

Self-Management Courses for Chronic Pain

Overall outcomes for all Courses 2020-2021

Contents

This report provides evaluation results from 29 Self-Management courses for Chronic Pain delivered in a slightly different way during the 2020-21 financial year due to the COVID-19 pandemic.

The courses were delivered on-line for people throughout Scotland in order to ensure an equitable service was delivered during such challenging times. 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 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 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*).¹

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).²

During this period the courses were delivered in direct collaboration with Chronic Pain Clinics in NHS Dumfries & Galloway, NHS Tayside, NHS Angus HSCP, NHS Western Isles, NHS Ayrshire & Arran. 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. However, referrals were also taken from NHS Fife, NHS Borders and NHS Lanarkshire – whilst there is no commissioning of these courses within their respective Service Level Agreements, given the nature of the pandemic and the effect on patients and the NHS, then anyone referred from any area of Scotland was accepted onto one of the courses.

29 Intensive Self-Management Courses were delivered for **610** referrals with **91%** completion rate.

It is during this COVID-19 crisis that we have seen an increased demand for our service where Scotland Chronic Pain sufferers were faced with the following scenario which naturally compounds their daily issues of heightened stress, anxiety and suffering:-

- ✓ 11 out of 14 Chronic Pain services ceased all new patient activity due to staff redeployment. This means that there were no first appointments at a chronic pain clinic for those referred so they will remain on a waiting list.
- ✓ There are no virtual groups being delivered by the NHS within the Pain Management Service.
- ✓ All procedures and interventions had ceased.
- ✓ Service provision varies greatly as a result of capacity therefore putting patients at risk of being in a postcode lottery.
- ✓ Chronic pain services are fearful of increased demands as the situation continues.

In response to such issues, the Association have continued to work in collaboration with various NHS chronic pain services throughout Scotland. The situation needed to be mindful of for the future is the increased demand to the pain services as a result of the two lockdowns and naturally their limited capacity when chronic pain services do resume along with the lengthy waiting lists. We have therefore been working with the Scottish Government to provide an on-line tool as a replacement for a first appointment at a chronic pain clinic so at least people can have some help with their chronic pain whom would otherwise be disadvantaged and having to endure lengthy waiting lists. This pathway then has the potential to help redirect people who in reality do not actually need that first physical appointment and would hopefully therefore help reduce future waiting lists.

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 29 Courses provided during this period, the Association have also provided monthly staff led groups on-line in Tayside and Angus (4) Dumfries & Galloway (2) Western Isles (2), Argyle and Bute (1), Fife (4), Borders (2), Lanarkshire (4) and Ayrshire & Arran (3). 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.

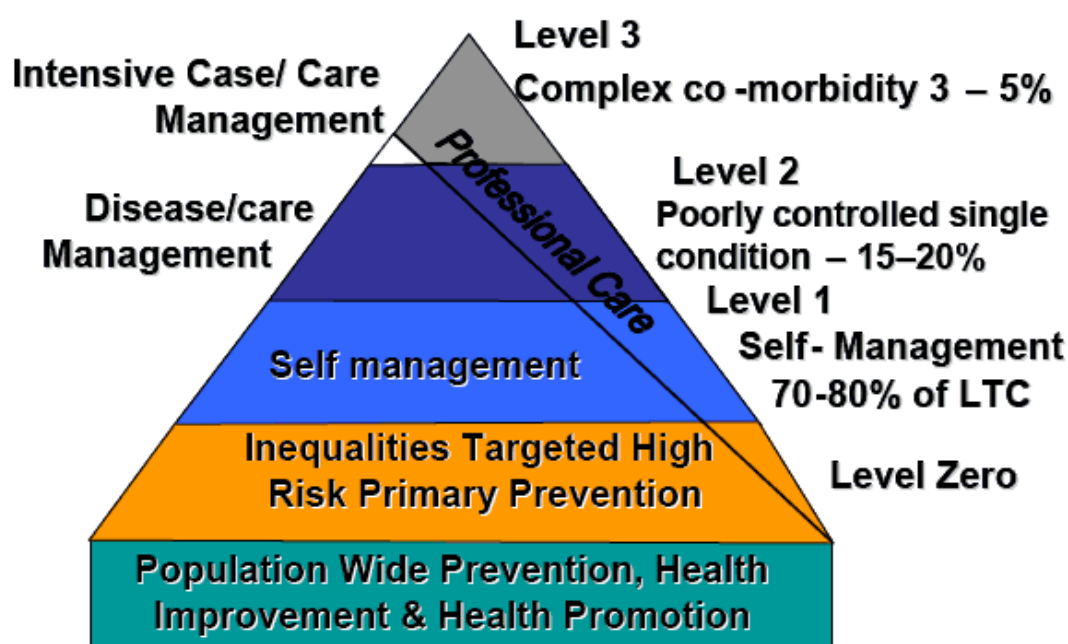
Terminology aside, there is considerable variation throughout the country in the nature and quality of both self-management courses and statutory Pain Management Programmes. This is why it is important to identify the features of the particular self-management that Pain Association Scotland provides.

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 conditions 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 136³.

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 2020-2021

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 **304** direct referrals to the intensive self-management courses and **610** people who were provided the opportunity to attend the courses given the pandemic.

Completion rate

The average completion rate for the 29 courses was 91%.

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.

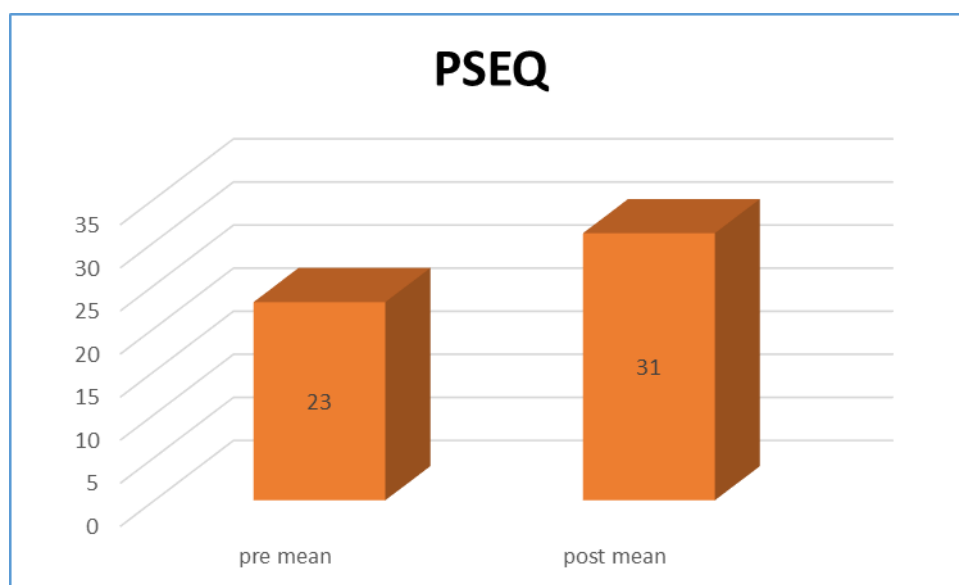
Pain Self-Efficacy Questionnaire (PSEQ)⁴

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 of 35% increase in perceived self-efficacy.

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.

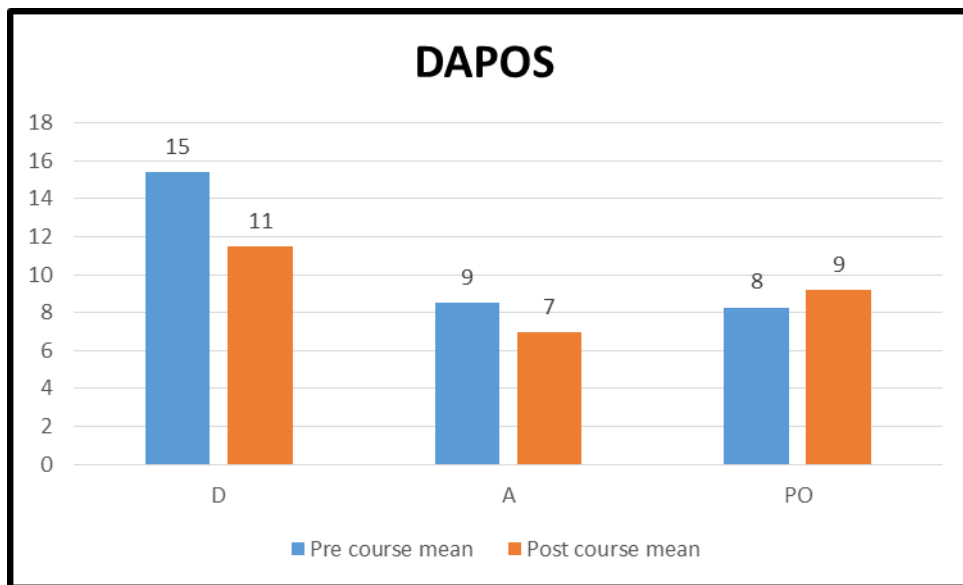
Depression, Anxiety and Positive Outlook Scale (DAPOS)⁵

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:-

- 27% improvement in the reduction of depression
- 22% improvement in the reduction in anxiety levels
- 11% improvement in positive outlook

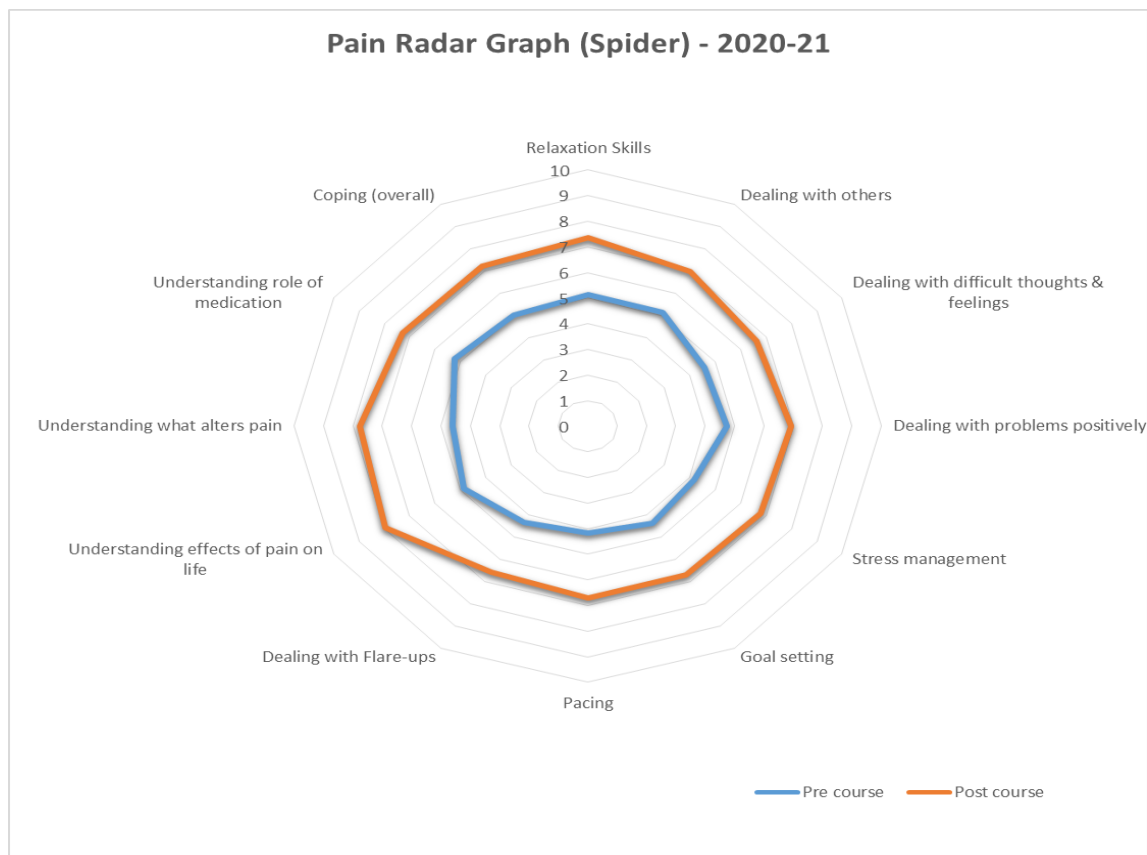
For the depression category, the two-tailed P value is less than 0.0001. Therefore by conventional criteria, this difference is considered to be extremely statistically

significant. For the anxiety category, the two-tailed P value is less than 0.0010. Therefore by conventional criteria, this difference is considered to be extremely statistically significant. For the positive outlook category, the two-tailed P value equals 0.1648. Therefore, by conventional criteria, this difference is considered to be not statistically significant. Whilst the increase in Positive Outlook is relatively small, one could argue that people may be reluctant to note this due to the COVID-19 pandemic. It can also be argued that over a period of five weeks it is rather difficult for people to make any substantial changes.

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.

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
- 91% 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*)⁽⁶⁾. 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 (*Ellis et al, 2012*) and healthcare professionals' experience inadequate pain education as undergraduates (*Briggs et al, 2011*)⁽⁷⁾. 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 overarched 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).

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 their 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. Having statistics to show that there is a 18 week waiting list for 400 for a first appointment does not help in identifying if all those people really need to be there and asking the question what is happening to people in the meantime whilst they wait?

Anecdotal Comments

- A random sample of comments has been taken from the many received following the course evaluations.
- I've found this course so interesting and helpful, I want to thank you so much for all your hard work and help, I can honestly say I will continue to use everything you've taught us.
- I really enjoyed the course, and felt I've gained a better understand of how to cope with pain. Phil was very good at explaining and listening and I found the interaction between everybody in the group very helpful. Pain management is something that I need continued practise, and I look forward to the monthly meetings.
- I really appreciate the course going ahead online despite the current pandemic. Having a small group on the online session made me feel comfortable and able to ask questions.
- Phil went above and beyond to help me by discussing effects of trauma on nervous system and pain. I gained better understanding of how my body/mind work together and ways of retraining my mind.
- Very grateful to be passed onto monthly course keep a check on progress, continue learning coping methods and being in contact with people experiencing similar things.
- I really enjoyed the course even with newly diagnosed glandular fever. I enjoyed the contents and Phil was patient and explained everything fully.
- Great course giving useful information to learn to cope with a lot of the side effects of living with pain. Have recommended it to a friend as I feel it would be beneficial for her. Thank you
- I really enjoyed the course and felt like I got a lot out of it. Boom/bust I realised has been my way of life and coping since I took ill. Since this course I've been trying to live my life at the 70% not go hell for leather and then crash. I have also been looking at my stress levels and have been using the meditations and tips Phil has given us. Pacing is also another tool that has been shown to me, as I've accepted now that I need to slow down and just do little bits

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