enjoy things, despite the pain," and "I can still live a normal lifestyle, despite the pain." Each of the ten statements is rated on a scale of 0 to 6 (where 0 is 'not at all confident' and 6 is 'completely confident').

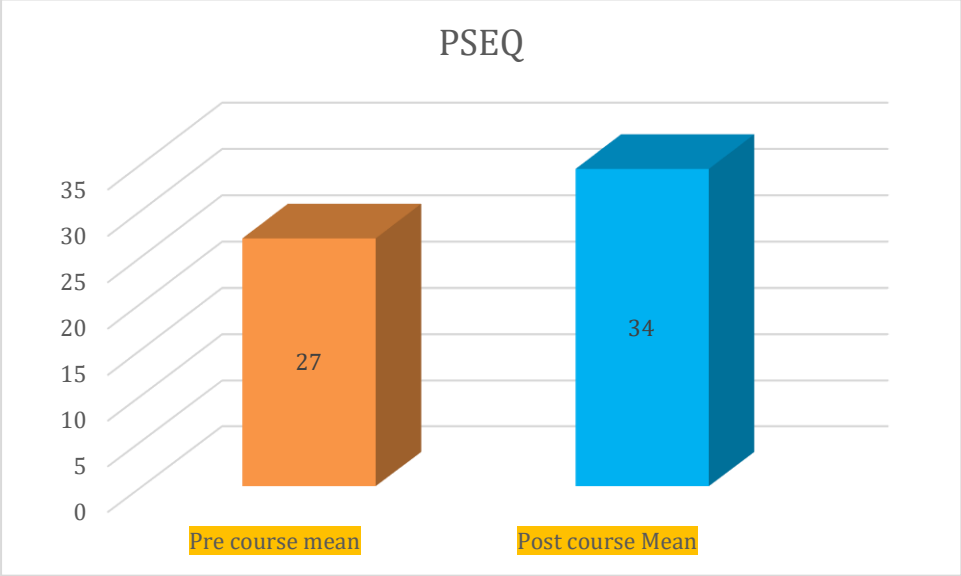
The PSEQ score is the sum of the ratings for each statement (i.e. the range is 0-60). The authors suggest that a score of less than 17 would indicate that a person believes that pain must stop before commencing activity, while a score of over 40 would lead a clinician to question why the person was seeking treatment for pain.

PSEQ data is available for all participants. The chart below shows that the group's scores are higher at the end of the course than they were at the start.

One of the mechanisms responsible for the improvements in health status, demonstrated by those attending self-management programmes, is self-efficacy. Adherence, or more precisely, concordance with medical treatment is closely linked

to the patient's ability to self-manage their chronic pain and is shown to be an important factor in determining increase in self-efficacy.

The measurement of PSEQ is used for assessing pain self-efficacy, reflecting a patient's confidence in performing daily activities despite the pain. It therefore addresses improving functioning capabilities.



The PSEQ scores for the course show a mean improvement of 26% increase in perceived self-efficacy.

Paired t test results
P value and statistical significance:

Confidence interval:
The mean of Group One minus Group Two equals -7.50
95% confidence interval of this difference: From -9.81 to -5.19
Intermediate values used in calculations:
t = 6.5715
df = 39
standard error of difference = 1.141

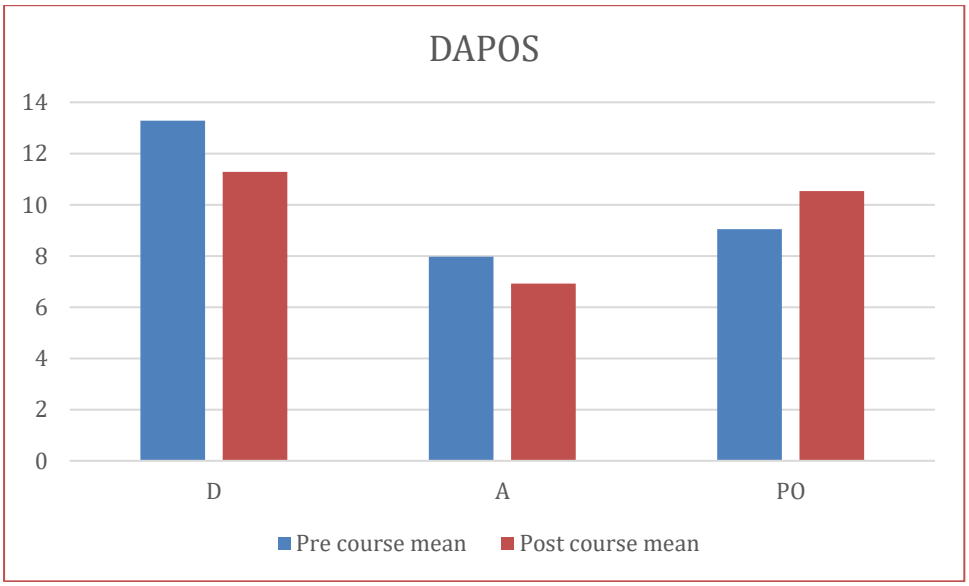
The two-tailed P value is less than 0.0001
By conventional criteria, this difference is considered to be extremely statistically significant.

Depression, Anxiety and Positive Outlook Scale (DAPOS) [8]

The DAPOS is a psychometric tool measure that has been specifically developed to assess symptoms of depression and anxiety in people with chronic pain. As chronic pain is a multifaceted condition influenced not only by physical but also psychological and emotional factors, DAPOS therefore provides insight into a patient's psychological frame of mind.

The overall outcomes provide insights into the psychological drivers of a patient's experience, enabling further tailoring of future interventions. It is therefore administered at baseline and at the end of the 5 week course – as you can appreciate, this is rather a short time scale to measure psychological changes as these are usually done over a longer period of time.

- The 'Depression' score is the sum of five items consisting of statements such as 'I feel like a failure' and 'I blame myself constantly'. These are rated on a scale of 1-5 (1 is 'almost never' and 5 is 'almost all the time'). Scores range from 5 to 25. The authors of this test do not provide cut-off scores, but tables of norms are provided. The tables of norms include the mean scores for a pain management treatment group of 82 people, pre- and post-treatment. For the 'depression' scale, the pre-treatment group's mean is reported as 15 and the post-treatment group's mean is reported as 11.
- The 'Anxiety' score is the sum of three items (eg 'I get sudden feelings of panic'), rated on the same scale of 1-5; the range of scores is 3-15. The authors' reported means for pre- and post-treatment are 7.51 and 5.96 respectively.
- The 'Positive Outlook' score is the sum of three items such as 'I can laugh and see the funny side of things' (rated on the same scale of 1-5; range 3-15). The authors' reported means for pre- and post-treatment are 8.05 and 10.24 respectively.



D = Depression A= Anxiety PO=Positive outlook

The DAPOS chart shows the participants scores for all three scales. Scores move in the expected directions for all three subscales (lower Depression and Anxiety scores at the end of the course, and higher Positive Outlook scores).

Summary
The DAPOS scores show that the mean changes in the group were:-

- **18%** improvement in the reduction of depression
- **14%** improvement in the reduction of anxiety
- **22%** increase in positive outlook.

For the Depression value, the two-tailed P value equals 0.0170. By conventional criteria, this difference is considered to be statistically significant.

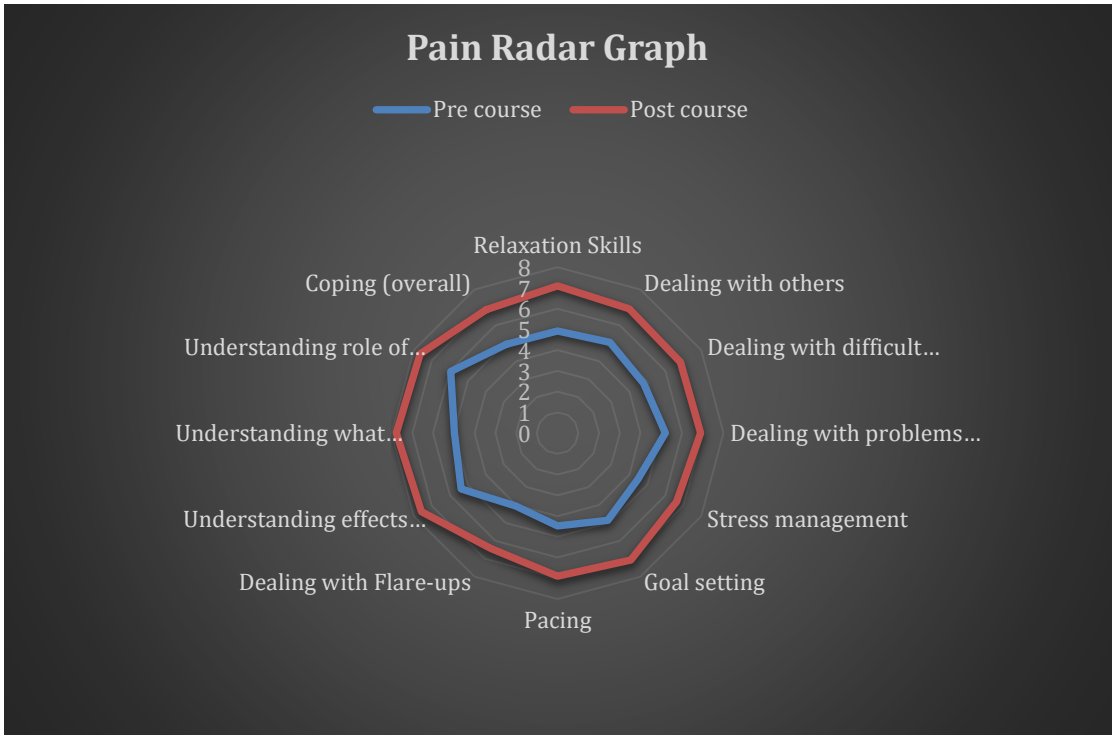
For the Anxiety value, the two-tailed P value equals 0.0196. By conventional criteria, this difference is considered to be statistically significant.

For the Positive Outlook value, the two-tailed P value equals 0.0008. By conventional criteria, this difference is considered to be extremely statistically significant.

Pain Association Skills and Strategies Chart

The Skills and Strategies questionnaire is presented in the form of a radar graph. Participants are asked to rate themselves on a scale of 0 to 10 on indicators such as 'pacing,' 'understanding chronic pain,' 'dealing with flare-ups,' 'stress management,' etc. There are 12 indicators in total. A rating of 0 indicates that the respondent does not understand or implement the strategy at all; a rating of 10 indicates that the respondent understands fully and/or implements the strategy all the time.

The following radar graph displays the group's mean pre and post scores on each of the 12 indicators.



The self-management skills and strategies chart shows that participants improved in all areas of self-management.

The two-tailed P value is less than 0.0001
By conventional criteria, this difference is considered to be extremely statistically significant.

Anecdotal Comments

A random sample of comments has been taken from the many received following the course evaluations.

"The course has helped me understand pain in a different way and manage it better. I found out things that I wish I had known years ago."

"I was not sure what to expect but I am so glad I came on this course. Talking to other people as well as the course leader helped me gain better perspective on my own situation. The thing that actually helped me most thought were the diagrams. From Phil and Louise were the graphics on the flip chart. Being able to see what was discussed worked very well for me."

"I loved the way I got encouraged and the coach let us talk and discus ideas as an equal group rather then it being a lot just teaching."

Evaluation Conclusion

The evaluation tools administered pre and post course show small improvements in all areas. However, we also need to be mindful that these improvements/measurements are just after five weeks.

The skills and strategies chart shows significant improvements, which means that participants have learnt the skills and strategies necessary to manage and cope better. The acquisition of these skills has demonstrated improved function and mood as measured in the DAPOS and PSEQ questionnaires.

Summary

- An answer to recommendations made by Health Improvement Scotland
- Enables Health Board to implement part of the Scottish Service Model
- Improved access to Self-Management for people with Chronic Pain
- Bio-Psycho-Social model
- Person centred approach
- Referrals from Primary & Secondary Care
- 97% completion rate
- Recognised tools used for evaluation
- Improvements in Self efficacy, Anxiety, Depression, Outlook, Skills and strategies

Strategic considerations

Pain Association offers a strategically significant contribution to the problem of chronic pain in Scotland.

Chronic pain is not just a medical condition. There is significant secondary suffering and impacts on physical, psychological and family health. Common issues include: anxiety, stress, isolation, depression, over-reliance on medication (prescribed and non-prescribed), poor mobility, lack of self-esteem, fatigue and a loss of self-efficacy.

Chronic pain can easily dominate life and impact widely on family, friends, work. Pain is often described as a Bio-Psycho-Social issue, but over and above personal impacts, there are also issues that need to be considered by policy makers looking at the funding of service and wider macro-economic issues. The key financial issues for policy makers to consider are:

- Loss of income and reliance on state benefits
- Job absenteeism and disruption in the work place often causing burden on colleagues
- Increased costs of healthcare and prescribed medication

People with chronic pain require far more than clinical help. The right medication can help, but it is rarely a complete solution. Many people continue to live with pain despite the best medical service possible. Even cases of expensive implant surgery for spinal stimulators, rarely mean that pain completely resolves, meaning that ongoing management is still needed.

There is a need for the service offered by Pain Association Scotland, which is professional, person centred and delivered in the community. It helps to address the on-going needs of people with chronic pain and helps them to deal with the issues that drive pain ie. stress, lack of sleep and maladaptive responses.

Pain Association offers an integrated service in which people can benefit from an intensive short course (results for which are in this report) and then build on what they have learnt through a network of local groups.

Ongoing evaluation of the courses (reported here) and our groups (see appendix) show the significant improvements that chronic pain patients can make in their daily lives. These show that work we deliver is a viable response to the significant non-medical issues that compound the suffering associated with chronic pain. Improvements in managing and coping mean that people have benefitted tangibly and able to live fuller better lives in which they can become part of the world again. For some this means contributing more to family and society. To others it can mean a return to work or staying in work. Much of what we are able to provide is congruent with SIGN guideline 136. [9]

Collaborating closely with Government, the NHS and other partners, the service makes a significant contribution to the wider health economy by addressing deep issues that health and social services

do not have the capacity to fully deal with. In fact. Post COVID, these issues are more pressing. On a numbers level, the service can help to reduce the costs of primary and secondary care.

It is a service that meets the Scottish Government's objectives of being, safe, effective and person-centred.

The future challenges and opportunities facing chronic pain services

- Currently NHS services are reactive rather than proactive in managing people with chronic pain and not enough emphasis on identifying those with acute pain who are at risk of developing chronicity or people who have chronic pain and are not, or are no longer, coping with their pain.

- There is a conflict between the pain-related evidence-based guidelines that NICE and SIGN (Scotland) produce and the complex reality of chronic pain. There are therefore challenges in developing pathways recommended by both NICE and SIGN.

- Looking at the chronic pain wait time data from Public Health Scotland for the period ending 31/12/24, there were 5021 referrals to the respective pain clinics in Scotland with only 1907 patients seen. From this, one of the highest numbers in wait time of 193 were waiting longer than 52 weeks, giving a total of 5329 people waiting. The question here for Boards is what service is being provided for people in the meantime, and what impact is this having on their quality of life?

- Opioid prescribing – a study of disability in relation to a range of physical and medical conditions showed that chronic pain was the single condition which contributed the most to disability measures in all European regions (*Barbaglia et al, 2017*) [5]. We know that there are many variations within chronic pain prescribing and there is much debate around addiction and misuse of chronic pain medications. In most countries of the world, self-management with little clinical intervention is actually the first and most widely used approach for the management of pain by patients. So, the question is why, in the UK, are we getting it so wrong?

- Pain education among clinicians needs to be drastically improved and healthcare professionals' experience inadequate pain education as undergraduates (*Briggs et al, 2011*) [10]. Anaesthesia is the only medical speciality that has recognised postgraduate pain training in medicine, although palliative care medicine does include pain management training as

a core activity. Therefore, considering the above, when one looks at the possible opportunities, there is certainly much to do within Scotland in terms of statutory pain education.

- Another opportunity is for chronic pain to be better addressed and recognised within Primary Care so that patients are provided with the best opportunity to deal with their chronic pain rather than faced with endless waiting lists for a secondary care intervention and allowing the chronicity process to escalate. Such early access needs to include primary care and community pharmacy.

Ultimately, for any provision of service, and definitely within the healthcare sector, it is vital that both health professionals and potential funders acknowledge clear benefits of improved patient health and well-being, cost effectiveness which are achieved by the adoption of self-management strategies and model architecture. Individuals who have participated in intensive self-management programmes report increased energy, less pain, less dependence on others and improved mental health. In addition to long-term management, pain management services in the community can play an important role in screening, diagnosis, treatment, referral, education, prevention and signposting (Barker & Collighan, 2015). [11]

If the value of self-management and reducing people's long-term reliance on specialist services and treatments which demonstrate low clinical efficacy is clear, then patients need help to be better engaged with the concept of self-management. It is appreciated that time is maybe limited to explain self-management and it is also recognise that many people might not absorb all the details during a GP appointment, but this is maybe an example of the type of action needed within future framework around pathways, language and a more holistic modelling approach.

In terms of Data as a Primary Driver, it would be welcomed for agreed key measured outcomes (not necessarily outputs) to be recognised for the effectiveness of third sector provision. In being introduced and dealing with new healthcare professionals enquiring about PAS's services, there are regular questions around the "evidence-base" for the work. Whilst PAS report on three recognised evaluation tools, the credibility for self-management would be greater enhanced if we had the data to understand for example, the reduction in secondary care referrals when self-management is introduced at the time of presenting in primary care, the reduction/effect on prescribing, increase in quality of life…….as well as the key powerful anecdotal comments being recognised. Moving the focus from simple wait times and incorporating "key difference" data can surely provide a much better picture of the **difference** being made (or not) and the ability to identify more clearly where the gaps are in service provision.

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