



**Report
of a six month
Pain Toolkit
Self Management
Pilot Programme
in Argyll & Bute.**

**Delivery partners: HSCP Highland Argyll & Bute
Arthritis Care Scotland volunteers and partners**

Report of a six month Pain Toolkit Pilot Programme in Argyll & Bute.



Introduction

Chronic and persistent pain, which is pain lasting longer than three months, was recognised by the Scottish government in 2008 as a long term condition in its own right.

The Scottish Service Model for Chronic Pain 2012 Annex A) recommends that people with persistent pain (and other long term conditions) are encouraged to self manage their condition.

The pain management service for people with persistent (chronic) pain in Argyll & Bute consists of a primary care pain service delivered mainly in GP surgeries and a secondary pain service which operates from Oban General Hospital covering Lorn and the Isles, Lochgilphead and Campbeltown. Islay, Cowal and Bute and Helensburgh are covered by Greater Glasgow Health Board. Ideally, the majority of people with chronic pain should be supported in primary care and only small numbers referred on to secondary/specialist services. At the moment, this number of referrals is relatively high, which results in long waiting times before patients can be seen. There is also a referral option to an intense (residential) pain management programme in Glasgow General Hospital. The Pain Association is commissioned to run a programme of monthly 2-hour self management sessions, which are held at the Oban Bay Hotel - 19 people attended at least one session between January and October 2016.

A gap had been identified in pain self management services in remote and rural areas in Argyll & Bute (other than Oban) following queries by people with chronic pain and discussion and presentation to the specialist pain services improvement group who meet regularly in Oban. Recommendations were made to engage with Primary Care and run a training and pilot programme to enhance the current pain service, in line with the SIGN guidelines for chronic pain.

<http://www.sign.ac.uk/guidelines/fulltext/136/index.html>

The use of Pain Toolkit (PTK) Resource was chosen for this pilot.

The Pain Toolkit

The Pain Toolkit (PTK) is an easy to read 24 page informational booklet for both patients and health care professionals to use. It is endorsed by Professor Blair H. Smith, the Scottish Government's National Lead Clinician for Chronic Pain, as a useful resource to promote self management.

www.chronicpainscotland.org

'In my opinion, the Pain Toolkit exemplifies the self-management approach.'

Professor Blair H. Smith

It has proven to be particularly effective when used by health professionals in one to one sessions or in a peer led self management workshop.

The Pain Toolkit was co-authored by Dr Frances Cole, an experienced Pain Management Specialist and Pete Moore, and expert patient with multiple long term conditions including pain.

The Toolkit is routinely used in the UK, Australia, New Zealand and Europe having been translated in 11 different languages. There is a Pain Toolkit App for those who prefer to use this technology and an interactive website: www.paintoolkit.org. Around a million copies have been used since 2009.

Funding was received for training of staff and coaches in the use of the Pain Toolkit in various settings. 34 Physiotherapists and Allied Health Professionals attended training by Pete Moore to use the PTK in a time limited face to face consultation in February 2016. Further brief intervention training was held in July attended by 5 Community Nurses in Islay. In addition, 11 Coaches, who were already trained to facilitate the 6 week self management programme run by Arthritis Care Scotland's *Living Well with a Long Term Condition* programme, were further trained to lead a 3 hour long PTK workshop in a group setting.

A set of half day Workshops for people with chronic pain was scheduled to take place in Argyll & Bute's main towns between mid May and September 2016, as part of the extended ICF funded Service Level Agreement with Arthritis Care Scotland. Engagement with GP Practice staff supported the uptake by people living with persistent pain.

The Pain Toolkit Workshops are offering an introduction to pain self management, which can be extended with the above mentioned *Living Well* Self Management programme.

This is a report to update partners and funders on progress made so far and to decide on what steps can be taken to enhance the Chronic Pain Service in Argyll and Bute HSCP with a self management educational and peer support programme.

The Pilot

103 people participated in 15 Pain Toolkit Workshops that were held throughout Argyll & Bute between May and September 2016. The majority of participants live with chronic pain. Other participants were carers, health and social care staff and voluntary sector staff. Data was gathered from 82 participants. 280 Paint Toolkit Booklets were despatched to trained professionals for use in one to one sessions. It is seen as a valuable tool in their toolbox to encourage self management alongside their therapy.

Overview of Pain Toolkit Workshops			
Area	Number of workshops	Number of participants	Bespoke/with partners
Bute	3	14	
Campbeltown	1	7	
Dunoon	2	9	
Helensburgh	2	9	
Lochgilphead	1	10	MS Centre – Mid Argyll
Oban	2	11	Arthritis Care/Lorn Healthy Options
Islay and Jura	1	9	MS Centre Outreach worker LTC/McTaggart Leisure Centre
Rothesay	1	12	Parkinson Group and Specialist Nurse
Strachur	1	17	Strachur Hub and GP practice Nurse
Tarbert	1	5	Tarbert GP practice
Total	15	103*	*Data was collected from 82 participants

Some workshops were well attended, others less so, which gave us the opportunity to compare the merits of larger and smaller size groups and it looks like restricting the maximum number of participants at a workshop to 8, would be an ideal number.

If there are only 1 or 2 participants, then there isn't as much interaction and sharing, whereas if there is a group of 6 or more, you inevitably have to split the group into smaller groups so that people get the benefit of being able to share their personal stories. Groups larger than 12 inevitably are less involved and there is less opportunity for personal engagement between participants.

Marketing of the workshops was done in a similar way for all of the scheduled workshops:

3 emails to GP practice managers offering the following options:

The practices were asked to engage with the pilot by:

- a) Highlighting the workshop or referring/signposting their patients
- b) Displaying the poster in their practice or tv screen
- c) Organising a session in their practice by inviting patients with chronic pain to attend
- d) Offering a training session for front line staff to work with the pain toolkit in a time limited consultation

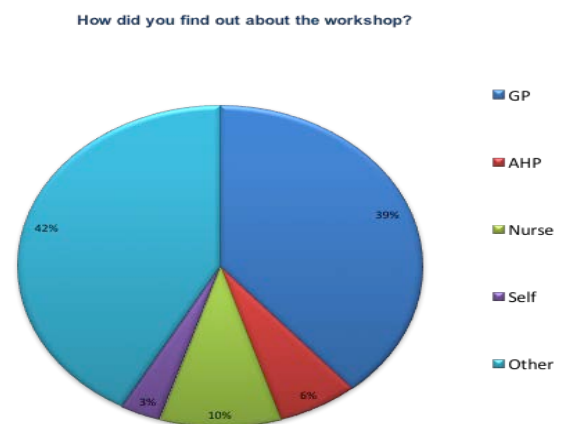
The practice in Tarbert organised a workshop in their practice, the Strachur practice nurse worked with the Strachur Community Hub and organised a session in their Community Hall.

In Lochgilphead, the MS Centre took the lead in promoting the PTK with people who regularly attend the centre or engage with the service. In Islay, we worked with the assistant locality manager and the long term conditions outreach worker from the Mid Argyll MS Centre. We also developed and delivered a PTK 90 minute brief intervention training session for health professionals to start using the PTK in one-to-one sessions, with permission from the PTK owner, Pete Moore. The latter was attended by 5 staff from the community nursing team covering Islay and Jura. This focused workshop was found to be very beneficial and can be delivered widely to appropriate front line staff.

As you can see from the above table, and adjacent diagram, the sessions that were arranged with support from a coordinating practice or agency were better attended. Otherwise marketing was done via the following channels:

- The Health and wellbeing Networks following a brief presentation to the Coordinators
- Facebook pages linked to the various local websites and Arthritis Care Website
- TSI networks
- AHP Lead
- Lead nurse

They received both the full schedule for the whole of Argyll & Bute and further reminders were distributed nearer the workshop dates for local areas via



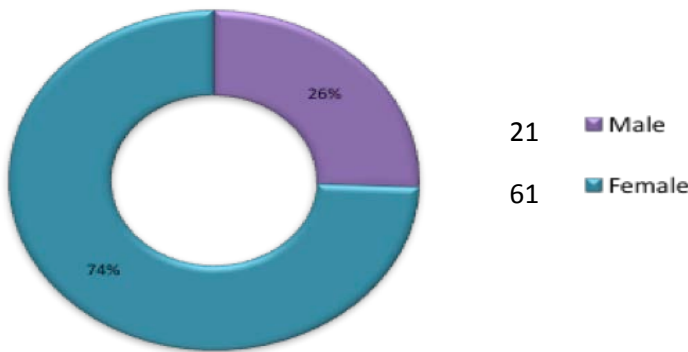
- Each locality manager’s PA for onward distribution
- Posters in public places
- GP practices
- Local radio (via networks) where available

The overall marketing strategy seemed to work as many people heard about it from GP Practice staff and other sources, such as Carers Centres and partners. It is worth noting that only a small percentage was signposted via Allied Health Professionals such as Physiotherapists, Occupational Therapists etc.

A presentation was given to members of the Academic Programme for Mental Health, who meet monthly at Argyll & Bute hospital. They were interested in using the Pain Toolkit in one to one sessions for people who had been referred to their service as a result of the detrimental effects on mental health and wellbeing of living with chronic pain.

The following tables and diagrams show details of the participants in the PTK workshops.

Gender of Participants



Age Group of participants

(74 total)

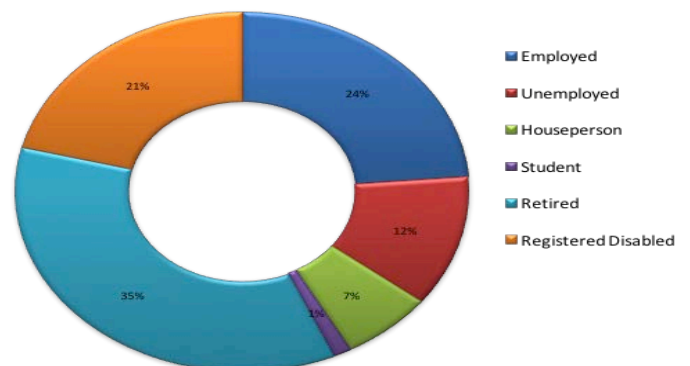
< 40	-	3
40-49	-	20
50-59	-	5
60-65	-	13
65-79	-	25
> 80	-	8

It will come as no surprise that there were more women than men attending the workshops. Not everyone disclosed their age. It is worth noting that there were 20 participants in the 40-49 age range, but only 5 in the 50-59 age range. As you would expect, the largest numbers are in the over 60s. 96% of participants have lived with chronic pain for more than 1 year.

Employment Status

Of the 25 participants who were employed, 9 remained at work (with difficulty) and 14 were absent due to pain. Anecdotal evidence showed that although most employers had been made aware of their employee’s condition, that it was not always taken into account when being asked to do their job and there was a worry that if they didn’t get on with it, that they would lose their job. 75% of participants were retired, disabled or registered unemployed.

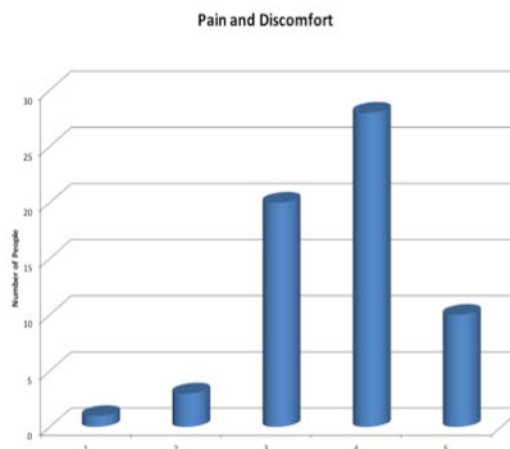
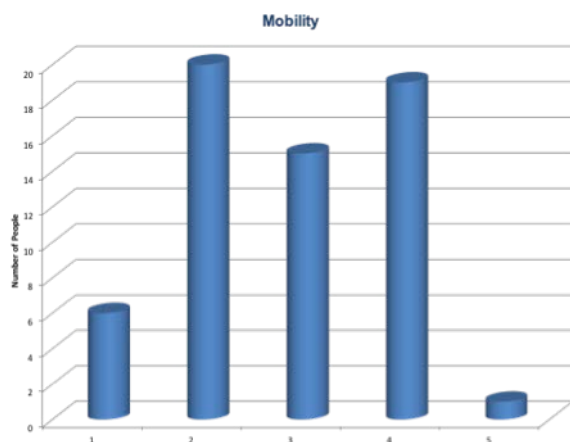
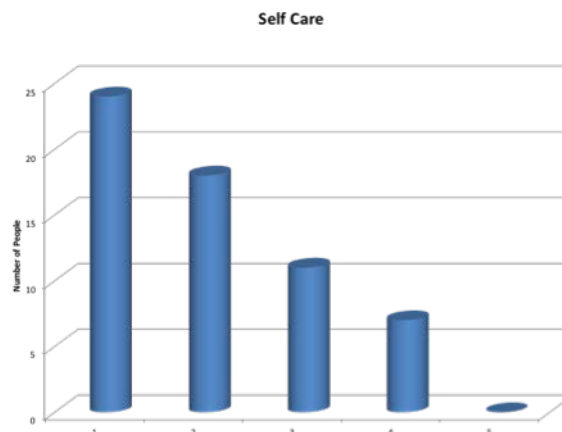
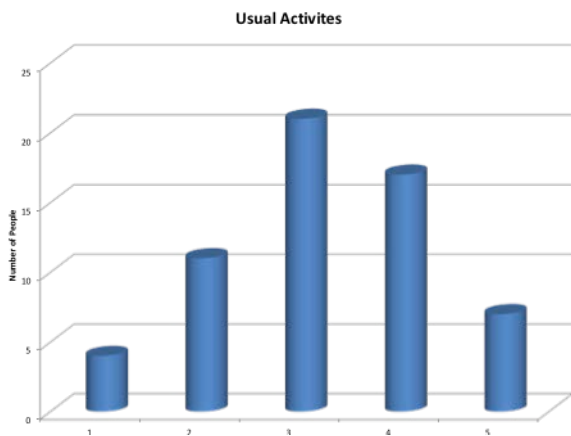
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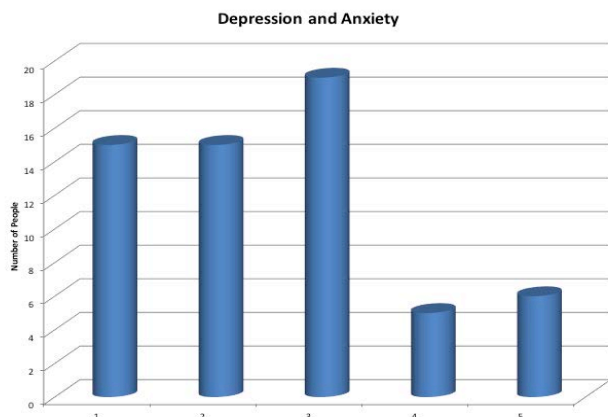
Quality of Life Measure (EQ-5D-5L)

This questionnaire has 5 scaling questions relating to the following quality of Life measures: Mobility, Self Care, Activities of Daily Living, Pain/Discomfort and Anxiety/Depression.

The participants were asked to assess the severity of the above areas ranging from 1 (no problems) to 5 (Severe problems) to show the impact of their pain on their day to day life.



There is a marked effect on the participants' ability to get on with usual activities, due to moderate to severe pain that people reported and the negative side effects of prescribed pain medication.



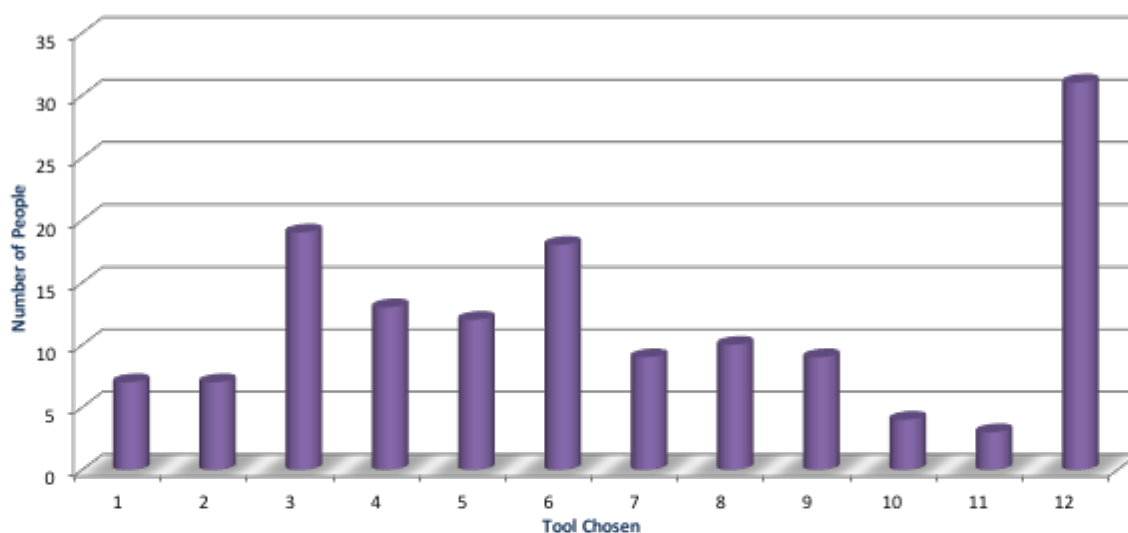
34 people reported to be slightly to moderately anxious and depressed and 11 people reported to feel severely or extremely anxious or depressed.

Anecdotally, a larger number reported that their pain has a big impact on their mental wellbeing.

We are planning to evaluate sustained benefit by repeating the above questionnaire.

At the end of the workshop, participants were asked to rate the workshop and which tools they were likely to use in the future. *Pacing* (3) and *Being Patient With Yourself* (6) scored high, but Tool (12) *Keeping it Up, Putting all the Tools into Daily Practice* topped the range. It was interesting to see that tool (1) scored quite low. *Accepting that You Have Persistent Pain/a Long Term Condition* is a prerequisite for moving on and self management. Tool (2) and (11) (*Building Support Around You and Team Work*) also scored particularly low; people value their independence and see it as a sign of weakness to ask for help. One of the key strategies in self management is knowing what it is that you need and building your team around you to support you. *Having a Set-back Plan* (tool 10) was also not chosen by many participants and it seems that most people tend to “take it as it comes” without planning for good and bad days.

Which Tool would you use following the workshop?



Tool 1 - Accept that you have persistent pain

Tool 2 - Get involved - building a support team

Tool 3 – Pacing

Tool 4 - Learn to prioritise and plan out your days

Tool 5 - Setting Goals/Action Plans

Tool 6 - Being patient with yourself

Tool 7 - Learn relaxation skills

Tool 8 - Stretching & Exercise

Tool 9 - Keep a diary and track your progress

Tool 10 - Have a set-back plan

Tool 11 - Team Work

Tool 12 - Keeping it up...putting into daily practice tools 1-11.

Most people left the workshop on a high note, feeling more confident, supported by the workshop coaches and by each other. 80% of participants expressed an interest in the “Living Well with a Long Term Condition” Self Management Programme that is currently run by Arthritis Care Scotland Volunteer Coaches throughout Argyll & Bute. Here are some of their comments post workshop.

‘Knowing that you are understood and that it doesn’t make you weak to find things difficult.’

‘Talking to people in a similar situation. Not feeling alone.’

‘To change how I look at my life and accept that this is **MY** normal.’

At the end of the pilot a workshop was held to review the experiences and ongoing commitment of the PTK coaches and to discuss options for the way forward. This was also attended by two members of the Oban based Chronic Pain Service Team. Four members of the wider Arthritis Care team, and a member of the Edinburgh HSCP Team also attended to hear about our experiences and to look at using the Pain Toolkit in other areas in Scotland. Participants acknowledged that there is an appetite in communities to see more of this work. Coaches expressed their commitment to deliver PTK workshops, followed by the Living Well with a Long Term Condition self management programme.

The programme for this and refresher training will be set in January 2017.

Recommendations for the way forward 2017

1. Recognise and endorse a pain self management approach as an integral part of all levels of Chronic Pain Service in Argyll and Bute with referral/signposting protocols in place (see Anex A).
2. Endorse and support delivery of Brief Intervention/Motivational Interviewing Training for all staff who work with people with chronic pain (or other long term conditions) in health and community settings, including mental health, to promote self management and the use of the Pain Toolkit in one to one sessions for people with persistent pain and long term conditions. This can be delivered by current Motivational Interviewing trainer.
3. Present to HSCP local planning groups to highlight availability of training/workshops in their area.
4. Purchase 1000 PTK booklets and make them available from HIRS/Healthy Highlanders, so that all trained staff in Argyll & Bute can order them when required.
5. Hold a workshop with PTK and Self Management Coaches at the beginning of 2017 to revalidate coaching skills and plan a programme of delivery throughout Argyll and Bute.
6. Evaluate the PTK/*Living Well* Self Management Programme (delivered throughout Argyll & Bute) and the Pain Association Support Programme (delivered in Oban) and define ongoing cost and benefit to HSCP.

Scottish Service Model for Chronic Pain

Person With Chronic Pain

