

**TITLE:** The significance of Health and Social Care Sector involvement for Scottish chronic pain patients.

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**Abstract:** Chronic pain is a major clinical challenge in Scotland and across Europe as a whole. It is estimated that 18% of the population are currently affected by severe chronic pain<sup>1</sup>. In the United Kingdom, approximately a third of the population suffers from chronic pain<sup>2</sup>. The severity, cost implications and effect of Chronic Pain on sufferer's lives has delineated the importance of third sector involvement for chronic pain patients. This involvement focuses on improvements to the quality of life for sufferers, through the controlled delivery of self-management support groups. Through monitoring and diligent reporting mechanisms, quality of provision is able to be matched to specific requirements of patient cohorts. This enabling characteristic is an important resource for many sufferers and validates the important position held by third sector providers of resource for chronic pain sufferers.

### **Introduction.**

This article will discuss Health and Social Care Sector (Third Sector) involvement with Chronic Pain patients from the perspective of Pain Association Scotland. This viewpoint is important because, as some observers <sup>3</sup> note, the third sector is by nature unsuited to singular definitions and often narrowly concomitant with the idea of voluntarism. The view of this proponent is that a third sector organisation comprises of a mixtures of social organisations both private and public, hierarchic and anarchic, most certainly a societal process and far beyond deleterious provisions of something which is "not-for-profit". Additionally, to conclude an acknowledgement of differential focus, in that, on the one hand economic focus may be on the associated NHS wealth distribution of long terms conditions, whereas sociologists maintain a perspective of value driven motivation by a patient or cohort of patients. Therefore, it is important to reveal the underlying boundaries and parameters which encompass a third sector organisation, specifically related to chronic pain patients.

### **Background.**

In addition to the Chronic Pain statistics quoted above, low back pain (LBP) is internationally recognised as a significant health, social and economic burden e.g. 0.8% and 2.1% of gross domestic product (GDP) in some US and European countries<sup>4</sup>. In the United Kingdom, approximately a third of the population suffers from chronic pain<sup>5</sup> in some shape or form. The consequences of this have a significant impact on quality of life, suffering and disability. Chronic pain affects individuals and their families, and comes at a significant economic cost. Lower back pain is estimated to cost in the region of £12 billion per annum in the UK in 1998, and arthritis-associated pain costs around 2.5% of the gross national product of Western nations. (SIGN 136 – Management of chronic pain)<sup>6</sup>. More recently it was estimated that people with chronic pain are responsible for almost 5 million GP appointments in the UK by people seeking help and relief from chronic pain and in many cases, they leave without answers and without effective pain relief<sup>7</sup> with a related cost of almost £70 million to the NHS<sup>8</sup>. On 29 May

2013, the Scottish Government, announced the need to accelerate improvement across all levels of care for Chronic Pain sufferers. This initiative resulted in Service Improvement Groups (SIGs)/Managed Clinical Networks (MCNs) established or in the process of being established within all NHS Boards in Scotland to drive improvements in the management of chronic pain. Informed by this national position, Pain Association Scotland has been developing support programmes for Chronic Pain Sufferers for 25 years and more recently aligned to the Public Bodies (Joint Working)(Scotland) Act 2014, which puts in place the statutory framework for integrating health and social care in Scotland.

### **Is pain a Reality?**

Chronic pain has a high impact upon physical, psychological and family health. Issues include, but are not limited to; depression, long-term stress, isolation, high levels of medication, poor mobility, lack of self-esteem and fatigue. Pain can be interpreted as being an isolating experience, as there may be a stigma associated with the condition.

*“Chronic pain is not simply a physical problem. It is often associated with severe and extensive psychological, social and economic factors. Apart from poor general physical health and disability there may also be depression, unemployment, and family stress. Many of these factors interact, and the whole picture needs to be considered when managing individual patients. The impact of chronic pain on patients' lives varies from minor restrictions to complete loss of independence.”<sup>10</sup>*

The Pfizer Health Report Chronic Pain Survey<sup>9</sup> found that 58% of the people surveyed felt that other people ‘sometimes’ doubt the reality of their pain. In this regard, Chronic pain often sets the stage for the emergence of a complex set of physical and psychological changes which add greatly to the burden of the pain sufferer.

- Isolation from society and family
- Anxiety, stress, fear, bitterness, frustration, depression, suicide
- Over-dependence on family and other carers.
- Depression of the immune system and increased susceptibility to disease often associated with poor appetite and nutrition
- Overuse and inappropriate use of professional healthcare systems

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, friends and employers
- Job absenteeism and disruption in the workplace
- Increased dependence on benefits
- Costs of healthcare services and medication

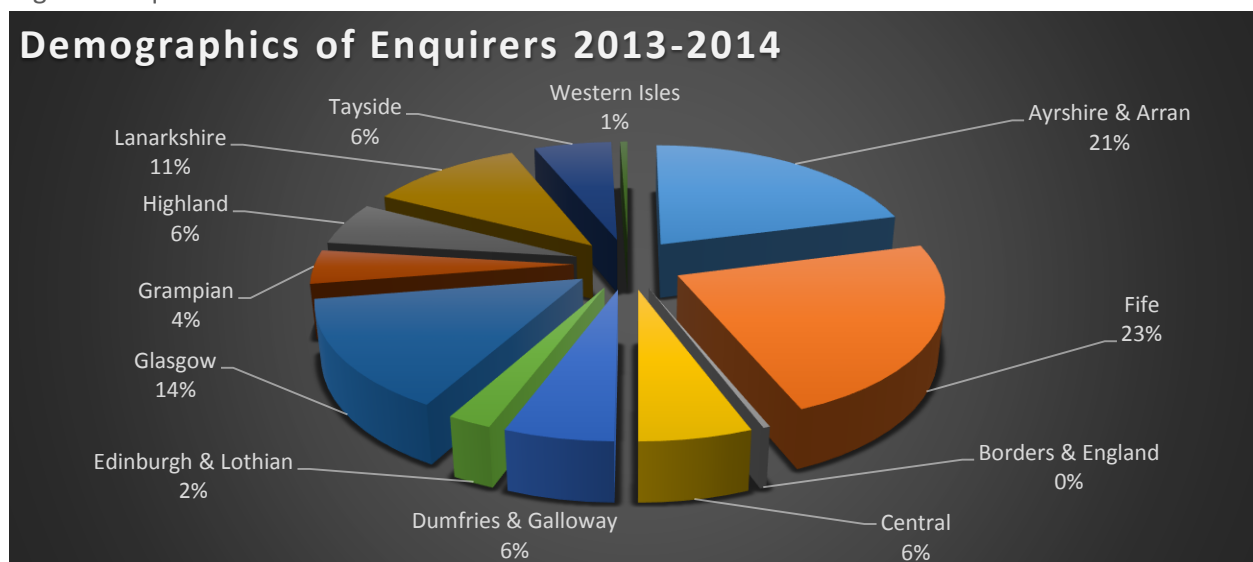
## Self-Management of Pain

Supporting patients with Chronic Pain is more than just handing out medication. Over two-thirds (68%) of patients report that their medication is inadequate at times and over one in five 22% have discontinued prescribed pain medication<sup>11</sup> The Association has continued to provide a high quality staff-led community based service for people burdened with chronic painful conditions. This is because chronic pain is multifactorial, comprising of neuropathic and nociceptive components, based on a bio-psycho-social understanding. To support patients with this condition, the Association has developed appropriate service delivery through collaborative working relationships with Health Care Professionals and extended new joint working opportunities with the majority of Scottish Health Boards. Through the delivery of training courses and self-management groups, service objectives continue to be focused on empowering people with self-management capabilities. This inevitably leads to the improvement in quality of life, health and wellbeing for many chronic pain sufferers, their families and carers and colleagues as our resources allow. Such self-management has potential to improve health outcomes in many cases, with patients reporting increases in physical functioning. It can also improve the patient experience, with patients reporting benefits in terms of greater confidence and reduced anxiety.<sup>12</sup>

## Service Provision

The Association provides around 1710 hours of staff-led self-management training for approximately 1670 participants per month. The highest percentage of referrals come from NHS Ayrshire and Arran and Fife – 21% and 23% respectively with the lowest percentage from Edinburgh and Lothian and Borders at 2% and 0% respectively. Fig (1.0) indicates the number of referrals into the service for 2013/14 period.

Fig 1.0 Enquiries



For the intensive self-management course, the service delivers an average of 24 courses per year and receive an average of 850 clinical referrals from NHS Chronic Pain Services. Figure (2.0) indicates that the highest percentage of those referred to the intensive self-management courses are between the age of 40-59, and therefore of working age. As

indicated in figure (2.1), this position is in line with the outcomes of the National Scotland-wide Healthcare Improvement data collection.<sup>13</sup>

Fig 2.0 Age Range

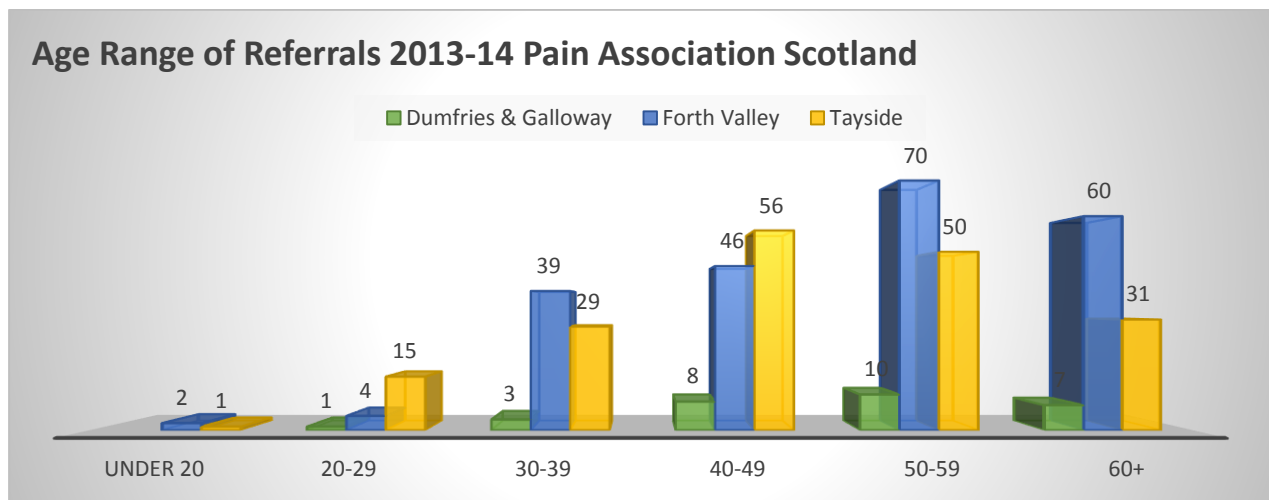
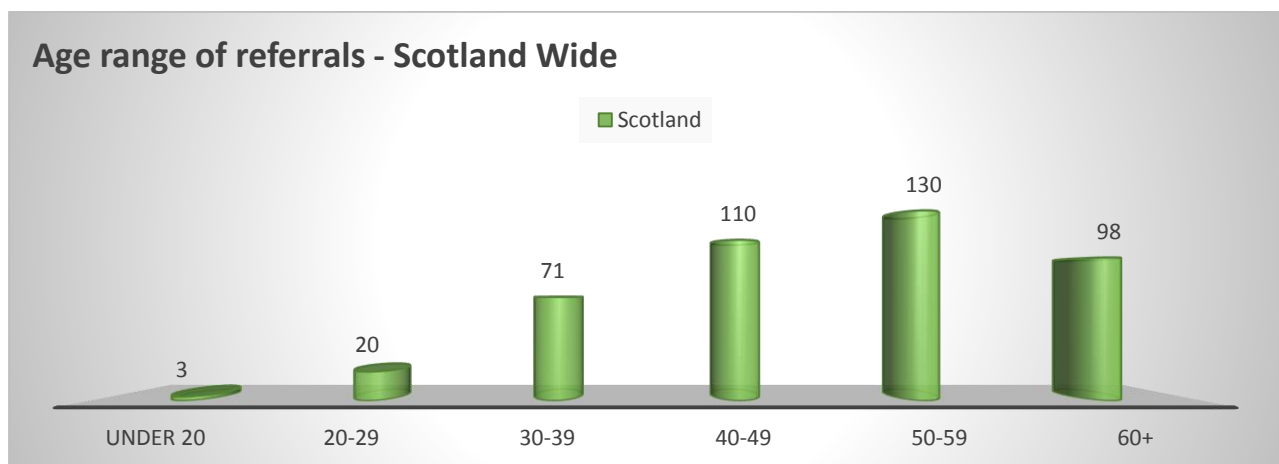


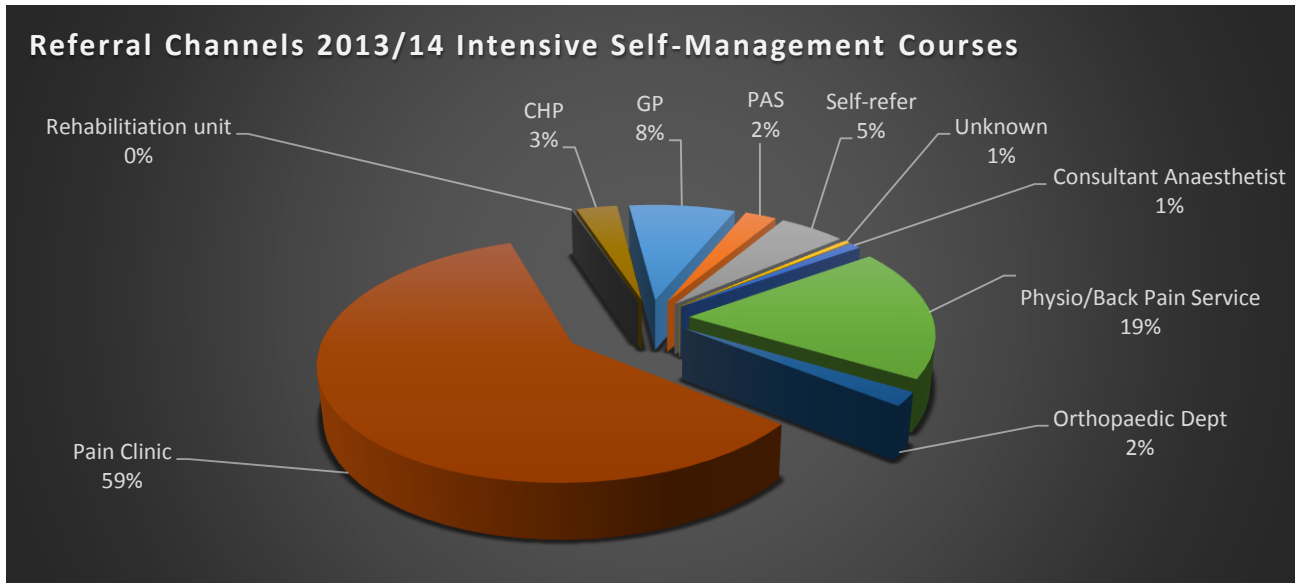
Fig 2.1 Age Range- National Indicator



This clearly demonstrates the importance of self-management to support patients back into employment, keep those who are in work at work and also to be able to enjoy and have the benefit of an improved quality of life in the long-term. Overarching the referral routes, Fig (3.0) indicates the referral channels of patients to the intensive self-management courses, and shows that although the majority of referrals are from Pain Clinics (59%) for 2013/14, the percentage of GP referrals demonstrated an increase of 3% from 2012/13. This increase relates to supporting infrastructure from work going on with the respective Service Improvement Groups (SIG's) in each health board.

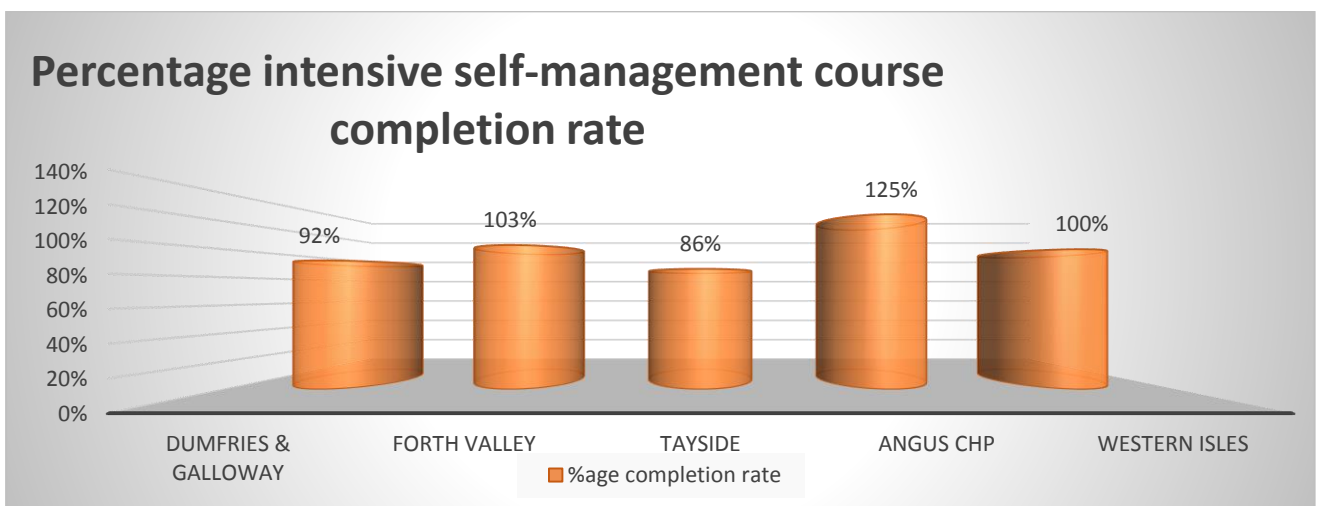
This initiative encourages more referrals to self-management from Primary Care in order that chronic pain sufferers have the option to access self-management at a much earlier stage. This is a positive step in preventing unnecessary referrals to Secondary Care at an average cost of <£20 per patient per course.

Fig 3.0 Referral Channels



The course content underpinning these figures includes; the relationship between stress and health (bio-psycho-social), understanding chronic conditions, relaxation, breathing and distraction techniques, experience of combined breathing and gentle stress reducing movement, communication and understanding, pacing and goal setting and dealing with unhelpful thoughts and feelings. Since these topics are inter-related the experienced staff member leading the group can guides the pace and individual needs of participants attending each session. Figure (4.0) indicates the completion rates for the self-managed courses for the period 2013-14, which cumulates to an overall average of approx. 95%

Fig 4.0 Completion rates



### Service Alignment (*Health and Social Care*)

NHS Board's collaboration with voluntary sector organisations such as PAS has significant potential to improve self-management, reduce inappropriate referrals and reduce the costs for acute and secondary care services<sup>14</sup>. PAS supports the current Scottish model of pain by delivering a series of self- management programmes.

The service is accessible for all Chronic Pain sufferers, even in remote and rural areas and those who are often isolated, the website enables people access to on-line self-management 24/7. In this way, the service supports the vision of the Scottish Chronic Pain Service Model by shifting the balance of care to the community. Thus, supporting patients to self-manage their pain, this service structure can reduce the impact on both primary and secondary care resources, investigations and treatments. The Association meets the Scottish Government’s objectives of being **Safe**, **Effective** and **Person-Centred** in the following ways:-

**Safe** – a key feature of this type of service delivery is that it offers an open door policy to local self-management groups whether people are referred by a clinician or simply self-refer; at no time is anyone more than four weeks away from a group meeting in their local area. These groups provide the coping skills and strategies which enable people to maintain and support an independent lifestyle.

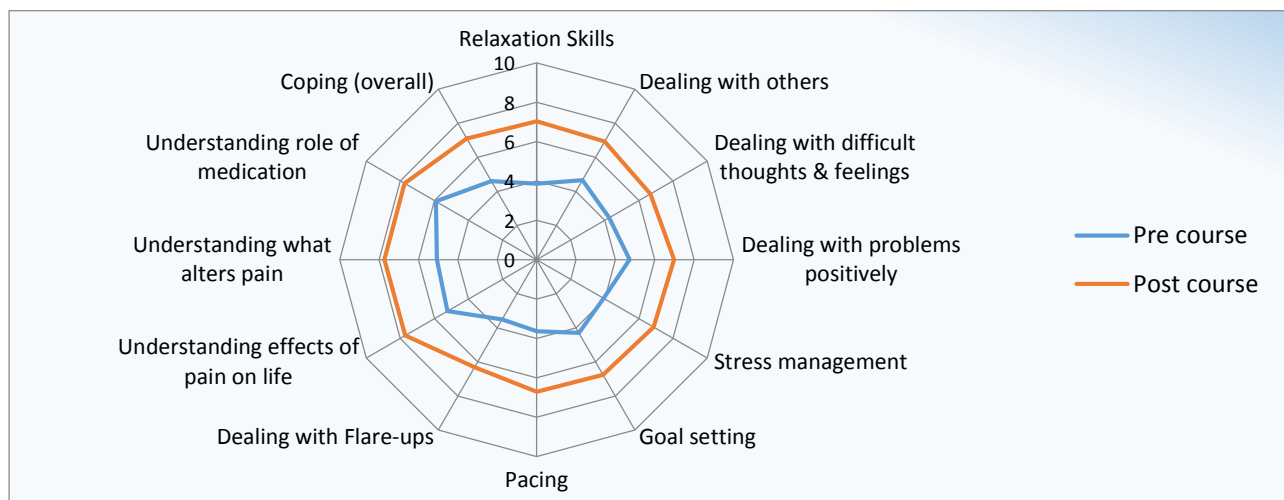
**Effective** – the service provides an approved exit strategy for health and social welfare professionals and this effectiveness has enabled more Chronic Pain sufferers to access our service as a first step in their pathway of care. The Scottish Government’s Steering Group for Chronic Pain nominated the Association as the preferred/approved provider of self-management training and support and included our model as an integral part of the new Service Model for Chronic Pain services in Scotland enhancing local Chronic Pain Services.

**Person-Centred** – when someone is in pain they may seek help at that specific time that time. Using this model of care delivery, no-one has to wait longer than four weeks to access a local self-management group or the on-line self-management course, which enables people to have access to the support 24/7. Sufferers have access to our Pain Radar Graph at any time, enabling them to monitor their own progress over and period of time.

### Service Assessment

Monitoring and evaluation is important as it can reinforce service user benefits, and importantly, can record their improvement by using standardised tools. Within Pain Association Scotland, the Pain Radar Graph (Fig 5.0, Spider) is used to reflect progress and note unique anecdotal comments.

Fig 5.0 Spider Model



This tool is supported by DAPOS (*Depression, Anxiety, Positive Outlook Score*) Fig (5.1) and the PSEQ (*Pain Self-Efficacy Questionnaire*) tool, as shown in figure (5.2). The use of appropriate evaluation tools underpins evaluation, and in most cases validates the patient report analysis, which indicates reduction in depression and anxiety and an increase in positive outlook and self-efficacy.

Fig 5.1 DAPOS Model

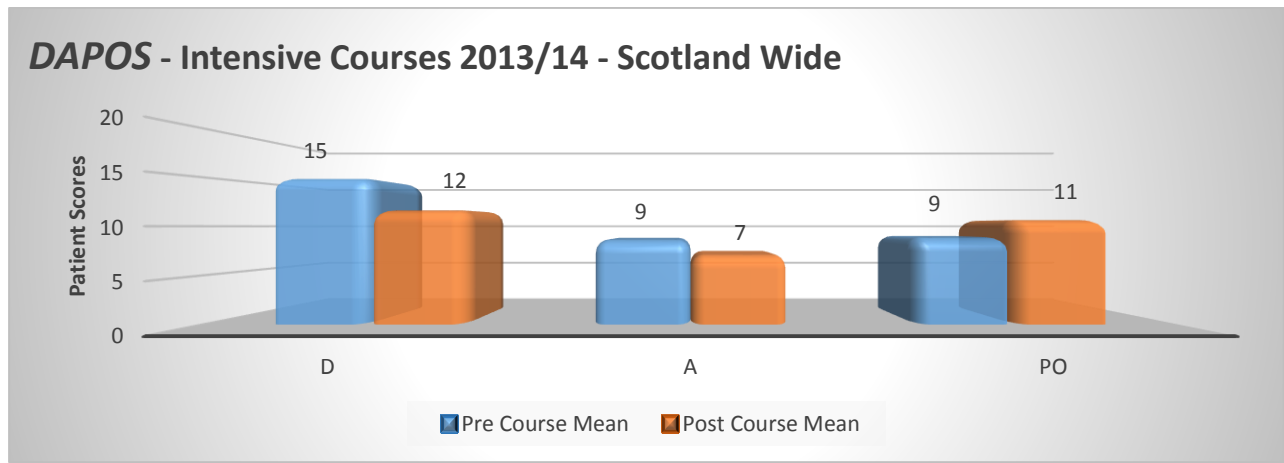
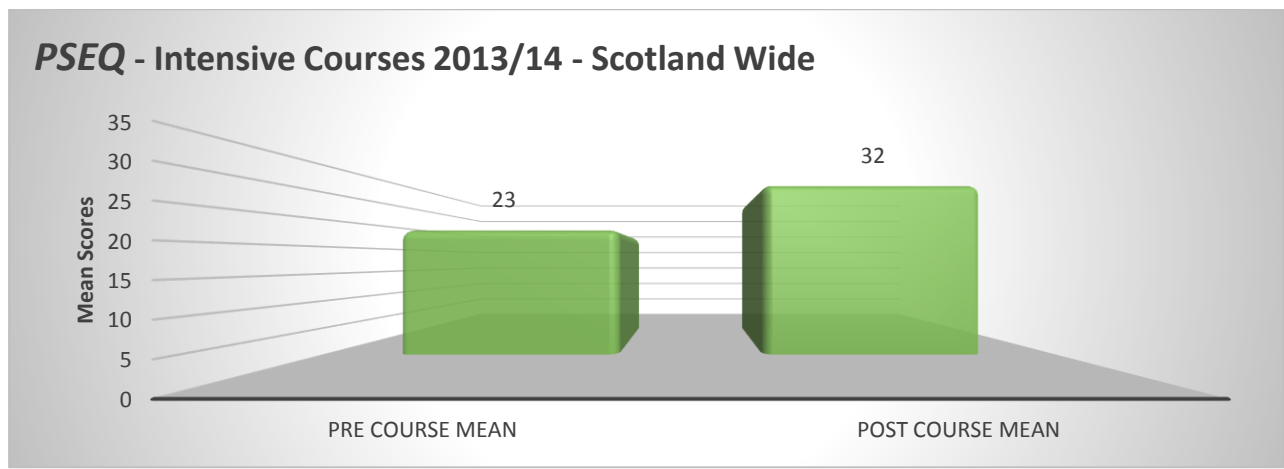


Fig 5.2 Pain Self-Efficacy Questionnaire



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 this tool and model architecture. As a consequence of this intense monitoring strategy, individuals who have participated in intensive Self-Management Programmes report more vitality, less pain, less dependence on others, improved mental health, and are more satisfied with their lives compared to those who have not taken part. Increased self-efficacy is closely related to successful rehabilitation. The service provision is specifically designed to target those in the community who are affected by Long Term (Chronic Painful) Conditions. Service provision under this paradigm, continues to address the non-medical

issues which impact on people's lives, thus, self-management programme offers a different paradigm – it is not a replacement for medicine – rather it focuses on highly relevant topics and can facilitate the change of locus of control and improve those aspects of life that only that person can improve by regaining control. In this way, the benefits are equated as giving a practical next step for someone who has reached the limits of medicine. This focus helps introduce people to, and quickly build, self-management skills, thereby creating practical positive change and leading to an improved quality of life and wellbeing. Chronic non-malignant pain continues to present a challenge not only for those affected but for all health professionals involved in their care. Additional feedback comes from staff working directly with our users, questionnaires, forums, calls to free 0800 enquiry line, positive collaboration with healthcare professionals.

## Conclusion

Sufferers of Chronic Pain have been poorly supported in the past, and many sufferers report that their pain is not believed or apathy to the condition. This discussion has shown that through a network of staff led community based self-management groups and training programmes, utilised service provision can be developed to help with this situation. Utilised in this way, the correct service structure empowers chronic pain sufferers, their carers', family and colleagues to make positive practical changes leading to improved levels of coping, well-being and quality of life, without impacting on the already under resourced NHS services. Clearly, focused, managed and monitored resource can help sufferers understand and manage their chronic pain condition and unwanted changes in health outlook by seeking positive adaptive and coping mechanisms which can ultimately lead to a better quality of life.

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<sup>1</sup> <http://www.patient.co.uk/doctor/chronic-pain>

<sup>2</sup> Primary and Community Care Special Interest Group, British Pain Society, London, UK

<sup>3</sup> Osborne, S. P. (ed.) (2008). *The Third Sector in Europe: Prospects and Challenges*, London, Routledge

<sup>4</sup> Henmila, 2004 Quality of life and cost of back pain in patients in Finnish General Practice *Spine*, 27 (6) (2004), pp. 647–653

<sup>5</sup> Primary and Community Care Special Interest Group, British Pain Society, London, UK

<sup>6</sup> <http://www.sign.ac.uk/pdf/SIGN136.pdf>

<sup>7</sup> Scottish Government NHS QIS GRIPS Report 07

<sup>8</sup> Belsey J. Primary care workload in the management of chronic pain. A retrospective cohort study using a GP database to identify resource implications for UK primary care. *J Med Econ* 2002; 5: 39-50

<sup>9</sup> Health Report Chronic Pain. Pfizer New Zealand

<sup>10</sup> <http://www.patient.co.uk/doctor/chronic-pain>

<sup>11</sup> Pain In Europe Survey 2003 – Key facts and figures

<sup>12</sup> Challis et al 2010

<sup>13</sup> [www.healthcareimprovementscotland.org/our\\_work/long-term\\_conditions/chronic\\_pain/where\\_are\\_we\\_now.aspx](http://www.healthcareimprovementscotland.org/our_work/long-term_conditions/chronic_pain/where_are_we_now.aspx)

<sup>14</sup> Healthcare Improvement Scotland – report to the Directors of Regional Planning on Chronic Pain Management Services in Scotland – November 2011