Better Days Pain Support Programme

Evaluation

April 2022 - March 2023

Report date – September 2023

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1. Introduction

Project Overview

1.1. Around 1 in 5 people in Northern Ireland (NI) live with chronic pain. Chronic pain is long term pain by which medication may have limited impact after long term usage (Health and Social Care NI, 2023)[1].

1.2. Better Days Pain Support Programme ("Better Days" or "the programme") is a collaborative cross-sectoral project aimed at improving social and mental health outcomes for people who live in NI and experience chronic pain. The project began as a successful pilot in 2017 and has evolved into a region-wide series of programmes facilitating self-management of pain using a community development approach.

1.3. Better Days is an innovative, flexible, programme of up to 12-weeks involving pharmacists, physiotherapists, complementary therapists, and community development workers who act as pain support facilitators. The facilitators encourage a peer-led approach which aims to:

- increase participants knowledge of pain,
- challenge their reliance on medication,
- encourage personal ownership of plans to overcome pain,
- improve participants mental health through social inclusion and self-efficacy,
- facilitate an appropriate gentle exercise regime, and
- involve participants in determining elements of the course and nature of the programme.

1.4. The pain support facilitators are based in Healthy Living Centres (HLCs) which are community-led health and well-being organisations throughout NI and members of the Healthy Living Centre Alliance. The HLC Alliance provides regional co-ordination of the programme and quality assurance is provided by a cross sectoral steering group, which is comprised of representatives from the HLC Alliance, Public Health Agency, Strategic Planning and Performance Group (SPPG – Department of Health), Queens University, doctors, and pharmacists.

1.5. During this evaluation period, funding for the programme was provided through the SPPG Pharmacy budget. The funding provided was £120,000.

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[1] Health and Social Care NI (2023) Long-term pain, Available at: https://online.hscni.net/our-work/pharmacy-and-medicines-management/patient-initiatives/long-term-pain/#:~:text=It's%20been%20estimated%20that%20around,as%20well%20for%20chronic%20pain.

Evaluation Approach and Report Layout

1.6. This evaluation covers the period 1 April 2022 to 31 March 2023 and an outcomes-based accountability approach has been adopted to review the programme during this period, considering three questions:

- How much was done? (Quantitative information) – Section 2
- How well was it done ? (Qualitative Information) – Section 3 and,
- What difference has it made? (Impact) – Section 4.

1.7. We have drawn conclusions from our evaluation and highlighted some observations and recommendations in section 5.

Caveat

1.8. The information used for this evaluation has been extracted from reports and supporting documentation provided by the Programme Co-ordinator and we have not sought to verify the accuracy or completeness of this information.

1.9. As highlighted in Section 4, some survey information included in this Section is based on that reported by Tranche 3 participants only.

1.10. As noted in Sections 3 and 4, there are limitations in the robustness and completeness of survey information and as a result care should be taken in interpreting this information. Summaries in this report based on survey information should be seen in this context and as an indication of apparent trends only.

1.11. Information contained in this report should not be re-produced without our permission. This permission will not be unreasonably withheld.

Acknowledgements

1.12. We would like to thank those who contributed to this evaluation including Natasha Moore, Programme Co-ordinator, Tony Doherty, HLC Alliance Regional Co-ordinator and the steering group members and facilitators who attended focus groups.

2. How much was done ?

Introduction

2.1. This section focuses on quantitative information about the programme. The information has been derived from quarterly reports produced by the Programme Co-ordinator.

Programme overview

2.2. The table below provides a summary of the overall activity delivered by the programme in the evaluation period.

Activity	Total
HLA Staff trained to deliver chronic pain support programmes (2 sessions)	38
HLCA Staff trained in Chi Me	35
Number of programmes delivered	44
Total number of hours Better Days support programmes delivered	656
Total number of beneficiaries	486
Number of Pain Steering Group meetings	8
Number of Pain facilitators support meetings	8
Number of Pain facilitators training sessions	6

Staff Training and development

2.3. The table shows that during the review period, 38 community-based staff were trained on how to deliver chronic pain support programmes. Through this training, a valuable, community-based resource with knowledge of chronic pain support has been created. In addition to Better Days, this resource is able to provide relevant input into other community-based programmes delivered by Healthy Living Centres.

2.4. Training on Chi Me was also delivered to 35 of the 38 community-based staff. Tai Chi is a practice that is often used in community-based programmes to help people relax. It involves a series of slow gentle movements and physical postures, a meditative state of mind, and controlled breathing. Chi Me is a softer version of Tai Chi more suited to people living with chronic pain. As with the training on chronic pain support programmes this training provides a wider resource for community-based organisations to use in Better Days and other programmes.

Programmes delivered

2.5. In total, 44 Better Days pain support programmes were delivered by participating Healthy Living Centres during the evaluation period. These programmes were delivered to 486 beneficiaries and typically lasted 8-12 weeks. Participating HLCs reported that a total of 656 hours support was delivered through the Better Days programme during the review period. Details of participating HLCs are provided later in this section.

Tranche 1 April – June 2022	•12 HLCs •128 participants
Tranche 2 September – December 2022	•16 HLCs •165 participants
Tranche 3 January – March 2023	•16 HLCs •193 participants

2.6. The graphic above shows that the programme was delivered in 3 tranches during the evaluation period. It also outlines the numbers of participating HLCs and participants in each tranche. Further details on programme participants are provided below.

Steering group and support meetings

2.7. During the evaluation period, the steering group met 8 times. The role of the steering group is further discussed in Section 3 of this report.

2.8. The Programme Co-ordinator also convened 8 support meetings for the facilitators. These meetings provide valuable opportunities for facilitators to learn from, discuss mutual issues with, and provide support to their peers.

Participating HLCs

The table below shows the HLCs who delivered the Better Days Pain Support programme during the evaluation period. The table is set out by HSC Trust area and also shows which tranche(s) of the programme each HLC participated in.

Healthy Living Centre	Tranche
Belfast Area	
Ligoniel Healthy Living Centre	Tranche 1 - April - June 2022
Newlodge Duncairn Community Health Partnership	Tranche 1 - April - June 2022
H.E.A.R.T Project	Tranche 1 - April - June 2022
Maureen Sheehan Centre (West)	Tranche 2 - September - December 2022
East Belfast Community Development Agency (East)	Tranche 2 - September - December 2022, Tranche 3 - January - March 2023
Shaftesbury Healthy Living Centre (South)	Tranche 2 - September - December 2022
Top of the Rock Healthy Living Centre	Tranche 3 - January - March 2023
Ardoyne Shankill Health Partnership	Tranche 3 - January - March 2023
Western Area	
Bogside and Brandywell Health Forum	Tranche 1 - April - June 2022
Oak Healthy Living Centre	Tranche 1 - April - June 2022, Tranche 2 - September - December 2022, Tranche 3 - January - March 2023
Old Library Trust	Tranche 2 - September - December 2022, Tranche 3 - January - March 2023
Derg Valley Healthy Living Centre	Tranche 2 - September - December 2022, Tranche 3 - January - March 2023
Waterside Neighbourhood Partnership	Tranche 3 - January - March 2023
Southern Area	
Verve Healthy Living Network	Tranche 1 - April - June 2022, Tranche 2 - September - December 2022, Tranche 3 - January - March 2023
Kilkeel Development Association, Mourne Matters	Tranche 1 - April - June 2022, Tranche 3 - January - March 2023
The Clanrye Group/ SLNRA	Tranche 1 - April - June 2022, Tranche 2 - September - December 2022, Tranche 3 - January - March 2023
South Lough Neagh Regeneration Initiative	Tranche 2 - September - December 2022
Rural Health Partnership	Tranche 3 - January - March 2023
Northern Area	
TIDAL at Toome	Trance 1 - April - June 2022, Tranche 3 - January - March 2023

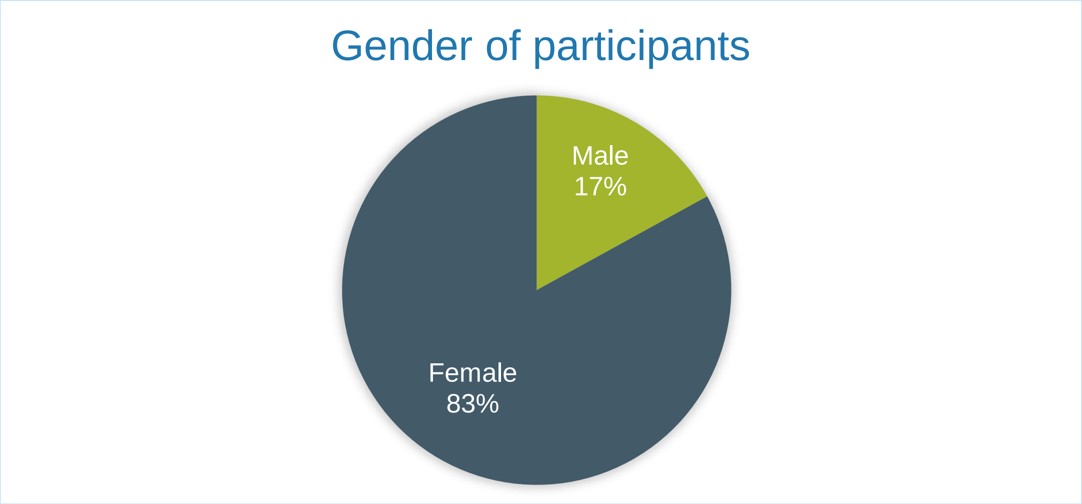
Healthy Living Centre	Tranche
Northern Area Community Network	Tranche 2 - September - December 2022
Cookstown and Western Shores Area Network/ TIDAL at Toome	Tranche 2 - September - December 2022
Loughgiel Healthy living Centre	Tranche 2 - September - December 2022
Causeway Rural & Urban Network	Tranche 3 - January - March 2023
South Eastern Area	
Poleglass Community Association	Tranche 1 - April - June 2022
Resurgam Healthy Living Centre	Tranche 1 - April - June 2022, Tranche 2 - September - December 2022, Tranche 3 - January - March 2023
Ballymote Community Centre	Tranche 1 - April - June 2022, Tranche 2 - September - December 2022
Peninsula Healthy Living Partnership	Tranche 2 - September - December 2022, Tranche 3 - January - March 2023
Regional	
Regional online programme	Tranche 2 - September - December 2022
Clanrye Group	Tranche 3 - January - March 2023

2.9. The table shows that during the evaluation period 27 HLCs across NI ran programmes; 8 in the Belfast area; 5 in each of the Western, Southern and Northern areas and 4 in the South-Eastern area. Additionally, a regional programme was delivered online in Tranches 2 and 3.

Participant information

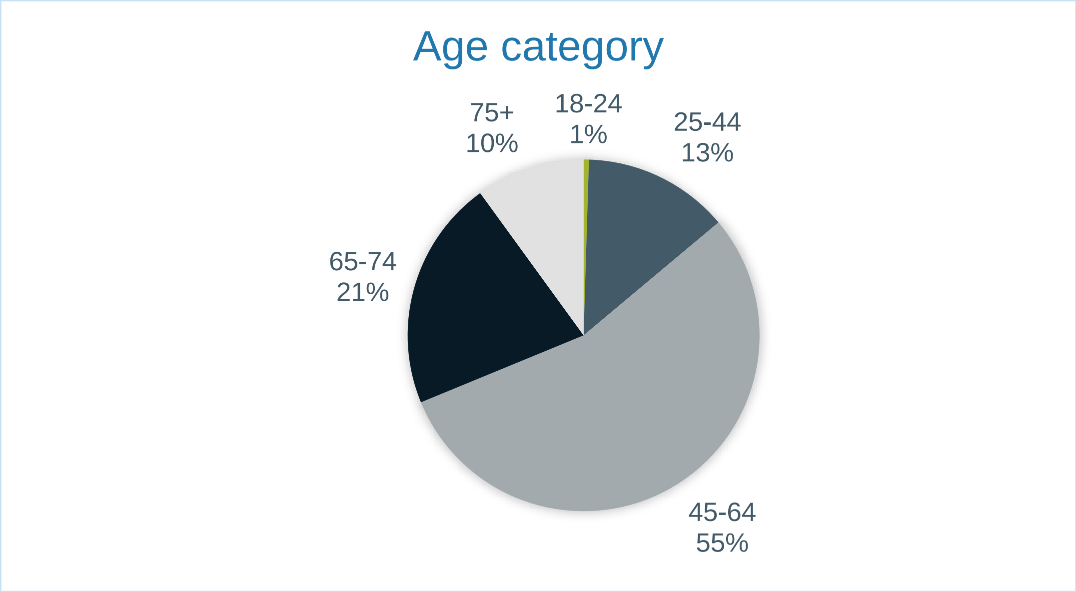
2.10. The information below on programme participants has been provided by the Programme Co-ordinator. It is sourced from the pre programme questionnaires completed by participants and covers the entire evaluation period. These questionnaires are further reviewed in Section 4 of this report.

Gender of participants



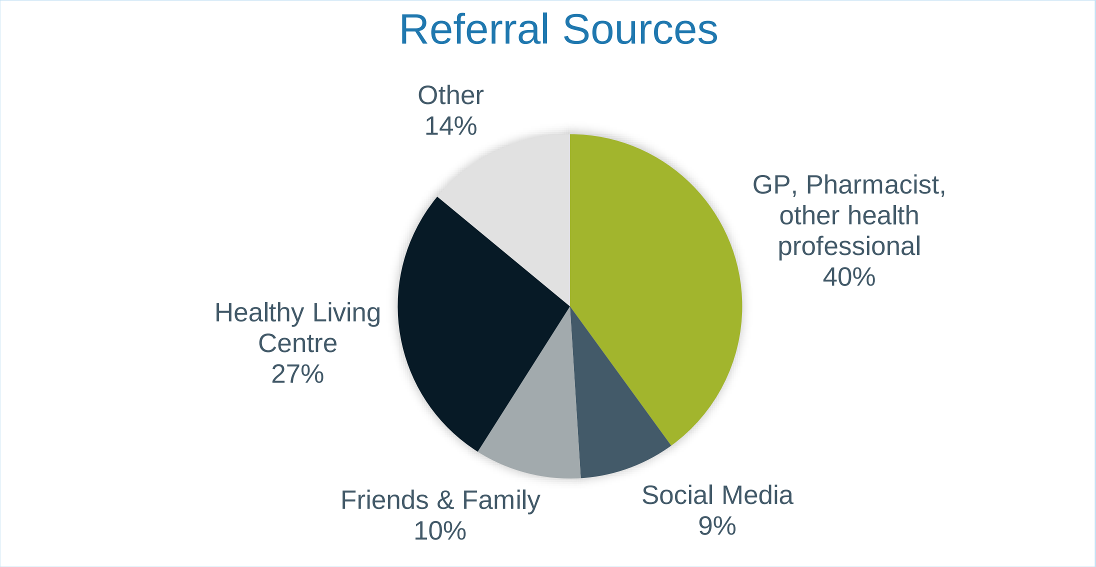
2.11. The chart shows that 83% of participants on the programme were female and 17% were male.

Age of participants



2.12. The programme is open to ages between 18-85+. The chart above shows that 55% of participants were aged between 45 and 64 years. 31% were aged 65 or over and 14% were under 45 years of age.

Referral sources



2.13. Participants were asked how they found out about the programme. The chart above shows that 40% of participants reported that they heard about the programme through a GP, Pharmacist or other healthcare professional. 27% of participants reported that they heard about the programme through a Health Living Centre, whilst 10% reported they heard about the programme through friends and family and 9% through social media.

Programme Costs

2.14. As noted in Section 1, during the evaluation period funding for the programme was provided through the SPPG Pharmacy budget. The funding provided was £120,000.

2.15. Details of programmes and participant numbers in the evaluation period are set out in the table below:

	Programmes	Participants
April – June 2022	12	128
September – December 2022	16	165
January – March 2023	16	193
Total	**44**	**486**

2.16. Based on this information, the cost per participant during the evaluation period was approximately £247 (i.e., £120,000 divided by 486).

Summary of information in Section 2

In the evaluation period (April 2022 – March 2023):

- 44 Better Days pain support programmes were delivered to 486 participants in 3 tranches by 27 Healthy Living Centres across NI.
- Programmes typically lasted 8-10 weeks and participating HLCs reported that a total of 656 hours support was delivered through the programme.
- 83% of participants were female and 55% of participants were aged between 45 and 64 years.
- 40% of those who participated on the programme heard about it through a GP, Pharmacist or another healthcare professional.
- The average cost of the programme per participant was £247.

3. How well was it done?

Introduction

3.1. This section focuses on qualitative information about the programme. The information has been derived from the following sources:

- Focus groups
- Mental Health Foundation research
- Case studies

3.2. Each area is reviewed in turn below.

3.3. In addition, a sample of quotes from participants and facilitators expressing their views about the programme has been included throughout the remainder of this report.

Focus groups

3.4. As part of this evaluation process, online focus groups were undertaken with steering group members and facilitators involved in the programme to explore their views on the programme. The groups consisted of semi structured discussions around a series of areas which had been shared with respondents in advance. Participants were assured of their confidentiality and questions were structured to elicit open and honest responses.

3.5. It was clear from these discussions that everyone who took part in the focus groups felt the programme is doing well and having a positive impact on those participating.

3.6. The main themes emerging from the focus groups are summarised in the next few sections of the report.

Medicines management

3.7. There was recognition that the programme has demonstrated that although medication is often prescribed to address chronic pain, it is not the only solution to dealing with this issue. It was acknowledged that Better Days aims to help people make informed choices on the use of medicines by providing information and education to people experiencing chronic pain on:

- Alternatives to medication (including lifestyle changes)
- Means of managing chronic pain, and
- The impact of medication (for example the risks associated with the use of opioids)

3.8. The involvement of community pharmacists in delivering the programme is seen as a significant strength in this area. Pharmacist participation is arranged at a local level by HLCs, and it was noted that the pharmacists involved in the programme come from a variety of backgrounds and have different levels of experience. Presentations for pharmacists to use in programme delivery have been developed centrally via the steering group and there is recognition if more resources were available, these could be updated and enhanced.

Summary
The programme has demonstrated that medication is not the only solution to helping people deal with chronic pain through providing information and education to help people make informed choices on the use of medicines.

Education support and skills training

3.9. In addition to providing information and education to people experiencing chronic pain, the role of the programme in providing education support to non-healthcare professionals who work on the programme was also highlighted, particularly through promoting understanding of chronic pain and how it is difficult to manage. The impact of this should not be underestimated as it often helps shape and inform other community-based health programmes and initiatives delivered by the organisations in which these people work.

Summary
The information on pain support provided through the programme to non-healthcare professionals is helping to shape helps shape and inform other community-based health programmes and initiatives.

Social isolation

3.10. The programme has helped to identify that many people experiencing chronic pain also experience social isolation because of their conditions and the restrictions they perceive it brings. It was highlighted that the programme has had a positive impact on participants in pain who experience social isolation. It has also helped enable people to normalise their experiences through having a network of peers who attend their group who are experiencing similar issues.

> *"Thoroughly enjoyed the class. Good to be able to meet up with people who have the health issues and there's no judgement."*
> *- Participant A*

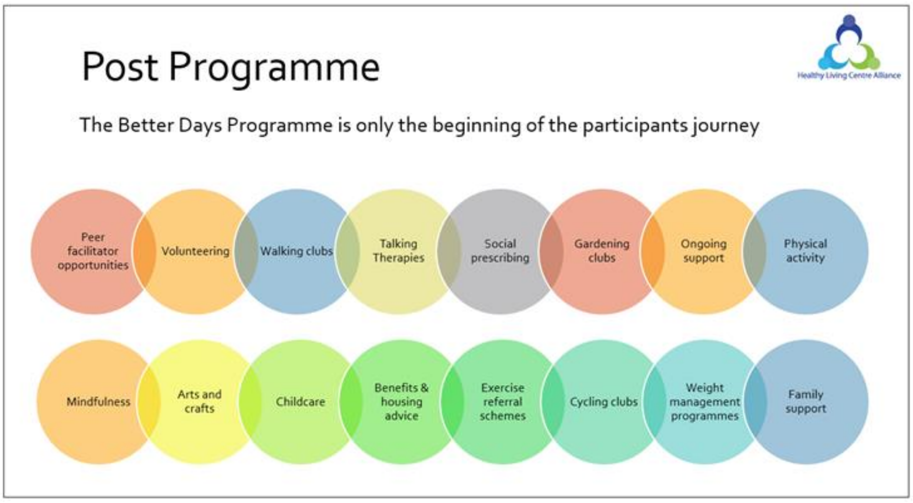
Summary

Through peer support, the programme is seen to have had a positive impact on participants in pain who experience social isolation.

Programme content

3.11. The programme length at 8-12 weeks is seen as an appropriate timeframe to encourage behavioural change amongst participants, with some observing that 'acceptance' for most participants typically comes around week 5 of the programme (see also sections below on Mental Health Foundation research for further evidence of acceptance by those who have participated on the programme).

3.12. Not being too rigid on programme timeframes was also considered important along with achieving balance between session length and comfort for participants who are in pain. It was noticed that this balance can be achieved for example by having 'formal' elements for say 1 hour, followed by more informal question and answer sessions or tea and coffee which encourage networking within the group. It was recognised that many participants continue to engage with HLCs after the programme (see diagram below) and some centres run step down programmes to encourage this.



Post Programme

Healthy Living Centre Alliance

The Better Days Programme is only the beginning of the participants journey

- Peer facilitator opportunities
- Volunteering
- Walking clubs
- Talking Therapies
- Social prescribing
- Gardening clubs
- Ongoing support
- Physical activity
- Mindfulness
- Arts and crafts
- Childcare
- Benefits & housing advice
- Exercise referral schemes
- Cycling clubs
- Weight management programmes
- Family support

3.13. The role of facilitators in being able to read the group and participants and shape the programme and content accordingly was also considered important to its success. At times, facilitators will use a mix of online and face to face classes and the participants have benefitted from this – the online classes are seen to be very helpful for people who cannot leave their home and help secure their participation.

3.14. Enabling people to go at their own pace and gain support from others in the group were seen as important components of the programme. It was also pointed out that not all programmes need to be accredited and there should be space for the human factor, which is often difficult to measure.

3.15. Having said that, the mix of 'formal' and 'informal' content of the programme is also seen as both important and appropriate. We were advised that currently approximately 80% of the activities covered on the programme are 'prescribed by the steering group' based around scientifically supported methods of pain improvement. These activities include advice and information on medication, sleep, movement, managing mental health, and general education about what chronic pain is. It is considered important to ensure there is consistency of message across programme delivery in these areas. The remaining 20% of activities are more informal and as noted earlier are tailored to reflect the needs of the group and individuals. Examples of these activities include networking, self-care, relaxation, and gentle exercise.

3.16. It was pointed out that since the inception of the programme, the content has evolved largely based on feedback from participants and facilitators and often facilitated by members of the steering group in their quality assurance role. During the evaluation period, optional sessions from physiotherapists were added to the programme and these received positive feedback. As is the case with community pharmacists, the physiotherapists are recruited locally by participating HLCs. There was a view amongst some that physiotherapist input to the programme should be made mandatory for future programmes.

3.17. The programme also includes input to help participants focus on their mental health and emotional well-being. During the evaluation period this input covered several sessions and was based on the 'Take 5 Steps to Well-being'. As noted later in this section, the steering group entered into a partnership with the Mental Health Foundation during the evaluation period which led to the co-production of a specific mental health module through focus group-based research involving past and future participants. The new module was subsequently piloted in the April – June 2023 pain support programmes. Whilst the inclusion of this module was after the period covered by this evaluation, it should be noted that some feedback during the evaluation reported that some participants found this new approach to be too prescriptive and expressed preference for the more general Take 5 approach in a number of sessions rather than a dedicated mental health module. This was suggested because often programme participants do not consider they have mental health problems and see this in a negative manner, whilst the aim of the programme is to lift the participant's mood and focus on solutions rather than problems. It would be important to test these suggestions with the participating HLCs and the wider Facilitators' Group in due course.

Summary

8-12 weeks is seen as an appropriate timeframe to encourage acceptance and behavioural change amongst participants. The mix of 'formal' and 'informal' content of the programme is seen as important and appropriate. Participants are encouraged to go at their own pace. Programme content has evolved since its inception based on feedback and should be kept under continuous review (including physiotherapist input and the mental health component).

Referral pathways

3.18. It was noted that in the early years of the programme, the main source of referral was via GPs and primary care practices. It was acknowledged that in recent years, participation in the programme through referral by primary care has reduced and most participants now are from self-referral or via other programmes like social prescribing. This is seen as a reflection of the disfunction within the current health and social care system, rather than dissatisfaction with the programme and it is recognised that steps should be taken to further promote Better Days within primary care. The primary care branch of SPPG could play a role in this.

3.19. It was suggested that the mix of healthcare professionals and people from a community development background on the steering group and the quality assurance role the steering group carries out (see below for further details) should help give GPs, physiotherapists, pharmacists and other health care confidence to refer people to the programme.

Summary

In recent years, participation in the programme through referral by primary care has reduced.

Monitoring the benefits for participants

3.20. As noted in Section 4 of this report, participants in the programme are asked to complete surveys before they take part in the programme (pre), immediately after participation (post) and 3 months post participation. These surveys seek participants views on the impact of the programme and include questions from 4 monitoring tools covering a variety of areas.

3.21. There is also a wide range of anecdotal and 'soft' information available to demonstrate the impact of the programme, including case studies and feedback from participants and facilitators.

3.22. Being able to objectively demonstrate the impact of the programme is seen as an important step to further develop and enhance the programme. In particular, it was noted that there is a desire from the current programme funders to measure the impact the programme has on the use of medicines.

3.23. Whilst the current monitoring arrangements through surveys are an understandable attempt to collect empirical information within the resources available, they are seen as less than ideal by facilitators, participants and some steering group members for a number of reasons. This should not be seen as a negative reflection on the Programme Co-ordinator who despite the circumstances described below, plays an important role in collecting the survey information currently available.

3.24. From a participant's viewpoint, the volume of information being sought is seen to be 'overwhelming' by some. This is understandable as some people who participate in the programme have traditionally been difficult to engage and in some circumstances, facilitators feel that based on their experience with the person they are working with, it is inappropriate or difficult for them to complete either one or all of the surveys.

3.25. Facilitators and Healthy Living Centres also report experiencing significant pressures to deliver the programme and collect the information required within the available resources. This is not helped by the fact that most of the current survey data is collected in paper-based formats before being manually entered into the chosen electronic survey tool. When faced with limited time and resources it is reasonable that the focus is on the participants and programme delivery, rather than collecting monitoring information.

3.26. There is a tension between obtaining complete data and the mechanisms for data collection, and the circumstances described in the previous paragraphs result in incomplete data (especially post programme information) that is difficult to match directly to individuals taking part in the programme.

3.27. As noted previously, being able to objectively demonstrate the impact of the programme is seen as an important step to further develop and enhance the programme. Therefore, it is important to have appropriate and robust data collection mechanisms in place coupled with appropriate arrangements to analyse the data and draw conclusions from the content. Now that the programme is established, there is an opportunity to do this, but this must be adequately resourced and appropriately planned. Robust results will not be achieved 'on the cheap' as an add on to existing activities. Future data collection and analysis for the programme may lend itself to a research programme and the existing links with QUB may be an opportunity to further explore this.

3.28. Components of quality research into the programme could include:

- Ensuring data collected is of appropriate quality.
- Being able to match pre and post information per participant.
- Using a control group.
- Having fidelity of programme delivery (to ensure consistency across the programme).
- Having follow up information after say 3 months (in addition to immediately after the programme).

3.29. Whilst some facilitators and participants consider the current data set to be onerous, there is also a feeling that it may be appropriate to capture information currently being sought. Agreeing a robust and appropriate data set should be an important first step in any research project. In future programmes, there may be an opportunity to collect data from a sample of participants rather than everyone, possibly using as approach similar to that used for clinical trials. The use of electronic methods to capture data could also be explored along with dedicated administrative resources to help with data collection. Should longer term funding be secured for programme delivery, there may be an opportunity to carry out a longitudinal study over a number of years.

3.30. As noted previously, and demonstrated elsewhere in this report, in addition to survey information, there is also a wide range of case studies available showing the social impact of the programme. It may be worthwhile exploring whether these could also form the basis of academic qualitative research and analysis.

> *"I feel that the programme has helped me tremendously and am feeling a lot more positive about life and more understanding of how to help with my pain."*
> *- Participant B*

Summary

Being able to objectively demonstrate the impact of the programme is seen as an important step to further develop and enhance the programme. The current surveys are considered to be less than ideal by facilitators, participants, and some steering group members, for a variety of reasons including the volume of information sought, the resource requirements involved, the collection methods used, and the robustness of information obtained.

Role of the steering group

3.31. The steering group is considered to be very effective, providing leadership and direction to the programme. It was acknowledged that the steering group membership has evolved since the pilot project in 2017, and the key players to ensure effective delivery of the programme are considered to be represented in the current membership. The fact that many steering group members have remained involved with the programme since its inception is seen as a demonstration of the effectiveness of the programme which was described by some as 'a community development approach in action'. Some highlighted that they found the passion and commitment of steering group members to the programme to be inspiring. Steering group members highlighted that they had learned a great deal about the needs of local communities and community development through being involved in the programme.

3.32. It was noted that the steering group also provides an important quality assurance role on programme content, acting as a central anchor to ensure content is appropriate, aligned and based on evidence-based approaches.

Summary

The steering group is seen to play an important role in providing, leadership, drive, direction, and quality assurance for the programme.

Programme Co-ordination

3.33. The role of the Programme Co-ordinator is seen as vital to the successful delivery of the programme and experience to date shows that co-ordinating in excess of 16 delivery partners per tranche requires dedicated resources in the form of an effective Programme Co-ordinator. It was also highlighted that the steering group could not function without the input of the Programme Co-ordinator.

3.34. The role of the HLC Alliance is also seen as important to the programme, enabling the involvement of appropriate community-based health organisations to deliver the programme throughout NI, and contributing positively to the work of the steering group. It was highlighted that the HLCs involved in delivering the programme are embedded in local communities and have vast experience in delivering community-based healthcare in urban and rural settings. It was noted that the programme is a small part of the activities undertaken by HLCs and can provide a gateway for participants to become involved in other community-based activities that help their health and emotional well-being.

Summary

The role of the Programme Co-ordinator is seen as vital to the successful delivery of the programme. The HLC Alliance enables the involvement of appropriate community-based health organisations to deliver the programme throughout NI and contributes positively to the work of the steering group. The programme can provide a gateway for participants to become in other community-based activities that help their health and emotional well-being.

Programme Funding

3.35. It was noted that although the programme has been running successfully since 2017 and whilst recent funding through the Pharmacy and Medicines section of the SPPG has been appreciated, it is disappointing that decision makers in health and social care have been unable to provide recurring long-term resources to secure the programme's future, especially since the sums of money involved are relatively small. It was also pointed out that the programme is also helping to address gaps in service provision for those living in pain highlighted in reports like 'The Painful Truth' by the Patient Client Council.

Summary

Whilst recent funding through the Pharmacy and Medicines section of the SPPG is valued, it is disappointing that decision makers in health and social care have been unable to provide recurring long-term resources to secure the programme's future.

Programme scope

3.36. A view was expressed that funders and commissioners may see the programme as a complete and cheap programme to manage pain for everyone. There is evidence that the programme can help certain groups of people, especially those who benefit from peer advice and are below the threshold where their chronic pain is becoming very disruptive to functioning on a social, physical, educational, or scholastic level. However, it is considered less likely to achieve robust outcomes for people whose lives are severely disrupted by pain and suffering high levels of chronic pain.

3.37. In particular, it was highlighted that the programme cannot replace informed GPs skilled in dealing with complex chronic pain. In these circumstances, it is important to manage expectations in line with what the programme can realistically deliver and it may be important for those leading the programme to push back at times to continue to ensure the programme focuses on the areas where it can make a difference by delivering the right care to the right people at right times in the right setting.

Summary

It is important to manage expectations of decision makers in line with what the programme can realistically deliver. There is evidence that the programme can help certain groups of people, especially those who benefit from peer advice and are below the threshold where their chronic pain is becoming very disruptive. However, it is considered less likely to achieve robust outcomes for people whose lives are severely disrupted by pain and suffering high levels of chronic pain.

Mental Health Foundation Research

3.38. During the evaluation period, the HLCA was working in partnership with the Mental Health Foundation (MHF) and in February 2023, MHF issued an exploratory research report entitled "Better Days for Mental Health".

3.39. The main aim of the research was to explore the experiences of those living with a long-term condition to inform the development of a mental health wellbeing module within the Better Days pain support programme.

3.40. The research was based on four focus groups facilitated by the Mental Health Foundation involving 21 respondents who had either previously participated in the Better Days Programme or were on the waiting list.

3.41. Whilst the research is based on a relatively small sample of respondents and was primarily carried out to inform the development of a mental health and wellbeing module within the programme, some of the findings draw interesting comparisons between the feelings of people experiencing pain who have undertaken the programme and those who had yet to undertake the programme.

3.42. In our view, these findings help to illustrate some of the benefits of the programme, and we have summarised relative extracts from the MHF report below. We would like to acknowledge the research carried out by MHF to arrive at these findings.

3.43. The MHF research observed that respondents who had not yet undertaken the programme were:

- Less likely to use positive words to describe their general feelings.
- More likely to lack confidence, be overwhelmed and experience depression.
- More likely to demonstrate feelings of perceived stigma (about being judged by family and friends as they cannot participate in day-to-day activities or health professionals and others in relation to taking medication).
- Likely to exhibit more pronounced feelings of frustration, and
- Less likely to discuss their own mental health and wellbeing struggles.

3.44. With regard to respondents who had participated in the Better Days pain support programme, the MHF research observed that these respondents

- More readily suggested proactive coping strategies to deal with their condition and the associated impact on their mental health.
- Valued being in a space with others who had similar experiences and frustrations to them.
- Were much more accepting of their situation and this was leading to reduced frustration and greater agency about their lives.

Summary of relevant MHF Report findings

People who had participated on the programme were more likely to be positive about their condition, mental health and wellbeing and circumstances than those waiting to participate on the programme.

Case Studies

3.45. As part of the monitoring process, participants and facilitators are encouraged to submit case studies illustrating the experiences of programme participants to the Programme Co-ordinator.

3.46. A sample of six case studies have been included below to demonstrate the views of participants and facilitators about the programme during the evaluation period:

Case Study 1 – H.E.A.R.T. Project, Belfast

A 41-year-old was referred to the Better Days Pain programme by a physiotherapist in their GP practice. The person was referred as they were experiencing anxiety and depression stemming from trying to cope with long-term back pain.

The participant learned on the programme how to relax, understand how sleep impacts pain and understand their pain medication including long term impacts. After enjoying the physio session, they now attend swimming in the mornings and the Healthwise programme at the HLC with a goal to reduce their weight based on techniques learned from nutrition classes. They add that "The programme has helped me to get back to the person I use to be".

Case Study 2 - H.E.A.R.T Project Belfast

A 73-year-old woman who had been suffering from rheumatoid arthritis and facet arthrosis attended 10 sessions of the Better Days pain support programme. She was referred by her physio.

She learned other ways of coping with chronic pain where the facilitator gave useful advice about deep breathing, movement, and gentle exercise which she now does every morning to start the day. She commented on the addictiveness of the strong medication she had been prescribed and she enjoyed reflexology, acupuncture, and hydrotherapy.

Attendance on the programme has made her feel that chronic pain is not ruling her life while she came away from the sessions feeling good and positive about herself.

Case Study 3 - Ardoyne Shankhill Health Partnership

A 62-year-old suffering from fibromyalgia and an underactive thyroid attended the programme after being engaged with the partnership for other programmes which they enjoyed. They liked the group sessions and socialising through participation in the group. They also found that the pain management sessions were very helpful especially the physiotherapy, pharmacy and relaxation sessions which helped the participant to understand their pain better. The coping mechanisms were considered useful as the participant enjoyed being able to help themselves and mixing with others.

Case Study 4 - East Belfast Community Development Agency

A 45-year-old female attended the pain programme with severe back and leg pain as a result of an accident. She was lacking in self-confidence and didn't know how to deal with her pain on a day-to-day basis. She would have regularly overdo it and this left her reeling in pain for days after. She attended 6 sessions in total and feels so much better about continuing her journey with chronic pain.

She was able to use the tools and tips she learned during the programme to help her pace herself better and she now knows to use this approach when setting her goals. She found the pharmacist input extremely helpful as being on medication is the one thing over time she would like to reduce, and her mindset has shifted to wanting to look at this.

After COVID, speaking to and being in a room face to face with others again who are also living with chronic pain has benefitted and helped her, she knows now that she is not alone. The participant said: "Very useful programme which has helped me pick up some good tips to use".

Case Study 5 - Oak Healthy Living Centre, Lisnaskea,

A 39-year-old gentleman self-referred himself and his mother to attend the Better Days programme after seeing it advertised on the Oak Healthy Living Centre Facebook page. Both himself and his Mum are living with long term conditions and had been self-isolating during the pandemic. As this programme was being offered as a hybrid approach it meant they could access via Zoom from the comfort of his home as leaving home wasn't an option.

The participant explained that the reason he was interested in taking part in the programme was that his pain levels had increased due to inactivity during Covid, and this had also taken a toll on his mental health. He has been having periods of low mood due to isolation.

He lives with his mother, so this was also something that would stimulate both their days. The participant at first was quiet and didn't interact much in the group for the first couple of weeks. His camera was also kept off. It was session 3 with the pharmacist that he started to interact with the group and engage and ask questions. Especially with his opioids intake as he noticed this had increased over recent months and he worried about addiction.

The pharmacist responded, and he took action with the support of his GP. He was also willing to engage with the self-help techniques he was learning on the programme and was hopeful he may be able to reduce his opioid use.

He found the relaxation elements very useful and also the Chi Me techniques. He had been given gentle movement exercises by his physiotherapist which he had stopped doing and he started re-engaging with these again.

He reported a dramatic reduction in his pain level and that he was coping better. He has reduced his use of pain medication which he says are back to his normal levels before the Covid pandemic. He would like to reduce these further if he can.

He really felt the programme has helped him to motivate himself and get back into a routine again. He feels he has started to take back control of his life rather than letting the pain he experiences control him. He finds that learning and understanding about chronic pain, the support of the WhatsApp group, and being able to access recordings all help him to cope better.

Case Study 6 Oak Healthy Living Centre, Lisnaskea

A 54-year-old lady's referral was picked up through the HLCA website, where she completed an online expression of interest, this then bounced into the co-ordinator's email account and was followed up with a call.

This lady lives in Ballymena but because this programme was running as a hybrid approach, she able to access the programme via Zoom. She missed the first week but attended faithfully for the remaining 7 session. As the sessions are recorded, she was able to pick up any missed live session via the private WhatsApp group page.

She is delighted with this approach as it has made everything so accessible, she felt she hasn't missed anything.

She said she has not attended any type of group programmes before and found these to be very interactive and supportive. The sessions she most enjoyed were the pharmacist session and the nutritionist session. She had changed her diet and has found a small decrease in her pain levels. The pharmacist session has given her a better perspective and understanding of pain, and she is aiming to try to decrease her pain medications. She had been signposted to the stress management programme within the centre as this will continue to provide relaxation techniques and chi me and may help her to continue to cope better with her pain levels.

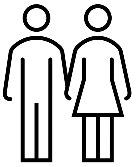
The following poem was received by the programme steering group from the wife of one of the participants of the programme and has been included here with her permission:

Poem – Betty's Story – Take 5

Chatter, chatter in his head,
He sometimes wished that he was dead,
Just to escape those negative thoughts,
Every day he fought and fought,
He slept all day
And paced all night,
He knew deep down
This wasn't right,
He was just existing,
This was no life,
His kids were worried,
So was his wife.

Then he heard about "Take 5"
And slowly started to feel alive,
He connected with people
And started to give,
He exercised daily,
Was excited to live,
He noticed around him
The trees and the ferns,
He opened some books
And started to learn
His life became busy,
He slept well at night,
His happier future
Was well within sight.

His family noticed
The changes in him.
His eyes were now glowing
When they used to be dim.
His family joined in,
They wanted this too,
They realised "Take 5"
Was easy to do.
He no longer wishes
That he would die,
His life's full of life
And no longer a lie.



4. What difference has it made ?

Introduction

4.1. This section considers the difference the programme has made. The information contained in this section has been derived from surveys completed by participants.

4.2. Participants in the programme are asked to complete surveys before they participate in the programme (pre), immediately after participation (post) and 3 months post participation.

4.3. These surveys aim to gather participants' views on the impact of the programme and in addition to seeking demographic information from participants (see Section 2 for further details), the survey questions are based on 4 monitoring tools which steering group members and programme funders feel are relevant to the programme. These monitoring tools are:

- HSCB medicines management questionnaire – designed by the pharmacy team at the SPPG. The questions focus on the use of medicines by the participants.
- COMM – a brief patient self-assessment to monitor chronic pain for patients on opioid therapy.
- ES 5D – which considers the quality-of-life people are experiencing.
- PSEQ 2 - a self-administered questionnaire that consists of two items that measure an individual's self-efficacy for managing pain (self-efficacy is a person's belief in their ability to complete a task or achieve a goal).

4.4. The post programme surveys conclude with two questions that seek participants' views on the programme overall. A free text section is also included to provide an opportunity for participants to add further comments if desired (Some quotes from the comments provided have been included elsewhere in this report.)

4.5. The purpose of collecting information before and after people participate on the programme is to attempt to see if the programme is making a difference in the areas reviewed.

4.6. Section 3 recognises that whilst the current monitoring arrangements through surveys are an understandable attempt to collect empirical information within the resources available, they are considered to be less than ideal by facilitators and participants for a number of reasons. These include the volume of information being sought from participants who may be initially reluctant to engage, time pressures on facilitators who are focused on programme delivery and the paper-based format used to collect the initial information.

4.7. All this means that despite the efforts of the Programme Co-ordinator and the best intentions of facilitators the information collected is often incomplete. In particular, some participants did not answer all the survey questions; not all participants completed post programme surveys and only a relatively small proportion of participants completed follow up surveys after 3 months. Within the resources available for this evaluation, it was also not possible to match pre and post programme information for individual participants.

4.8. Despite these limitations, the surveys provide information that shows trends and patterns amongst participants and this section seeks to highlight these. The section considers each of the monitoring tools that comprise the survey in turn together with participants views on the programme overall.

4.9. Consolidated information from the HSCB medicines management questionnaire is available for the full evaluation period. For the other monitoring tools, due to resource constraints for this evaluation, the information analysed in this section is based on surveys completed by participants in Tranche 3 only (January to March 2023). A total of 49 follow up surveys (i.e., 3 months after completion of the programme) were completed by participants over the full evaluation period. This has been included in the analysis for comparative purposes, however it should be noted that this does not only relate to Tranche 3 participants.

4.10. Information on Tranche 3 participants in summarised as follows:

Programmes	Participants	Pre surveys	Post surveys	Follow up surveys*
16	193	174	126	49

Note: *Tranche 3 ran from January to March 2023.

Summary

Participants in the programme are asked to complete surveys before they participate in the programme (pre), immediately after participation (post) and 3 months post participation. The survey questions are largely based on 4 monitoring tools.

Whilst the current monitoring arrangements are an understandable attempt to collect empirical information within the resources available, they are considered to be less than ideal by facilitators and participants for a number of reasons and the information collected is often incomplete.

Despite these limitations, the surveys provide information that shows trends and patterns amongst participants and this section seeks to highlight these.

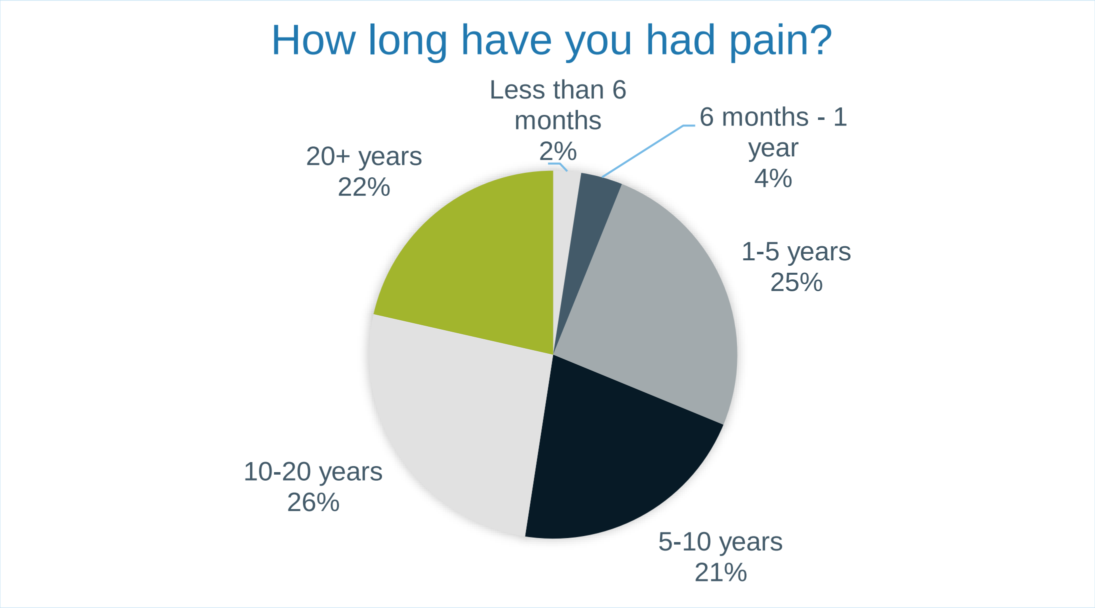
HSCB Medicines Management Questionnaire

4.11. The questions in this section of the surveys are based on a medicines management questionnaire designed by the pharmacy team at the SPPG. The questions focus on the use of medicines by the participants.

4.12. Relevant responses covering the evaluation period (April 2022 to March 2023) by participants are summarised below.

Length of time in pain

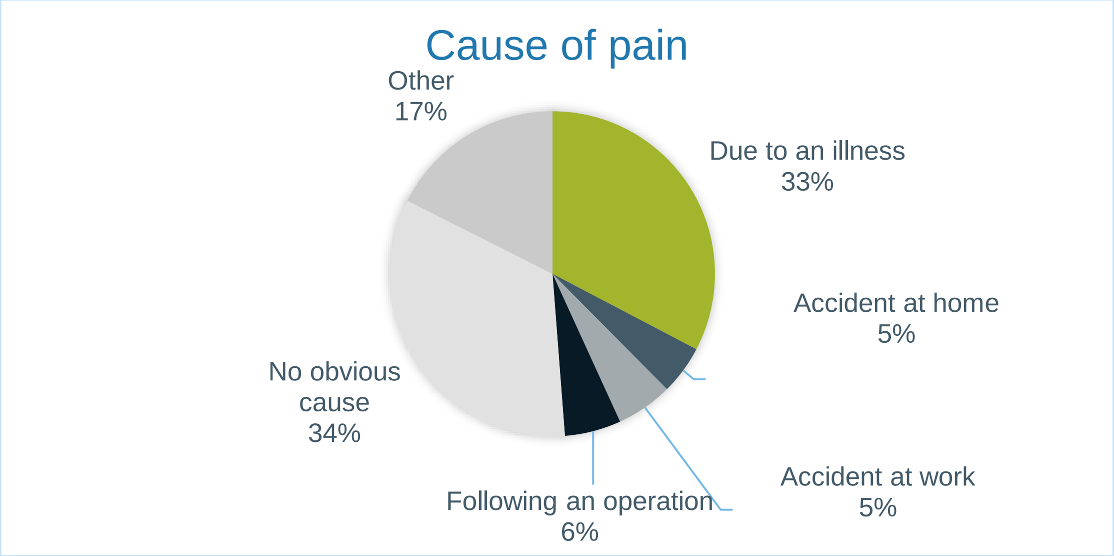
4.13. The pre programme survey asked participants how long they have been experiencing pain.



4.14. The chart above shows that the majority of programme participants have reported experiencing pain for a considerable period of time, with 69% of programme participants in the evaluation period reporting that they have experience pain for at least 5 years. Of these, 22% reported that they have experienced pain for over 20 years and a further 26% reported they have been experiencing pain for over 10 years.

Cause of pain

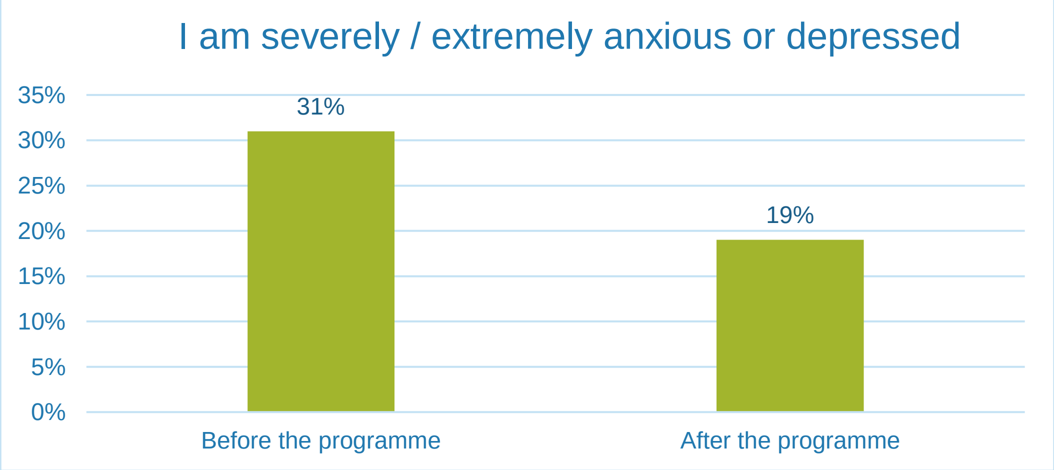
4.15. At pre-programme stage, participants were also asked to indicate the cause of the pain they are experiencing from a pre-determined list of possibilities. The results for the evaluation period are shown below.



4.16. The chart shows that 34% of participants indicated there was no obvious cause of their pain, whilst 33% attributed their pain to an illness. 10% of participants attributed their pain to an accident, with 5% stating the accident was at home and 5% at work.

Severity of anxiety and depression

4.17. The survey also asked respondents to indicate if they felt anxious and depressed. This question was asked before and after programme attendance and the chart below compares the % of respondents who indicated they felt severely or extremely anxious or depressed pre and post attending the programme.

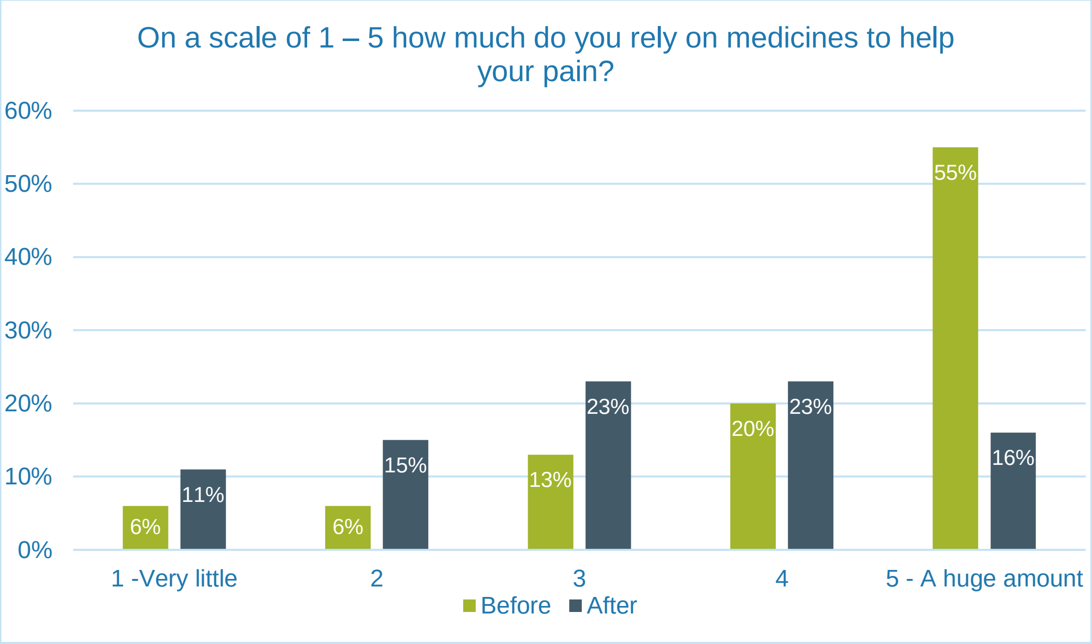


4.18. The chart shows an apparent reduction in the number of respondents who reported they felt severely or extremely anxious or depressed post programme. 31% of respondents indicated that they were feeling severely or extremely depressed before they attended the programme. After programme attendance the % of respondents who indicated that they felt this way was 19%.

Reliance on medication

4.19. Participants were asked to indicate how much they relied on medication to help their pain. Answers were sought on a scale of 1 to 5 (with 5 being a huge amount).

4.20. Respondents answered this question before and after attending the programme and the results are shown below.

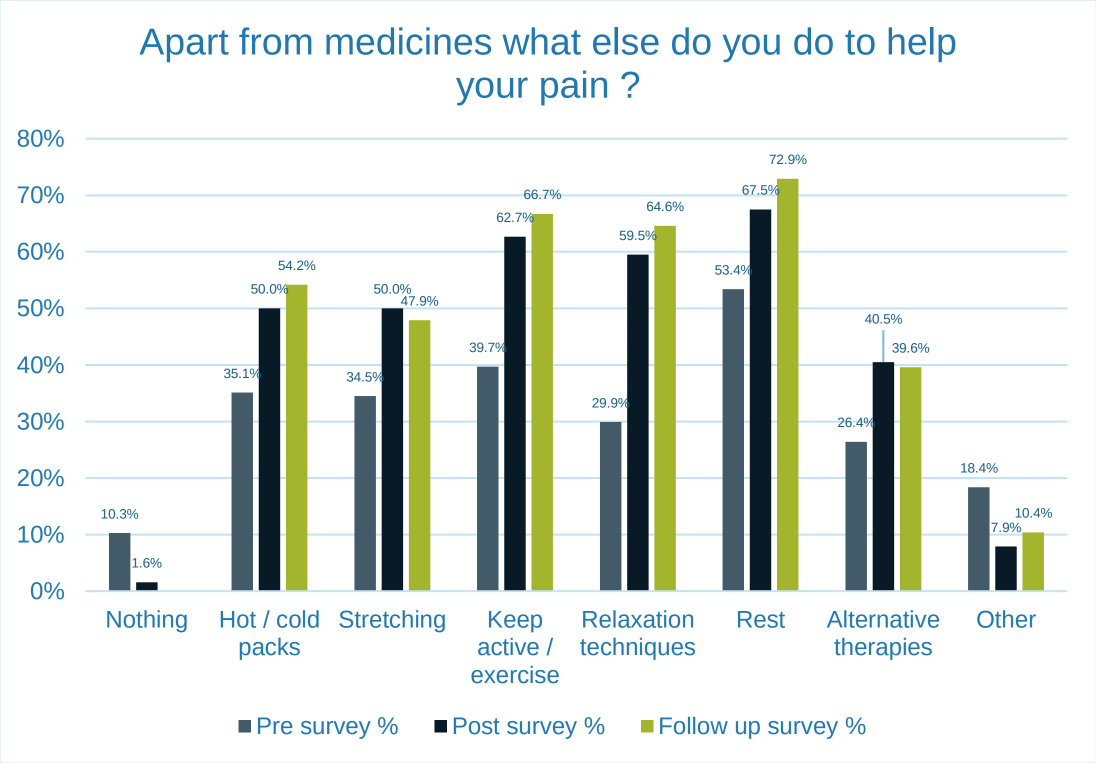


4.21. The graph shows that whilst most respondents continue to rely on medicine to help their pain, in general terms respondents appear to indicate that they relied less on medicine following the programme. In particular looking at those who indicated they relied on medicine a huge amount, pre-programme 55% of respondents considered themselves to be in this category. Post programme the relevant % was 16% of respondents.

Other methods to help ease pain.

4.22. Apart from medicines, participants were asked to indicate other methods of pain relief they used from a list of predetermined alternatives. As above this question was asked before and after programme attendance.

4.23. The chart below shows responses before and after programme attendance. Note the pre and post information here is for tranche 3 respondents only, and the chart also includes information from follow up survey responses (from those who responded across the entire evaluation period). Respondents could give more than one answer and the % in the chart are % of total responses rather than respondents.



4.24. The chart shows that 10.3% of Tranche 3 responses to this question pre programme attendance indicated that the participants used no forms of pain relief apart from medication, whilst post programme attendance 1.6% of responses were in this category and in the follow up surveys the relevant % was nil. In general terms the chart also shows higher % responses in all categories listed post programme than pre programme, which may indicate that respondents seem more likely to use other forms of pain relief in addition to medication after attending the programme. The responses to the follow up surveys appear to indicate that this practice has been sustained by those who responded 3 months post attendance at the programme.

> *"The program was very useful and beneficial to each person as everyone takes something different from it. I really look forward to more programs like this."*
> *- Participant C*

Summary – Medicines management questionnaire

Questions focus on the use of medicines by the participants.

Relevant participant responses covering the evaluation period (April 2022 to March 2023) show:

1. Pre-programme,
   - 69% of respondents reported they have experienced pain for at least 5 years.
   - 34% of participants indicated there was no obvious cause of their pain, 33% attributed their pain to an illness and 10% attributed their pain to an accident.
2. There is an apparent reduction in the number of respondents who reported they felt severely or extremely anxious or depressed post programme. (Pre-programme 31%; post programme 19%).
3. Whilst most respondents continue to rely on medicine to help their pain, in general terms respondents indicated that they relied less on medicine following the programme. (Relied a huge amount; 55% pre-programme; 16% post programme).
4. Survey results from Tranche 3 respondents may indicate that respondents seem more likely to use other forms of pain relief in addition to medication after attending the programme. (No other forms of pain relief; pre-programme 10.3% of responses, post programme 1.6%).

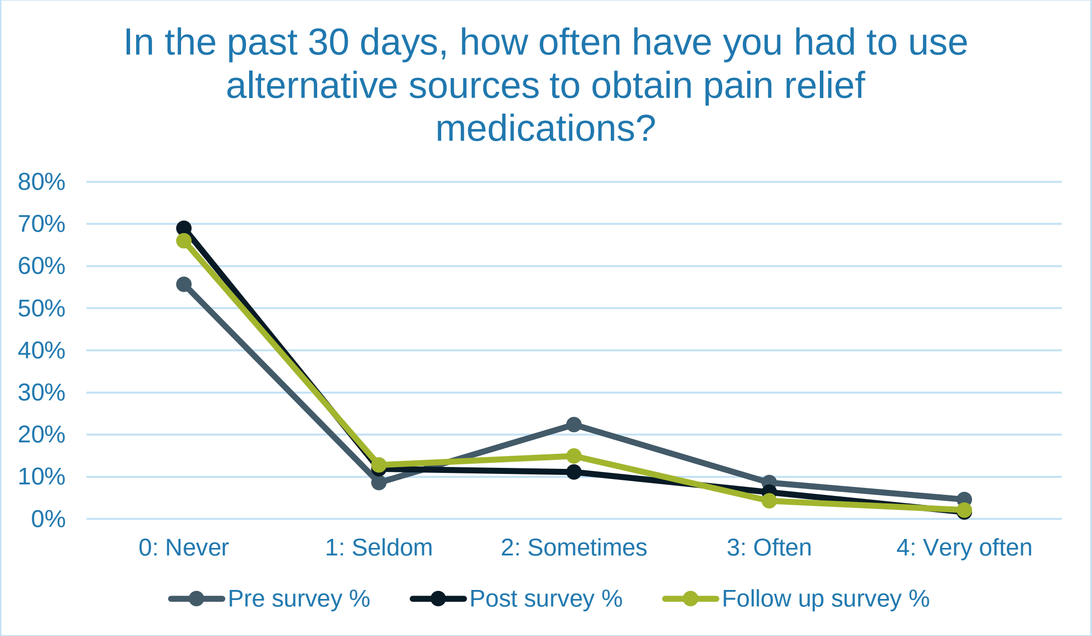
COMM

4.25. The Current Opioid Misuse Measure (COMM)™ is a brief patient self-assessment to monitor chronic pain patients on opioid therapy. The questionnaire was developed with guidance from a group of pain and addiction experts and input from pain management clinicians who identified six key issues to determine if patients already on long-term opioid treatment are exhibiting aberrant medication-related behaviours (i.e. behaviours that depart from 'normal' for example because of side effects or the medication losing its beneficial effects over time). Steering group members decided to include questions from COMM in the surveys completed by participants on the programme as a means of considering the impact of the programme on the use of pain medication.

4.26. Pre and post programme responses to some of the COMM questions by Tranche 3 participants are outlined below. Information from respondents to follow up surveys (3 months after programme completing) has been included for illustrative purposes – however, as noted before, these responses were provided by participants over the entire evaluation period, rather than in Tranche 3 only. Responses to COMM questions are on a scale of 0 to 4, with 0 being never and 4 being very often.

Seeking alternative sources of pain medication

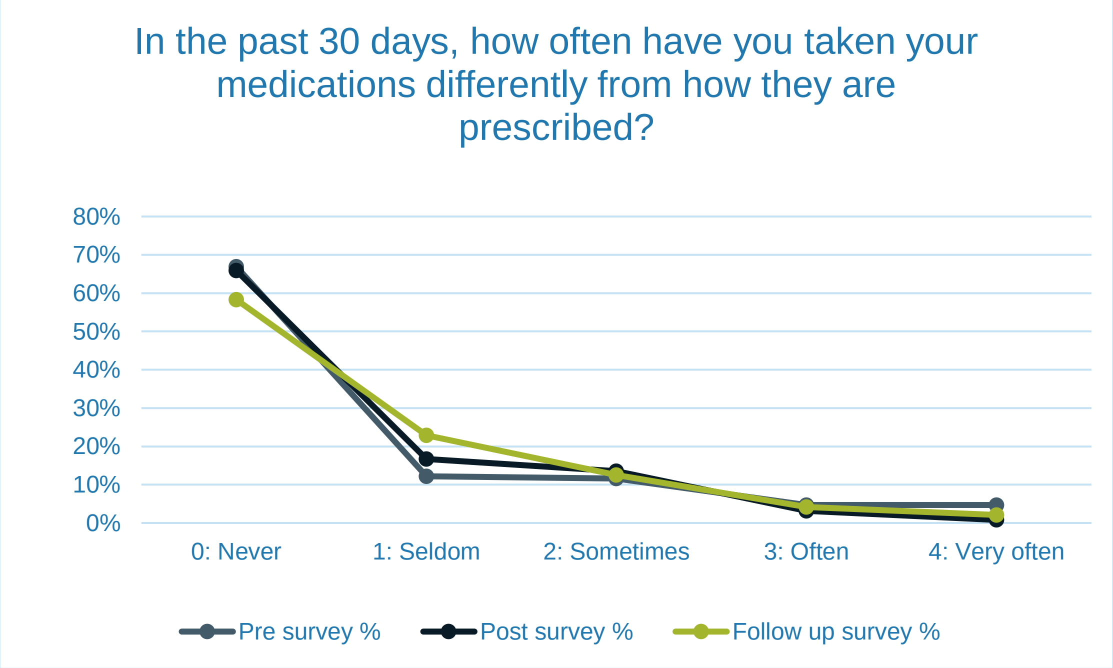
4.27. Participants were asked to indicate how often they sought pain medication from a source other than their normal prescriber in the past 30 days. In this instance, an alternative source includes another doctor, the emergency department, friends, or street sources.



4.28. The chart shows an apparent reduction in participants who sought pain relief medicines from alternative sources post programme. Pre-programme 4.6% of participants reported they had used alternative sources to access pain medication in the last 30 days very often, whilst post survey, 1.6% of respondents seeking pain medication from alternative sources and the relevant figure from follow up survey respondents was 2.1%. Looking at respondents who reported they never had sought medication from an alternative source, pre programme this figure was 56% whilst post programme 69% of respondents considered themselves to be in this category – a similar % to respondents in this category in the follow up survey. 20% of pre programme respondents reported that they sometimes sought pain medication from alternative sources in the past 30 days, whilst post programme 10% of respondents considered themselves in this category.

Using medicines differently from how prescribed

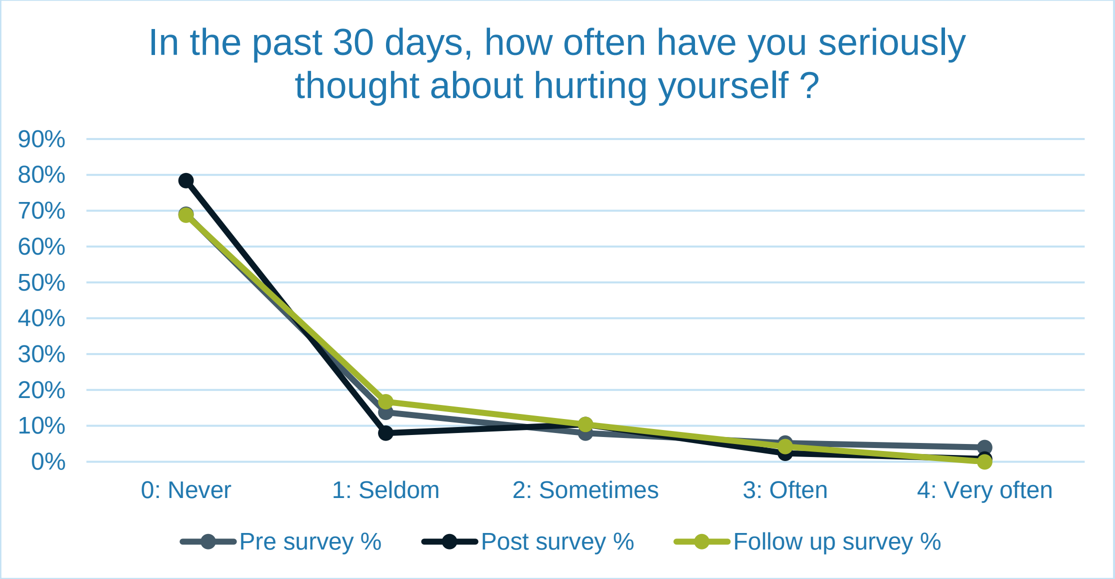
4.29. Participants were asked to indicate how often they have taken pain relief medication differently from how it was prescribed in the past 30 days.



4.30. The chart shows an apparent slight reduction in participants who reported they took pain relief medication differently from how it was prescribed post programme. Pre-programme, 4.7% of respondents reported they had taken pain relief medication differently from how was prescribed in the past 30 days very often, whilst post programme 0.8% of respondents reported they were in this category. The % of respondents to the follow up survey who reported they were in this category was 2.1%.

Self-Harm

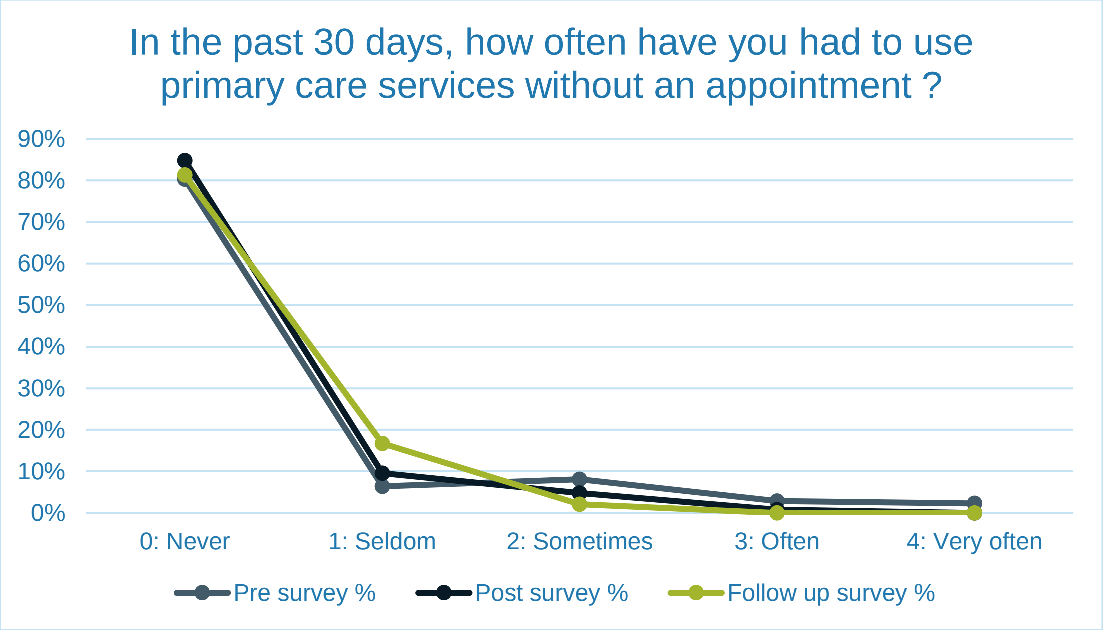
4.31. Participants were asked to indicate how often they have seriously thought about hurting themselves in the past 30 days.



4.32. The chart shows an apparent reduction in participants who reported they have seriously thought about hurting themselves in the past 30 days post programme. Pre programme, 4% of participants reported they had thought about this very often. In the follow up survey, no participants reported themselves as being in this category.

Use of primary care with no appointment

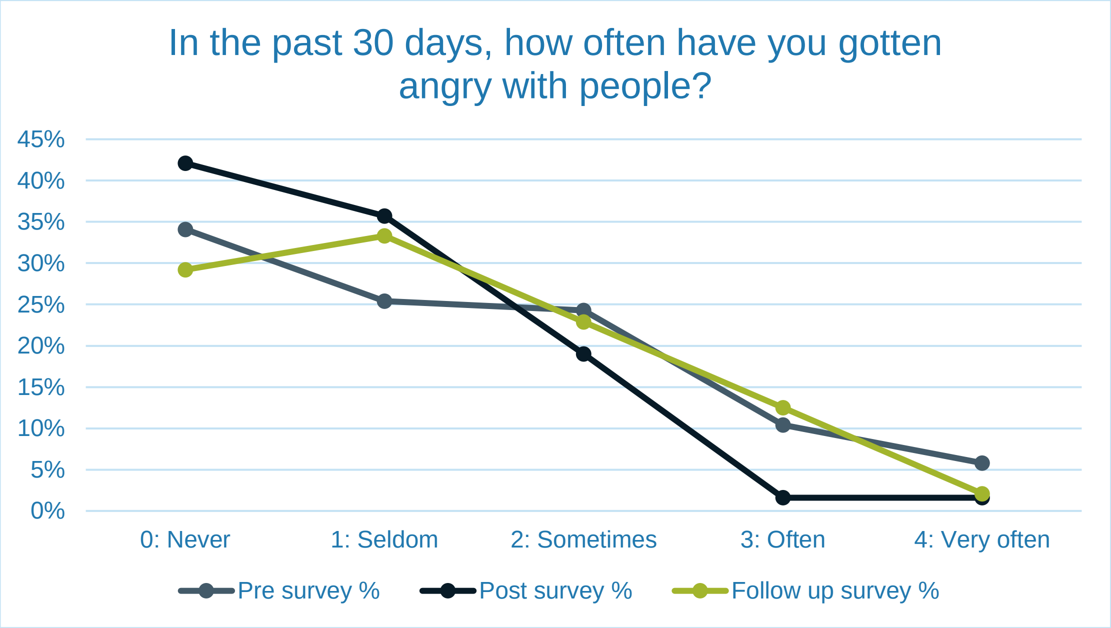
4.33. Participants were asked to indicate how often they have used primary care without an appointment or made an emergency phone call in the past 30 days.



4.34. The chart shows an apparent reduction in participants who reported they had used unscheduled primary care services or made an emergency phone call in the past 30 days, post programme. Pre programme, 2.3 % of participants reported they had done this very often and 2.9% reported they had done this often. In the follow up survey, no participants reported themselves as being in either of these categories. The % of participants who reported they were in the never category was 80.3% pre programme, whilst the % who reported they were in this category post programme was 84.8%.

Anger management

4.35. Participants were asked to indicate how often they have gotten angry in the past 30 days.



4.36. The chart shows an apparent reduction in participants who reported they have gotten angry in the past 30 days, post programme. Pre programme, 5.8 % of participants reported they had done this very often and 10.4% reported they had done this often. Post programme 1.6% of participants reported themselves to be in each of these categories. The % of participants who reported they were in the never category was 34.1% pre programme, whilst the % who reported they were in this category post programme was 42.1%. It is interesting to note that in the follow up survey, the % of participants who reported they were in the very often category is similar to the % of people in the post programme surveys. However, the % who reported they were in the often category increased compared to the reported % in the post programme survey and reported % in the never category decreased when compared to the reported % in the post programme survey. This may indicate that changes experienced post programme by some participants may not be maintained long term.

> *"I find it difficult to retain the information, but it is a very good program and available on zoom for those who want to attend but cannot for whatever reason. It's also reassuring that there are others out there with similar health problems that can play a major part in their lives. It's lovely to meet the other people and foster new relationships".*
> *- Beneficiary D*

Summary - COMM questions

Questions consider the impact of the programme on the use of pain medication by participants.

Relevant responses from Tranche 3 participants may indicate apparent reductions post programme in participants who reported they:

1. sought pain relief medicines from alternative sources post programme. (Very often; 4.6% pre-programme, 1.6% post programme; Never; 56% pre-programme, 69% post programme)
2. took pain relief medication differently from how it was prescribed post programme. (4.7% pre-programme, 0.8% post programme).
3. have seriously thought about hurting themselves in the past 30 days post programme. (Pre programme, 4%; follow up survey, 0%)
4. had to use unscheduled primary care services or make an emergency phone call in the past 30 days, post programme.(very often/often, 5.2% pre-programme; 0% post programme).
5. have gotten angry in the past 30 days, post programme. (Very often/often 16.2% pre-programme; 3.2% post programme).

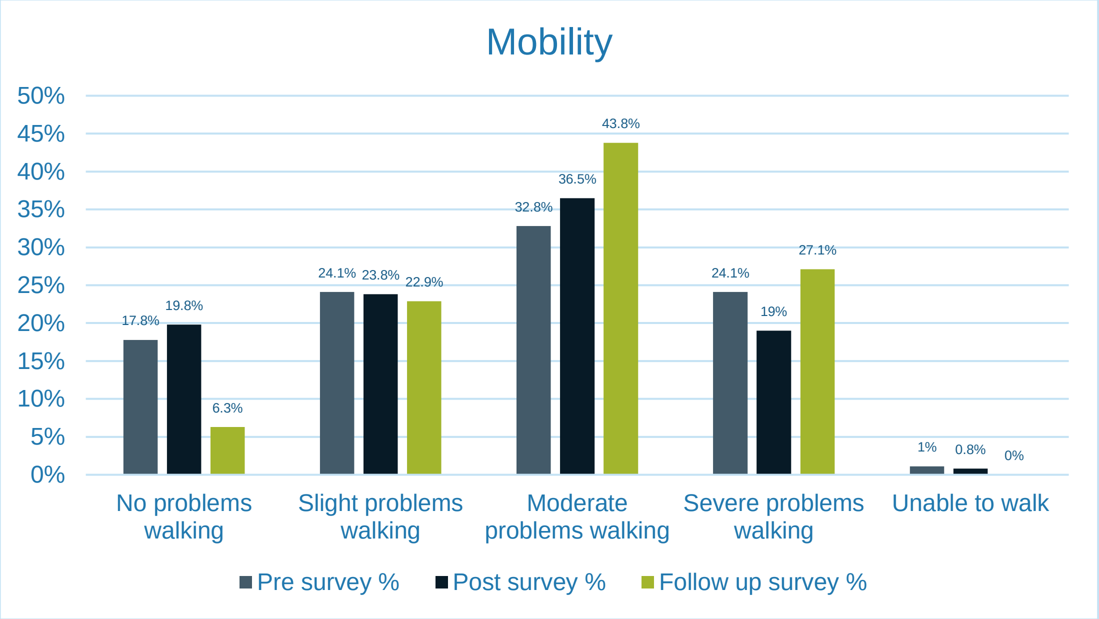
EQ 5D

4.37. EQ 5D (European Quality of Life Five Dimensions) is an instrument developed in Europe which is widely used to evaluate people’s generic health related quality of life (HRQL). It contains one question for each of five dimensions: mobility; self-care; usual activities; pain and discomfort; and anxiety and depression. Steering group members decided to include questions from EQ 5D in the surveys completed by participants on the programme as a means of considering the impact of the programme on people’s quality of life.

4.38. Pre and post programme responses to some of the EQ 5D dimensions by Tranche 3 participants are outlined below. Information from respondents to follow up surveys (3 months after programme completing) has been included for illustrative purposes – however as noted before, these responses were provided by participants over the entire evaluation period, rather than in Tranche 3 only. There are 5 possible pre-determined responses to EQ 5D questions for each dimension: no; slight; moderate; severe and extreme.

Mobility

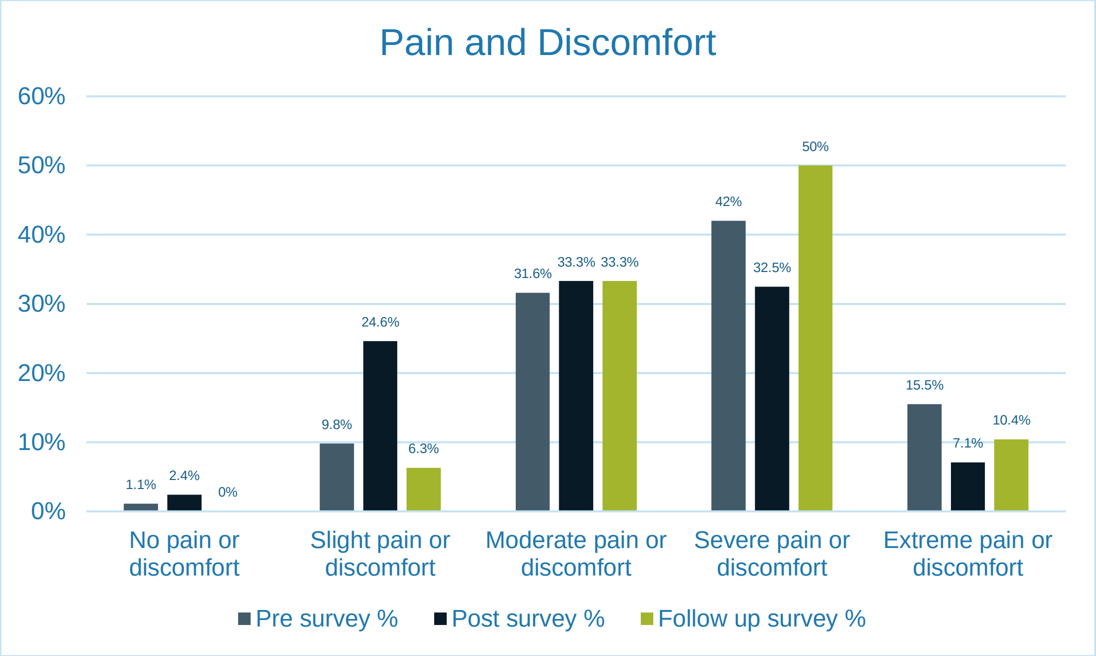
4.39. Participants were asked to indicate how well they feel they can walk.



4.40. The chart above shows an apparent slight reduction in participants who reported severe problems walking post programme. Pre programme 24.1% of participants reported severe problems walking and post programme the relevant % of participants was 19%. Pre programme 32.8% of participants reported moderate programmes walking and post programme 36.5% of participants considered themselves to be in this category. Although other factors may need to be considered, this may point to the fact that some participants considered themselves to have less problems walking post programme.

Pain and discomfort

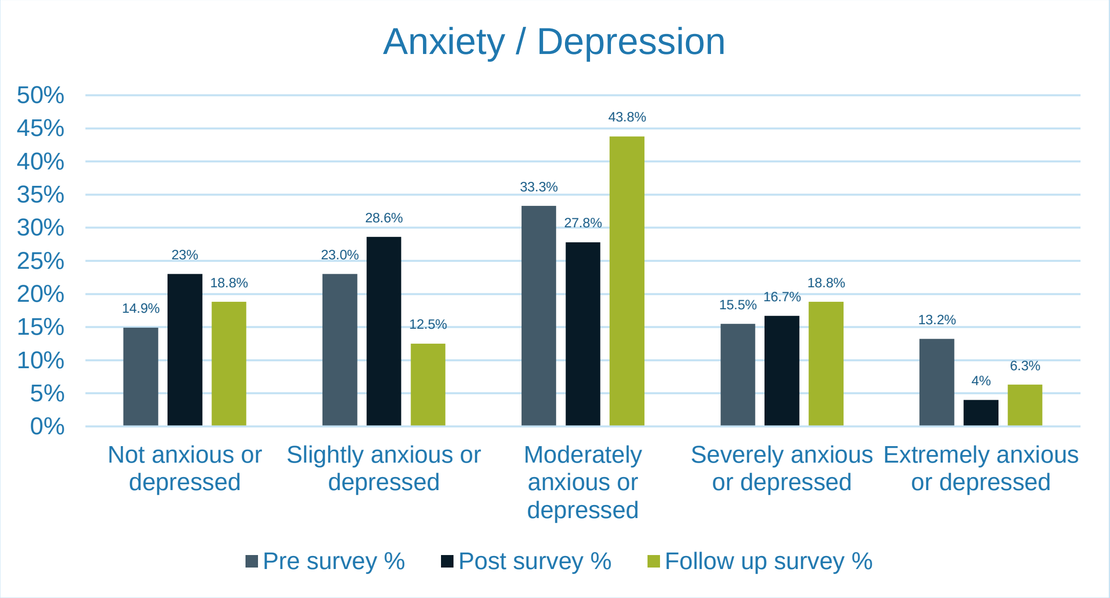
4.41. Participants were asked to indicate how much pain and discomfort they feel.



4.42. The chart above shows an apparent reduction in participants who reported experiencing extreme and severe pain and discomfort post programme. Pre programme 15.5% of participants reported experiencing extreme pain and discomfort and 42% reported experiencing severe pain and discomfort. Post programme, 7.1% of participants reported experiencing extreme pain and discomfort and the % who reported experiencing severe pain and discomfort was 32.5%. Conversely, 31.6% of people reported experiencing moderate pain and discomfort pre programme and the relevant % post programme was 33.3%. 9.8% of people reported experiencing slight pain or discomfort pre programme and the relevant % post programme was 24.6%. Again, although other factors may need to be considered, this may point to the fact that some participants considered the level of pain and discomfort they are experiencing to have reduced post programme.

Anxiety and Depression

4.43. Participants were asked to indicate the extent to which they felt anxious or depressed.



4.44. The chart above shows an apparent reduction in participants who reported feeling anxious or depressed post programme. Pre programme 13.2% of participants reported feeling extremely anxious or depressed. Post programme the relevant % of participants was 4%. Pre programme 14.9% of participants reported they did not feel anxious or depressed. Post programme the relevant % of participants who reported being in this category was 23%.

Summary -ES 5D questions

Questions consider the impact of the programme on people’s quality of life.

Relevant responses from Tranche 3 participants may indicate apparent reductions post programme in participants who reported they:

1. Had severe problems walking (24.1% pre-programme, 19% post programme).
2. Experienced extreme and severe pain and discomfort (57.5% pre-programme, 39.6% post programme).
3. Felt extremely anxious or depressed (13.2% pre-programme, 4% post programme).

PSEQ-2

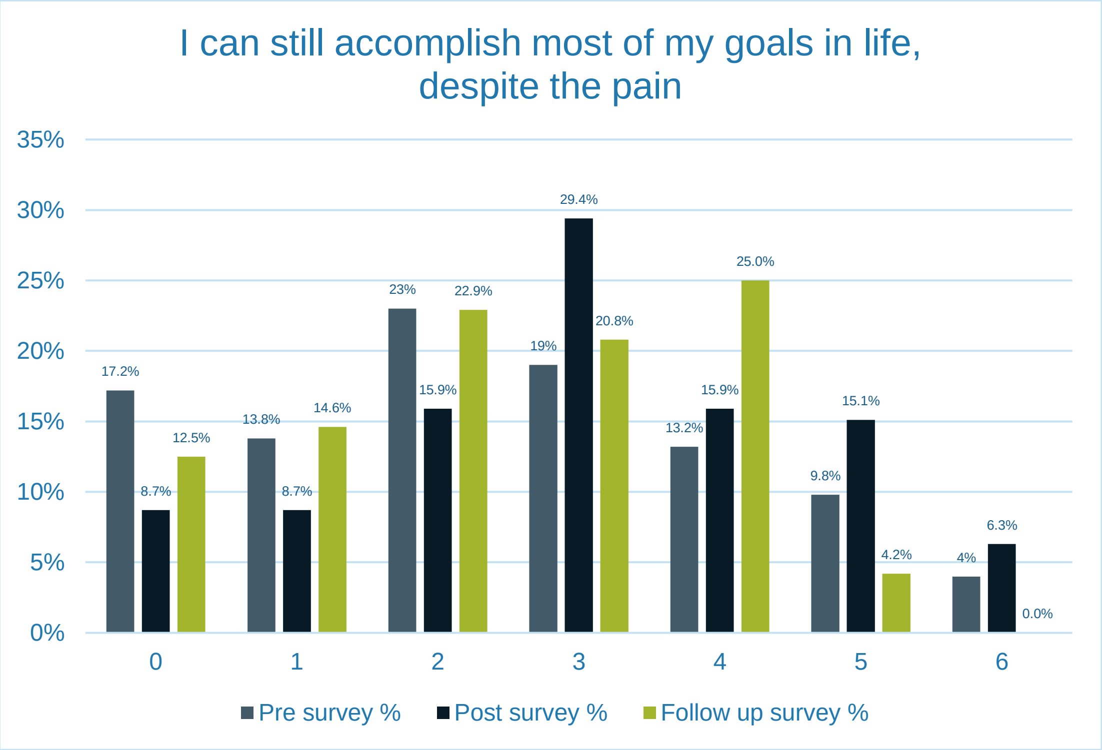
4.45. PSEQ-2 is a self-administered questionnaire that consists of two items that measure an individual's self-efficacy for managing pain (self-efficacy is a person's belief in their ability to complete a task or achieve a goal). The authors of PSEQ-2 developed this as a brief (shorter) alternative to the original 10 item Pain Self-Efficacy Questionnaire (PSEQ). The response options use a 7-point scale ranging from 0 (not at all confident) to 6 (completely confident).

4.46. Steering group members decided to include the 2 questions from PSEQ-2 in the surveys completed by participants on the programme as a means of considering the impact of the programme on people's self-efficacy for managing pain.

4.47. Pre and post programme responses to the PSEQ-2 questions by Tranche 3 participants are outlined below. Information from respondents to follow up surveys (3 months after programme completing) has been included for illustrative purposes – however as noted before, these responses were provided by participants over the entire evaluation period, rather than in Tranche 3.

Accomplishing goals despite the pain

4.48. Participants were asked to express how confident they are that they can complete their goals in life despite the pain they experience.

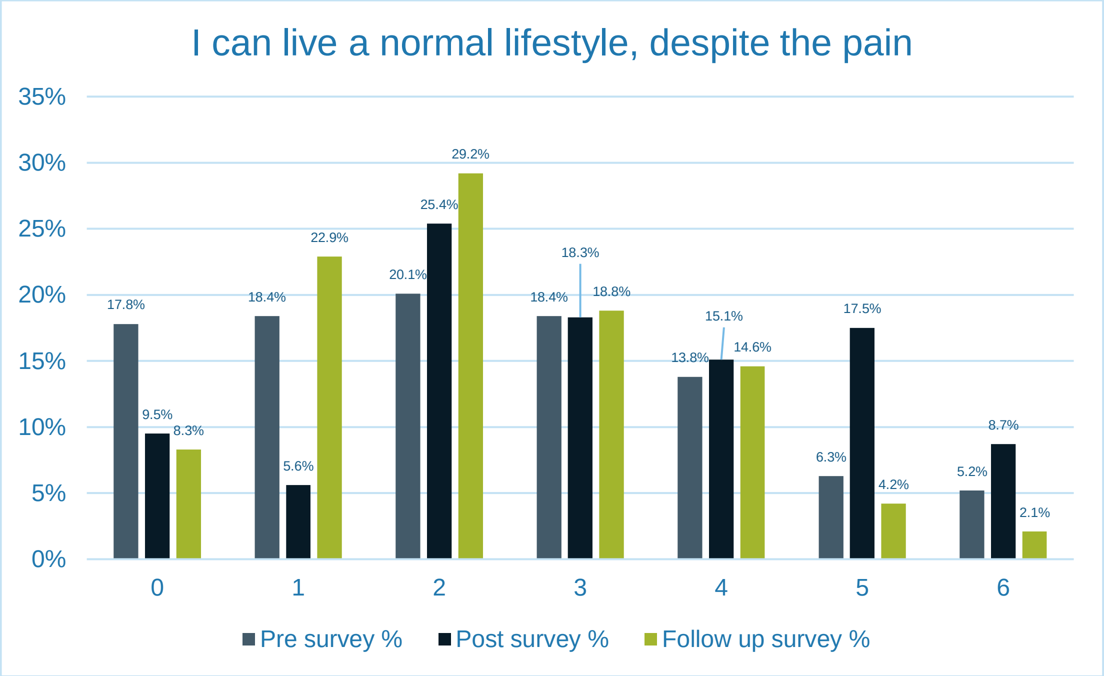


0- Not at all confident ; 6- Completely confident

4.49. The chart above shows an apparent increase in participants' confidence to accomplish their life goals despite pain, post programme. 17.2% of participants reported they were not at all confident in this area pre-programme. Post programme the % of respondents who reported to be in this category was 8.7%. At the other end of the scale, pre programme, 4% of participants reported they were completely confident in this area. Post programme, the % of respondents who reported to be in this category was 6.3%.

Living a normal life despite the pain

4.50. The second area of focus was participants' confidence in their ability to live a normal lifestyle despite experiencing pain.



0-Not at all confident ; 6- Completely confident

4.51. The chart above shows an apparent increase in participants' confidence to live a normal lifestyle despite pain, post programme. Pre programme, 17.8% of participants reported that they were not at all confident that they could live a normal life. Post programme the % of participants who reported they were in this category was 9.5%. At the other end of the scale, pre programme, 5.2% of participants reported they were completely confident in this area. Post programme, the % of participants who reported they were in this category was 8.7%.

Summary – PSEQ 2 questions

Questions consider the impact of the programme on people’s self-efficacy for managing pain. (self-efficacy is a person’s belief in their ability to complete a task or achieve a goal).

Relevant responses from Tranche 3 participants may indicate apparent increases post programme in participants’ reported confidence to:

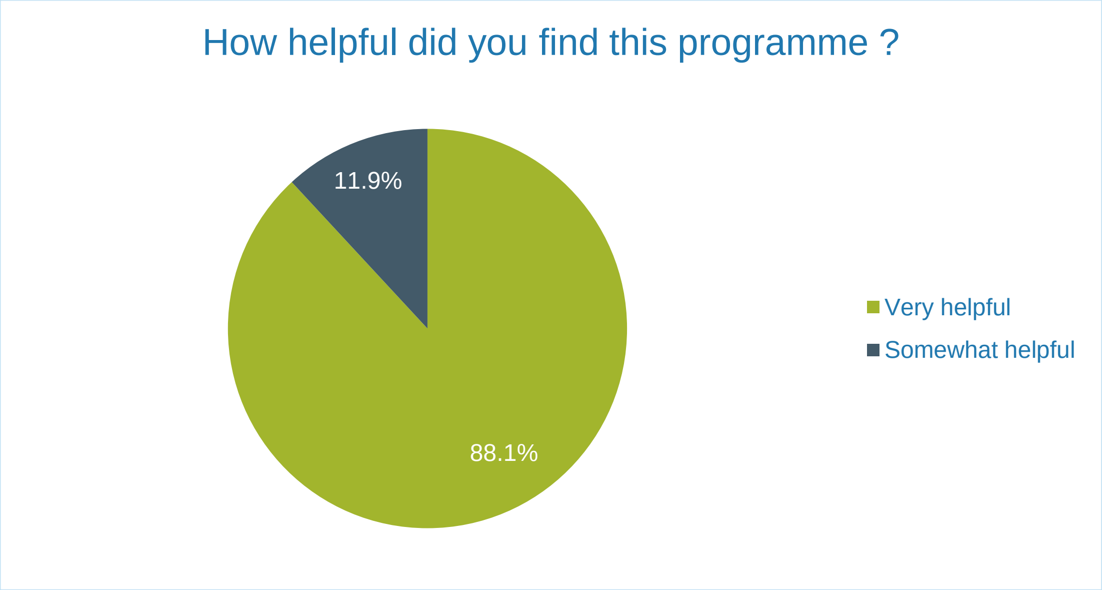
1. accomplish their life goals despite pain (not at all confident; 17.2% pre-programme, 8.7% post programme; completely confident; 4%, pre programme, 6.3%, post programme)
2. live a normal lifestyle despite pain (not at all confident; 17.8% pre-programme, 9.5% post programme; completely confident; 5.2%, pre programme, 8.7%, post programme)

Participants’ views on the programme overall

4.52. As noted earlier, the post programme surveys conclude with two questions that seek participants’ views on the programme overall. Responses to these questions by Tranche 3 participants are outlined below.

Helpfulness of the programme

4.53. Participants were asked to consider how helpful they found the programme against pre-determined alternatives ranging from not helpful to very helpful.



4.54. The chart above shows that all respondents in Tranche 3 considered the programme to be very helpful (88.1%) or somewhat helpful (11.9%).

Recommending the programme

4.55. Participants were asked if they would recommend the programme to others living with pain.

4.56. The chart below shows that 100% of Tranche 3 respondents indicated that they would do this.

> *"This programme has had a massive impact on my life. It was a game changer when struggling with long covid and should be prescribed to all battling long term effects from covid infection. Thank you to this course for really helping me with my rehab and recovery. I've been unable to work for over a year and hope to go back to work soon thanks to the measures taken and learned on this course ".*
>
> *- Beneficiary E*

Summary

Post programme,

1. all respondents in Tranche 3 considered the programme to be very helpful (88.1%) or somewhat helpful (11.9%).
2. 100% of tranche 3 respondents stated that they would recommend the programme to others living in pain.

5. Conclusions, Observations, and Recommendations

Introduction

5.1. This section sets out the overall conclusions from this evaluation which covers the period April 2022 to March 2023. We have also summarised some observations and recommendations in relation to the programme arising from our discussions and review of information.

How much was done ?

5.2. During the evaluation period:

- 44 Better Days pain support programmes were delivered to 486 participants in 3 tranches by 27 Healthy Living Centres across NI.
- 83% of participants were female and 55% of participants were aged between 45 and 64 years.
- The average cost of the programme per participant was £247.

How well was it done ?

5.3. Through our discussions with steering group members and facilitators and our reviews of case studies and research carried out by the Mental Health Foundation, we found anecdotal evidence that the programme:

- has demonstrated that medication is not the only solution to helping people deal with chronic pain through providing information and education to help participants make informed choices on the use of medicines.
- is seen to have had a positive impact on participants in pain who experience social isolation.
- has an appropriate mix of 'formal' and 'informal' content which has evolved since its inception.
- has an effective steering group that plays an important role in providing leadership, drive, direction, and quality assurance.
- can provide a gateway for participants to become involved in other community-based activities that help their health and emotional well-being.
- participants are more likely to be positive about their condition, mental health and wellbeing and circumstances than those waiting to participate on the programme.

What difference has it made ?

5.4. Participants in the programme are asked to complete surveys before they participate in the programme (pre), immediately after participation (post) and 3 months post participation. Although there are limitations in this information (see Sections 3 and 4 of this report) and care should be taken in interpreting it, the information does show some trends amongst participants pre and post programme attendance that may indicate areas where the programme is making a difference. These include:

Over the entire evaluation period:

5.5. An apparent reduction in the number of respondents who reported they felt severely or extremely anxious or depressed post programme. (Pre-programme 31%; post programme 19%).

5.6. Respondents appeared to indicate that they relied less on medicine following the programme. (Relied a huge amount; 55% pre-programme; 16% post programme).

Tranche 3 respondents:

5.7. Seem more likely to use other forms of pain relief in addition to medication after attending the programme. (No other forms of pain relief; pre-programme 10.3% of responses, post programme 1.6%).

5.8. Apparent reductions post programme in participants who reported they:

- Sought pain relief medicines from alternative sources post programme. (Very often; 4.6% pre-programme, 1.6% post programme; Never; 56% pre-programme, 69% post programme)
- Took pain relief medication differently from how it was prescribed post programme. (4.7% pre-programme, 0.8% post programme).
- Have seriously thought about hurting themselves in the past 30 days post programme. (Pre programme, 4%; follow up survey, 0%)
- Had to use primary care services or make an emergency phone call in the past 30 days, post programme.(very often/often, 5.2% pre-programme; 0% post programme).
- Have gotten angry in the past 30 days, post programme. (Very often/often 16.2% pre-programme; 3.2% post programme).
- Had severe problems walking (24.1% pre-programme, 19% post programme).

- Experienced extreme and severe pain and discomfort (57.5% pre-programme, 39.6% post programme).

- Felt extremely anxious or depressed (13.2% pre-programme, 4% post programme).

5.9. Apparent increases post programme in participants' reported confidence to:

- Accomplish their life goals despite pain (not at all confident; 17.2% pre-programme, 8.7% post programme; completely confident; 4%, pre programme, 6.3%, post programme)

- Live a normal lifestyle despite pain (not at all confident; 17.8% pre-programme, 9.5% post programme; completely confident; 5.2%, pre programme, 8.7%, post programme)

5.10. Post programme, all respondents considered the programme to be very helpful (88.1%) or somewhat helpful (11.9%) and 100% of respondents stated that they would recommend the programme to others living in pain.

Overall Conclusion

5.11. **Based on the information contained in this evaluation report and summarised above, in our view the Better Days pain support programme is highly valued by participants, community-based health providers and healthcare and other professionals involved with the steering group. The programme has reached a significant number of people (486, mainly female) many of whom have been experiencing pain for over 5 years, at a very reasonable cost (£247 per participant).**

5.12. **There are limitations associated with the information provided by the surveys completed by participants, however this does appear to indicate that the programme makes a positive difference to participants':**

- **overall mental health and well-being, their ability to cope with pain and their general outlook on life, and**

- **their reliance on and use of medicine for pain relief.**

Observations and Recommendations

5.13. As a result of our evaluation work, we have made some observations and recommendations. These are set out below and may be useful to help inform future delivery and development of the programme.

Observation 1 – Programme content and length

5.14. The 80:20 mix of 'formal' (or set) and 'informal' content of the programme is seen as both important and appropriate as it provides opportunity for evidence-based information and practice and local flexibility to meet the needs of the group and its individual members. The programme length at 8-12 weeks is also seen as an appropriate timeframe to encourage acceptance and behavioural change amongst participants. Not being too rigid on programme timeframes is considered important, along with achieving balance between session length and comfort for participants who are in pain.

5.15. Programme content has evolved positively since the inception of the programme often based on feedback from participants and facilitators and facilitated by members of the steering group in their quality assurance role. Recent developments in this area have included physiotherapist input and piloting a specific mental health module co-produced with the Mental Health Foundation.

Recommendation 1

5.16. The steering group should consider whether physiotherapist input should become a formal part of future programmes. Should this be the case, then it may be appropriate to develop a central resource of information for use by participating physiotherapists (similar to the pharmacy resource) to ensure a consider approach across the programme.

5.17. Should resources become available, then the central pharmacy resource should be reviewed and updated if appropriate.

5.18. The pilot specific mental health programme should be evaluated to ensure that it meets the needs of participants. In carrying out this evaluation, the views of facilitators and participants should be sought.

Observation 2 – Demonstrating the impact of the programme.

5.19. Being able to objectively demonstrate the impact of the programme is an important step to further develop and enhance the programme. The current monitoring arrangements through surveys are an understandable attempt to collect empirical information within the resources available, but they are considered to be less than ideal by facilitators, participants and some steering group members.

Recommendation 2

5.20. Now that the programme is established, dedicated resources should be sought to carry out a research study which seeks to demonstrate its impact. This study should be based on appropriate research principles and data collection techniques and should not be seen as an add on to programme provision. Robust, evidence-based results will not be achieved 'on the cheap' as part of existing activities. Consideration should also be given whether it is possible and appropriate to carry out longitudinal research over a number of years.

5.21. Current academic links through the steering group present an opportunity to explore and design this study and the HSC Research and Development fund may provide a funding source. If possible, a dedicated and suitably qualified data officer should be recruited as part of the project team to help with data collection and data analysis.

5.22. In addition to the above, there is a wide range of case studies available showing the social impact of the programme. It may be worthwhile exploring whether these could also form the basis of academic qualitative research and analysis on the social impact of the programme.

Observation 3 – Programme co-ordination and delivery

5.23. The role of the Programme Co-ordinator is seen as vital to the successful delivery of the programme and experience to date shows that co-ordinating a significant number of delivery partners across NI requires dedicated resources.

5.24. The role of the HLC Alliance is also seen as important to the programme, enabling the involvement of appropriate community-based health organisations to deliver the programme throughout NI and the HLCs involved are embedded in local communities and have vast experience in delivering community-based healthcare in urban and rural settings.

Recommendation 3

5.25. As the programme continues, adequate, dedicated resources should be provided for programme co-ordination and the central role of the HLC Alliance and participating HLCs should continue to be recognised. As noted above, if possible, a dedicated and suitably qualified data officer should be recruited as part of the project team to help with data collection and data analysis.

Observation 4 – Role of the steering group

5.26. The steering group provides leadership and direction to the programme and also fulfils an important quality assurance role, which provides a degree of confidence in the programme to health and social care organisations and professionals. Although steering group membership has been augmented since the inception of the programme, there has been a constant core membership that has demonstrated significant commitment to, and belief in, the programme. The current steering group membership contains appropriate representation from key players in the areas of pain support. The steering group seeks feedback from participants and facilitators to ensure the programme continues to evolve and develop.

Recommendation 4

5.27. The steering group may wish to consider succession arrangements to ensure the membership continues to be appropriate in future years as members retire or move to new roles. The steering group may also wish to consider putting formal feedback mechanisms in place with facilitators (e.g., joint meeting every 6 months).

Observation 5 – Referral sources

5.28. During the evaluation period, 40% of participants reported that they heard about the programme through a GP, Pharmacist, or other healthcare professional. Through our focus group work we were advised that in the early years of the programme, the main source of referral was via GPs and primary care practices.

Recommendation 5

5.29. Steps should be taken to further promote the programme within primary care. The primary care branch of SPPG could play a role in this. The mix of healthcare professionals and people from a community development background on the steering group and the quality assurance role the steering group carries out should help give GPs, physiotherapists, pharmacists, and other health care confidence to refer people to the programme.

Observation 6 – Programme scope

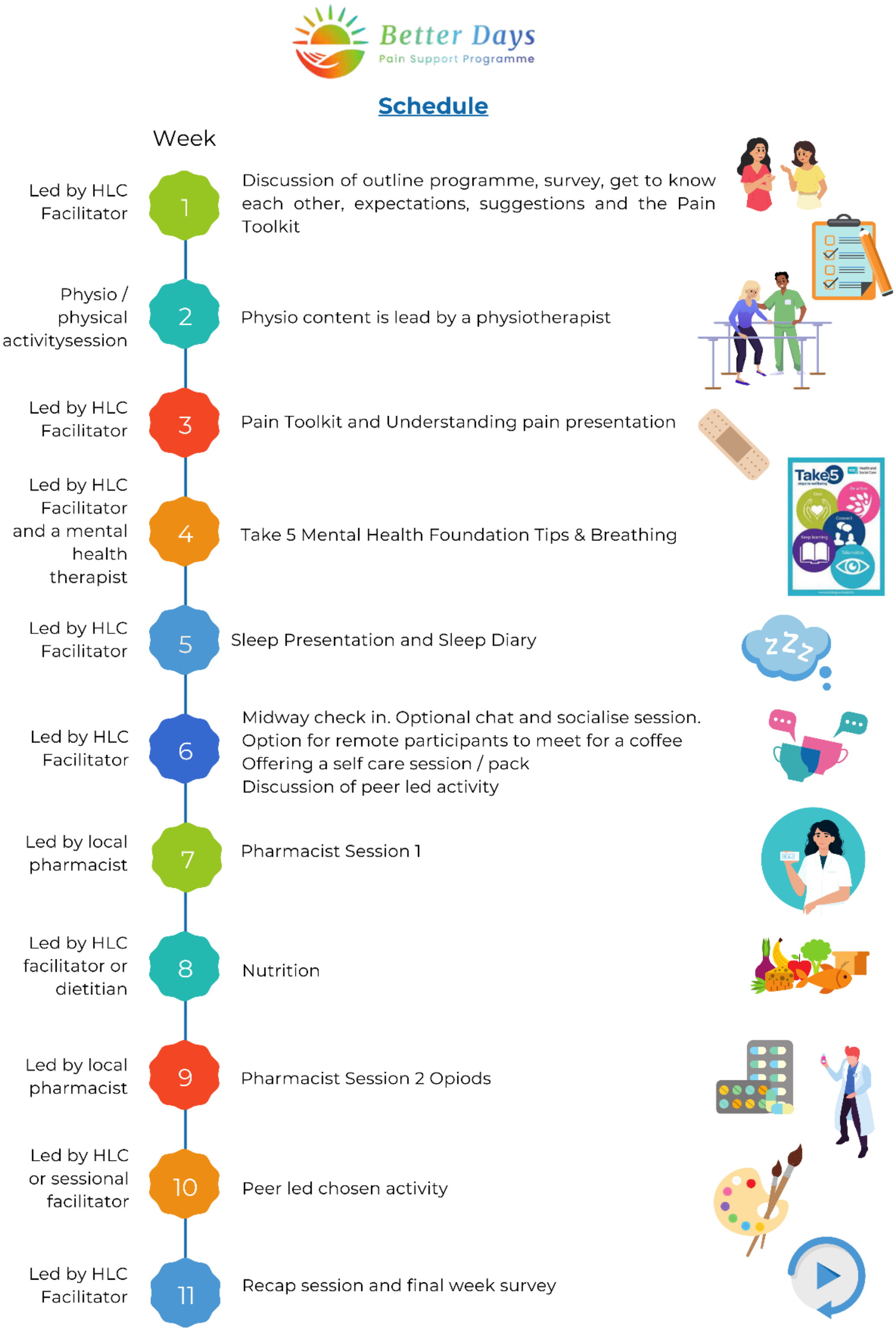
5.30. In our discussions as part of the evaluation process, a view was expressed that funders and commissioners may see the programme as a complete and cheap programme to manage pain for everyone. Whilst this report shows the programme can help certain groups of people, especially those who benefit from peer advice and are below the threshold where their chronic pain is becoming very disruptive, it is considered less likely to achieve robust outcomes for people whose lives are severely disrupted by pain and suffering high levels of chronic pain.

Recommendation 6

5.31. It is important to manage the expectations of funders and commissioners in line with what the programme can realistically deliver. The programme is not suitable for everyone experiencing chronic pain. This may result in those leading the programme challenging expectations to ensure the programme focuses on the areas where it can make a difference by delivering the right care to the right people at right times in the right setting.

Appendix 1 Programme content

Below is a sample of some of the content which may be included on the programme



Better Days
Pain Support Programme

Schedule

	Week	
Led by HLC Facilitator	1	Discussion of outline programme, survey, get to know each other, expectations, suggestions and the Pain Toolkit
Physio / physical activitysession	2	Physio content is lead by a physiotherapist
Led by HLC Facilitator	3	Pain Toolkit and Understanding pain presentation
Led by HLC Facilitator and a mental health therapist	4	Take 5 Mental Health Foundation Tips & Breathing
Led by HLC Facilitator	5	Sleep Presentation and Sleep Diary
Led by HLC Facilitator	6	Midway check in. Optional chat and socialise session. Option for remote participants to meet for a coffee Offering a self care session / pack Discussion of peer led activity
Led by local pharmacist	7	Pharmacist Session 1
Led by HLC facilitator or dietitian	8	Nutrition
Led by local pharmacist	9	Pharmacist Session 2 Opiods
Led by HLC or sessional facilitator	10	Peer led chosen activity
Led by HLC Facilitator	11	Recap session and final week survey

Appendix 2 Details of other pain support programmes in NI

Below is some information on pain self-management programmes delivered in NI with charity involvement.

Versus Arthritis Self-Management Programmes*

- Versus Arthritis runs a programme for people who suffer from long term chronic pain. The programme is open to anyone in this condition and is delivered by Accredited Peer Trainers who also live with a long-term health condition. The 6-week course aims to hep participants ease and manage symptoms. The course is free and available online or face to face through local providers. Face to face programme take place in Dromore (Co. Down), Lisburn, Bangor, Annalong (Kilkeel), Larne, Portglenone, and Belfast.
- Programme content includes:
  - Managing fatigue
  - Coping with anxiety and stress
  - Improving sleep and rest
  - Managing anger and frustration
  - Managing change and goal setting
  - Improving lifestyle including activity and healthy eating

* All information from the Versus Arthritis, Northern Ireland website (2023).

- Note that the content of the Versus Arthritis programme has influenced the Better Days pain management programme. The steering group incorporated physiotherapy input on the programme as a result of listening to the Versus Arthritis programme. Regional online programmes were also introduced as a result of considering the success of the Versus Arthritis programmes in this area.

Action Mental Health – Managing the Challenge of living with a long-term condition*

- Action Mental Health delivers a chronic pain/conditions self-management course in the Western Health and Social Care Trust area. The course is based on the Stanford model and consists of weekly 2.5-hour sessions for a 6-week period, designed in conjunction with healthcare professionals from the Trust. Hybrid delivery arrangements are used with groups of 7-10 people taking part in Limavady, Derry/Londonderry, Strabane, Omagh, Enniskillen.

- Programme content includes learning how to:
    - Communicate better with healthcare professionals and family.
    - Review your medication.
    - Sleep more soundly.
    - Eat mindfully.
    - Manage your energy levels.
    - Relax easier, move better and problem solve.

action mental health

* All information from Action Mental Health, Managing The Challenge website (2023).