

# **Self-Management Courses for Chronic Pain**

## **Overall outcomes for all Courses 2019-2020**

### **Contents**

This report provides evaluation results from 28 Self-Management courses for Chronic Pain delivered in five Scottish Health Board areas and two in North Wales in 2019-2020 financial year.

The 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.

### **Overview**

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 approach, which treats the individual as a person rather than as a patient. This approach helps to engage the individual in the principles of self-management and motivates them to adopt new ways of thinking based on a better understanding of their health and the options available to them.

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. 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.

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).<sup>1</sup>

The bigger picture of chronic pain is quite often forgotten such as direct costs associated with chronic pain. Such costs are mostly 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).<sup>2</sup>

During this period the following courses were delivered as a result of improved levels of collaboration within the Primary & Specialist Secondary Care Services in - Tayside (10), Angus CHP(4), Dumfries and Galloway(2), Forth Valley(6), Western Isles (4) and North Wales (2). Referrals are received from the Pain Clinics, other healthcare professionals, GPs and a small number who self-refer on to courses within their local area. (see supporting information - *overall outcomes*)

**28** Intensive Self-Management Courses were delivered for **406** participants with **97%** completion rate:-

• NHS Tayside	x 10	102% completion rate
• Angus CHP	x 4	92% completion rate
• NHS Dumfries & Galloway	x 2	100% completion rate
• NHS Forth Valley	x 6	92% completion rate
• NHS Western Isles	x 2	100% completion rate
• NHS North Wales	x 2	100% completion rate

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 has been further compounded by the initiation and 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 are designed 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 sufferers 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 provide better patient access to courses (speed and location) enabling them to utilise this vital paradigm of care. The service provides part of an approved exit strategy for people who have reached the end of their clinical pathway and as such helps to break the cycle of the ‘revolving door’ patients. There was a slight difference in the referral patterns which seemed to reflect how the respective Pain Clinics were attaining the 18 week waiting time criteria.

Our service delivery is person-centred and based on a bio-psycho-social model. It is not just about pain, rather the focus is on dealing with pain the wider context of life, health and well-being. We provide a combination of education, training and support provided 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.

People with chronic pain are in many ways their own primary carers; well controlled chronic pain often results in less productivity, hospitalisations and use of other healthcare resources. Self-management education and learning programmes are designed to help people to become more independent and ultimately less reliant on costly external resources.

In addition to the 28 Courses provided during this period, the Association have also provided monthly staff led groups in Tayside and Angus (4) Dumfries & Galloway (2) Forth Valley (2) Western Isles (2), Argyle and Bute (1), Fife (4), Borders (2), Lanarkshire (4) and Ayrshire & Arran (3). A further 4 groups were delivered in Northumbria for the NHS in collaboration with their chronic pain service and we will groups going in North Wales (Prestatyn and Rhyl).

These groups provide vital on-going learning, education and peer support which enables people attending the courses to maintain their skills, understanding and motivation and offers early access to self-management. The combination of self-management course backed up by an ongoing monthly group is a very effective way to create positive change and then keep it going throughout the year. Patients often comment that they are very impressed and comforted in the fact that there is continuity of support for them after the course has finished.

## **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.

### Terminology

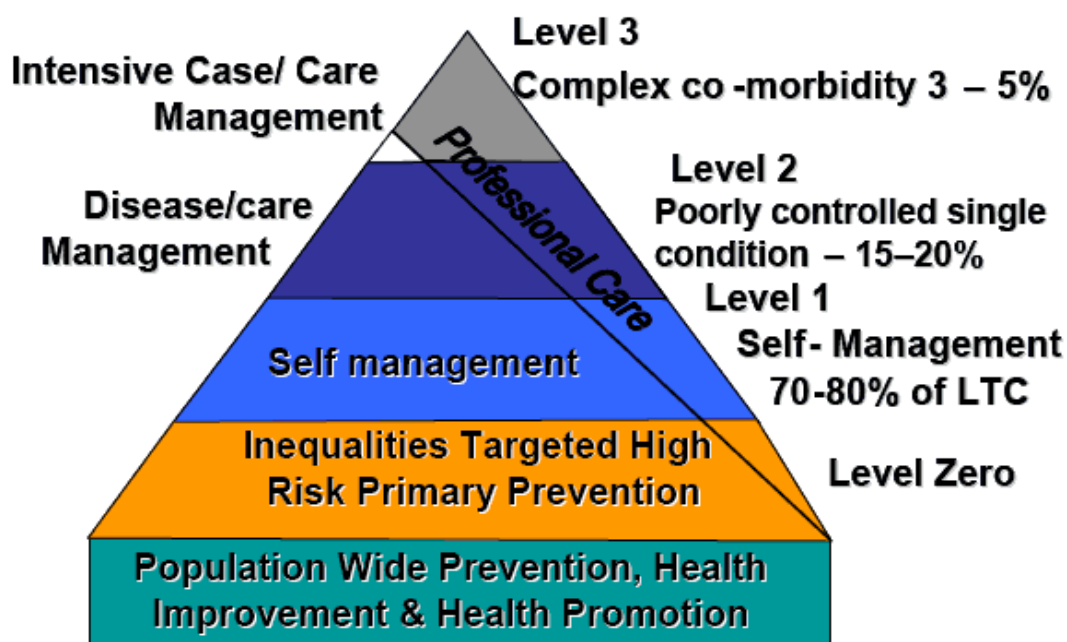
Traditionally the term self-management was used to apply to courses and practices that were essentially non-clinical and 'Pain Management' was the preserve of clinically focused interventions. However over recent years there has been considerable blurring of the lines as Clinicians have started to deliver what they call self-management.

Terminology aside, there is considerable variation throughout the country in the nature and quality of both self-management courses and statutory Pain Management Programmes. This is why it is important to identify the features of the particular self-management that Pain Association Scotland provides.

**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 self-management course has less stringent referral guidelines than highly specialist PMP's. This means that many people can access the self-management course who simply wouldn't be able to access the PMP either because they weren't suitable following triage process or that places weren't available due to lengthier wait 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 condi-

tions often need constant input. For example, self-management courses in other areas have had people attending who have previously attended residential Pain Management Courses in Bath; 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.

### **Aims**

Overall the aims of the self-management courses are similar to many PMPs. The course seeks to change someone'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' which 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 Trainer from Pain Association Scotland, who has delivered 300+ 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 21 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 using 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, but also non-clinical approach**

The SMC is expressly non-medical and unlike PMPs it is also non-clinical. The staff-led model means 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 you can do yourself as a 'normal' person without needing a clinical expert.

### **Use of story and metaphor and drawings**

Ideas are explained in simple down to earth terms that people can relate to. The use of stories, metaphors and drawings help to get concepts across effectively.

The story element can enable a form of 'bench marking' where people say that they have changed their thinking. The drawings are a central part of the approach - they have been developed over the years to pictorially explain ideas which help people to learn and remember. These approaches help to respond to the different ways in which people learn.

### **Handouts**

All sessions are backed up by handouts that have been written by the Lead Trainer. These help with additional home learning because a great deal is being packed in to 5 weeks.

### **Therapeutic alliance**

The self-management course is delivered in a way that creates a powerful therapeutic alliance. 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.

### **Techniques/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 the mal-adaptive behaviours that may have developed.

Core self-management approaches are explored especially pacing, stress management and improving Sleep. 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.

**The reality of Chronic Pain** Chronic pain has a high impact upon *physical, psychological* and *family health*. Issues include, but are not limited to; depression, stress, isolation, high levels of prescribed medication, poor mobility, lack of self-esteem and fatigue. This is not an exhaustive list and in most cases chronic pain eventually dominates the life and concerns of the sufferer, their family, friends and carers. In addition to the severe erosion in quality of life of the pain sufferer and those around them, chronic pain imposes severe financial burdens on many levels.

- Loss of income imposing financial burden on family and friends
- Job absenteeism and disruption in the work place often causing burden on colleagues
- Increased dependence on benefits
- Increased costs of healthcare and prescribed medication

Supporting patients with chronic pain needs more than just handing out medication; highlighting the need for a well-designed and delivered staff led self-management model in the community as provided by the Association. Patients report that their medication is inadequate and at times have discontinued taking prescribed pain medication. Through the delivery of intensive self-management courses and local self-management groups, these programmes encourage learning, and coping skills which empower people leading to improvements in quality of life and well-being, and providing regular peer support.

The outcomes reported by users of our services through the evaluation process and user questionnaires show the significant improvements that chronic pain patients can make in their daily lives.

We have shown that self-management has the potential to improve health outcomes in many cases, with users of our service reporting increases in physical functioning, coping and benefits in terms of greater confidence and reduced anxiety - this was something that was recognised in the SIGN Guideline 136 <sup>3</sup>.

Additionally our service aligns with Health and Social Care, as a result of good collaboration our services has the significant potential to improve self-management, reduce inappropriate referrals and reduce the costs for acute and secondary care services. Our service is accessible for all chronic pain sufferers, and meets the Scottish Government's objectives of being, *Safe, Effective and Person-Centred*.



# Course evaluations 2019-2020

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 **406** referrals to the intensive self-management courses.

## Completion rate

The average completion rate for the 28 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; Depression, Anxiety & Outlook; the acquisition of skills, strategies and understanding.

## Pain Self-Efficacy Questionnaire (PSEQ)<sup>4</sup>

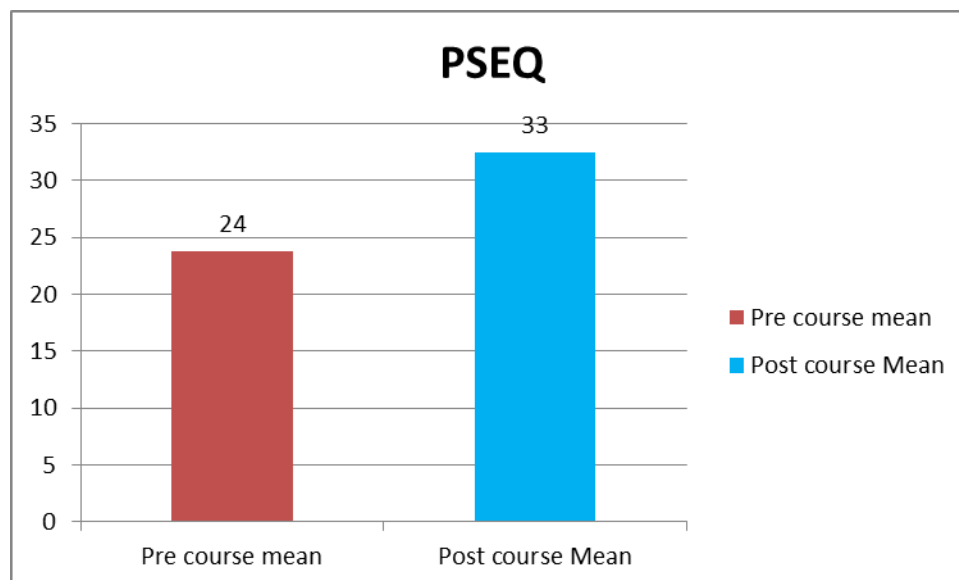
The PSEQ measures people's beliefs that they can continue to perform important activities despite the presence of pain. It consists of ten items, such as "I can still enjoy things, despite the pain," and "I can still live a normal lifestyle, despite the pain." Each of the ten statements is rated on a 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.



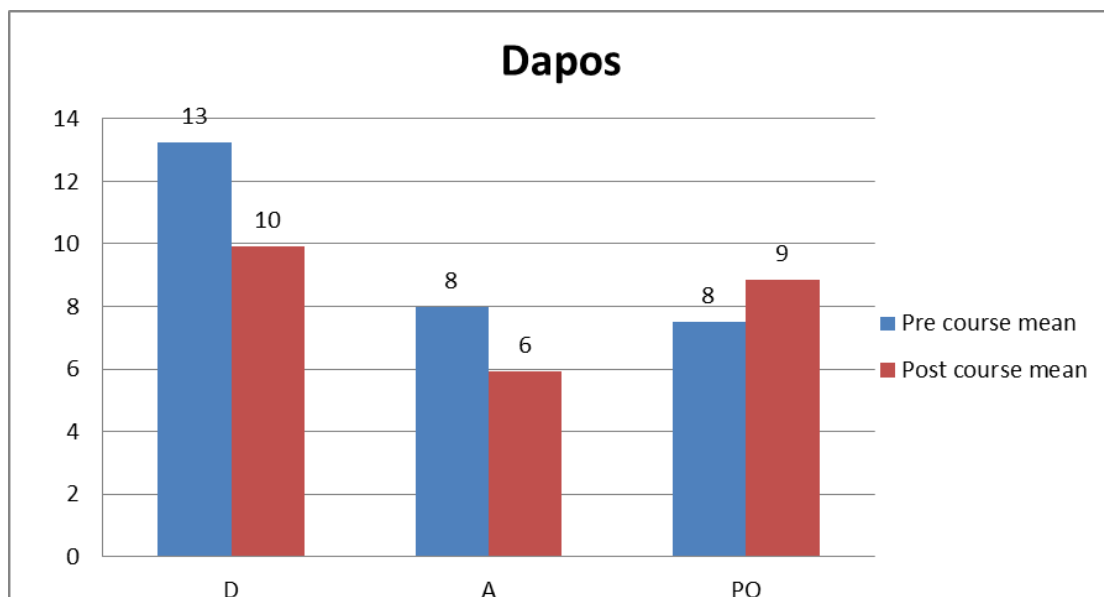
The PSEQ scores for the course show a mean improvement in perceived self-efficacy of 37% for the group.

Using the Paired T test results, the two-tailed P value is less than 0.0001. Therefore by conventional criteria, this difference is considered to be extremely statistically significant.

## Depression, Anxiety and Positive Outlook Scale (DA-POS)<sup>5</sup>

The DAPOS is a measure that has been specifically developed to assess symptoms of depression and anxiety in people with chronic pain.

- 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:-

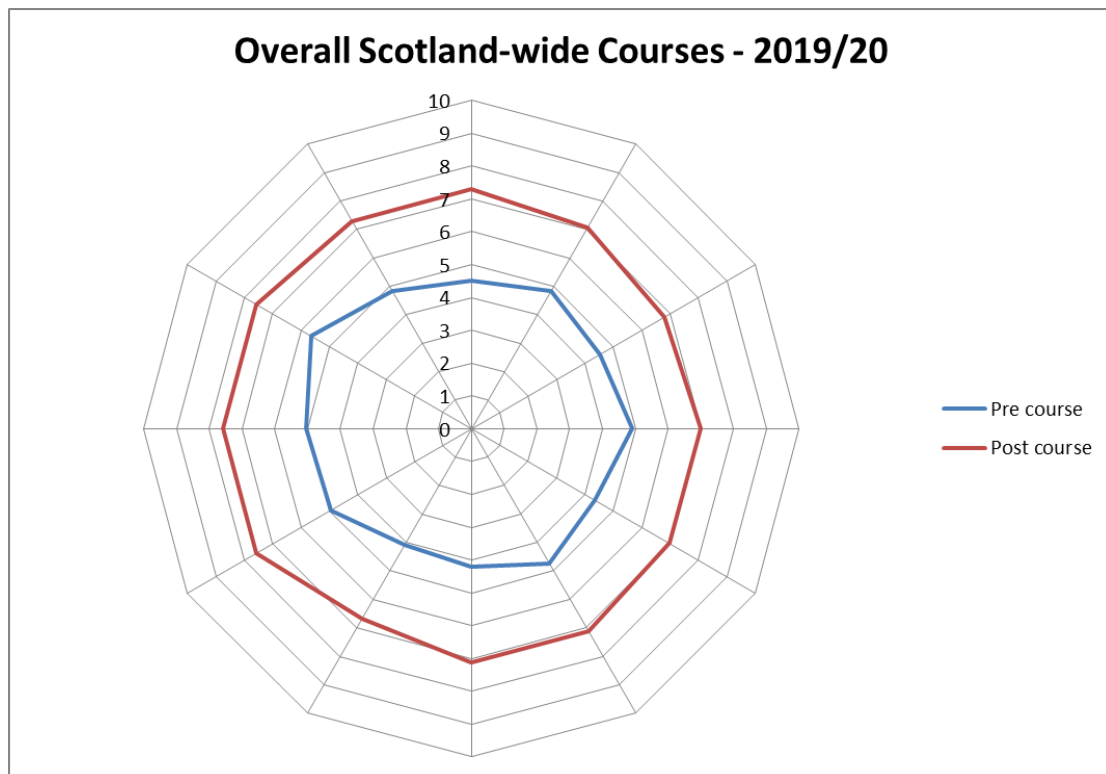
- 23% improvement in the reduction of depression
- 25% improvement in the reduction in anxiety levels
- 13% improvement in positive outlook

For all three categories, the two-tailed P value is less than 0.0001. Therefore 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. Therefore by conventional criteria, this difference is considered to be extremely statistically significant.

## Evaluation Conclusion

The evaluation tools administered pre and post course show improvements in all areas. 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.

## Overall Conclusion

The 28 courses provided in the various NHS Health Board areas with a high quality cost effective provision of Self-Management courses for people with Chronic Pain. The project represents a significant 'foot-print' for a relatively low cost service.

## 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

## 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 dichotomy between the pain-related evidence-based guidelines that NICE and SIGN (Scotland) produce and the complexity of persistent pain. There are therefore challenges in developing pathways recommended by both NICE and SIGN.
- 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.
- 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*)<sup>(6)</sup>. 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?

In a session I attended on Chronic Pain and Opioid Use Disorder - Neurobiology and Prediction, the following issues around unnecessary prescribing were identified:-

- ✓ It comes down to poor training
- ✓ Pain management has developed in opioid therapy as clinicians are under pressure to see more patients - it takes 30 seconds to say “yes” and write a prescription and 30 minutes to say “no” and take patients through what else they can do.

- ✓ Opioid crisis is highest amongst chronic pain patients.
  - ✓ The fact that education strategies for clinicians does not necessarily change behaviours in prescribing - there is a need for education at medical school.
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- Pain education among clinicians needs to be drastically improved (*Ellis et al, 2012*) and healthcare professionals' experience inadequate pain education as undergraduates (*Briggs et al, 2011*) <sup>(7)</sup>. 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.

## Anecdotal Comments

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

- Helped me understand about overdoing things, the need to pace things, not feel so guilty about why I can't cope or do things like I used to. Understand more of what could cause the problems pain i.e coffee/drinking chocolate, need to look into other food. Why people stress me out a lot more- need to find better ways to cope and express myself. It was often overwhelming and distressing.
- Have enjoyed the class, made me think more positive about pain and feel more positive about the future. Will help me to cope better in future.
- I feel a lot more confident in accepting pain, I don't say "I wish" all the time, I am moving on. I set out tasks and do them when I can and enjoy the gardening, house work, walking, shopping, holidays. Having met other people with pain I don't feel so isolated. Thank you Phil.
- I have enjoyed the course and it helped me in confidence, to think differently and more positive about life and being able to do things. That I'm not alone in the way I feel but I can change things for the better.
- At first was almost overwhelmed with all the extra factors dealing with pain. Taking one issue at a time, instead off all at once. Remembering to pace and put things in perspective before starting a project or task. Course was well presented and I feel it has a positive impact in my daily life.



- “Phil’s knowledge of the topics is extensive and very practicable. The course is broken down extremely well thought out topics, they are realistic to implement and extremely beneficial. As a result I have been able to significantly reduce medication, improve my mental state and improve my relationships and social life.
- I am very grateful for Phil’s expertise and consider myself very lucky to have had Phil as my trainer. I firmly believe Phil is one of the country’s foremost experts in dealing with pain having experienced other groups across the U.K and read books on the topic. Thank you for providing such an excellent course Phil.”
- The course has been of great benefit to me. Had given me the tools to think differently, be kind to myself, adapt, accept, space, understanding of coping and dealing with pain. Course has enlisted me in reducing my medication which now works better for me. Phil changes lives in doing pain courses.”
- “Thank you for being there at the right time.”
- Good to discuss with others different ways to help deal with constant enclometrosis pain and chronic pain. Different ways to help deal with pain around different situations. Follow different strategies to try help me relax my body to help my mind and body to sleep. Good to speak to others that understand the same pain an in same situation as myself. Try to encourage myself further to my own choices and decisions and goals in life. Would be interested to continue with further pain management.
- Have found the course helpful especially the relaxation techniques. Phil has been very helpful with everything that he has gone through with the group. My aim is to get back to my swimming and walking which I know helps me but do have to watch and pace myself with both.
- Really glad I came along, will try the relaxation more and also bought the book!
- Really glad I came along to the course. Felt comfortable in group as I have nervous, anxiety.
- I found the course more helpful than I expected it to be. It was a great group of people and a great group leader. I found the different relaxation styles helpful and will use them in future. Pacing was also helpful. I will try to use the 70% rule + fuel tank.
- I found the course helpful, various ideas of looking at pain from other angles. It was helpful and insightful thoughts to let me understand

my condition better. Different angles to look at pain from and how to deal with stress using a variety of ways. Looking at fillers and drainers of energy. How I need to gradually change so I am not cut off so much, back into using art as well as reading on the window seat”

- “This has been an eye opener. Thank you for the quiet methodical manner you used to point out a new way of thinking and working through pain. I travel more hopefully and look forward to being part of a group on a monthly basis and look forward to ordering your book. After two days I feel tired and more hopeful”

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