

**A CO-PRODUCED PROJECT WITH NHS FORTH VALLEY AND PAIN CONCERN:  
A TELEPHONE HELPLINE TARGETTING PATIENTS ON A PAIN WAITING LIST**

**Background:**

Pain Concern is a charity which has a track record of undertaking activities, and developing and promoting resources to help people cope with chronic pain.

It organised, Edinburgh's Astley Ainslie Hospital's first support group for people completing the pain management programme, and since 1995, it has run a telephone helpline, manned by trained volunteers with personal experience of chronic pain. It produces Pain Matters, a magazine in paper and digital form, which focuses on pain management skills, and has, for many years, created leaflets on pain management which have been continuously in demand by physiotherapy departments and pain clinics across the UK, as well as by individuals with chronic pain. Information on the Pain Concern's website is used by people living with pain, carers and family, as well as healthcare professionals.

In 2010, Pain Concern in collaboration with the UK's only disability internet broadcaster, Able Radio, created half-hour podcasts (called "Airing Pain") which informed and supported people in pain; these podcasts have continued as funding allows, and evaluation of them has been repeatedly positive. In 2015, the charity carried out a 2-year research project on the "Barriers to Self-Management in Primary Care" in 2015. As a result of this project, Pain Concern then proceeded to develop a "Navigator Tool" to help patient / HCP's (healthcare professionals') communications with regards to self-management of chronic pain; this tool's use was tested and reported in 2018. It was well positioned to provide a telephone helpline to support people in pain waiting for appointments for specialist pain management services.

**Introduction:**

Pain Concern's interest in self-management and supporting people in pain was continued when the charity received short term Winter Funding from the Scottish Government in 2021 / 2022. Pain Concern was then able to create a dedicated telephone number to all of those waiting for their first appointment with secondary care pain services across Scotland. This project's intention was to set up a new telephone helpline in addition to the existing support offered by Pain Concern, one that was specific for people in Scotland on pain waiting lists. The plan was to operate a professional helpline with an answering service to ensure that calls were responded to, with Pain Concern offering continuing support to those in pain.

From January to April 2022, Pain Concern set up a dedicated telephone helpline, with national reach, to support people in chronic pain as they waited for appointments to see specialist consultants in chronic pain management. As a result of the Winter Funded helpline, Pain Concern developed a productive collaboration with NHS Forth Valley's Pain Management Services, and thus the project outlined below took root and evolved.

## **EVALUATION REPORT:**

Below, is an independent overview of the current project funded by the Scottish Government.

The report uses the framework of evaluation proposed by Donabedian (1966) of ‘structure, process and outcome’ which offers skeleton headings around which the study is reviewed.

Donabedian in Evaluating the quality of medical care. The Millbank Memorial Fund Quarterly July Vol 44 No 33 p166-206

This report is organised by examining the following aspects:

**Structure:** factors in the system which determined the specific nature of the project and pace of delivery e.g. budget, staffing, facilities, equipment, training, supervision and management.

**Process:** the timescale of activities, key decisions and how the study was done.

**Outcomes:** the research report and findings, project results, changes and impact of the study.

The project is explored in terms of overall performance, by comparing what was included in the original proposal with what was actually done.

It has therefore been possible to demonstrate how the aims and objectives of the study were fulfilled, confirm and verify the achievement of quantitative and qualitative objectives, and make comment on the effectiveness of the outcomes by reviewing feedback comments. Lessons learned from delivering this project, which have implications for future work in chronic pain management are also detailed.

## **AIM OF THIS PROJECT:**

The aim of this current project was to build on the previous winter funded initiative when Pain Concern found that NHS Forth Valley was one of the few Health Boards in Scotland able to contact and communicate, by text, with their Pain Management Service waiting list patients. Additionally, it built on Pain Concern’s knowledge and long-standing experience of running a helpline for people in pain and took full advantage of Pain Concern’s resources.

Thus, Pain Concern and Forth Valley worked together on a dedicated telephone number with especially trained paid call handlers providing a service to all those waiting for specialist pain services in the NHS Forth Valley area. As well as emotional support and a listening ear, the team aimed to provide specific advice on joining the Forth Valley Pain Management Service, advice on self-management and access to Pain Concern’s range of pain management podcasts, its educational material, (publications and leaflets), including their Award-Winning *Self-Management Navigator Tool*.

The aim was to provide pain education, emotional support and a clear explanation of what to expect from one geographical area, and to prepare patients better for their Out-Patient appointment with NHS Forth Valley’s specialist pain management services.

## 1. Structure.

### 1.1. Budget and Funding:

Pain Concern, in collaboration with NHS Forth Valley's Clinical Lead for Pain Services sought several funding sources for the current project. Success was achieved from the Scottish Government's Clinical Priorities Directorate who awarded Pain Concern a total sum of £11,100 to cover the tangible direct costs of the project, as summarised below:

<b>COST ITEM / DETAIL</b>	<b>AMOUNT (£)</b>
Helpline call handler's payments (100%)	4000
Phone, printing distribution, marketing, publicising results (100%)	1900
Administration (100%)	1000
50% of helpline supervisor's salary	3000
Independent Evaluation (100%)	1200
<b>TOTAL</b>	<b>11,100</b>

The budget expenditure was tracked by the Treasurer. It was anticipated that the finance would be fully committed as the final accounts demonstrate (see Appendix 1).

The original proposal stated that progress on the project would be reported via the Chief Executive to the Board of Trustees in order to oversee the finances of the charity. The funds were to be placed by Pain Concern's accountant in a restricted fund and only used for the purposes detailed. This happened, and as anticipated, the People and Operations Manager (SM) monitored the spending on the project, and Trustees at their bi-monthly Board meetings were kept informed about the progress of the project by the CEO.

Given this was a three-month, discrete project, little communication needed to take place between the Clinical Priorities Team at the Scottish Government during the project. The People and Operations Manager within Pain Concern informed the team at the Scottish Government, (via email in April), that feedback from NHS Forth Valley about new and returning patients (about their experience helpline) may not be available for up to two years; she additionally, requested the format of the final report to be submitted. Forth Valley and Pain Concern kept in touch weekly, or sometimes more frequently as required.

The closing date for applications was 6<sup>th</sup> January. Throughout most of January, Pain Concern and NHS Forth Valley prepared to start the project (the helpline was in a state of readiness – with a dedicated telephone number, a voicemail facility, and an email account set to go live - staff training material was prepared, documentation agreed, and staff earmarked for recruitment into the project). When confirmation of funding was received from the Scottish Government by Pain Concern, the project began immediately, on 23rd January 2023, with joint training of the helpline call handlers: see below. It is to the credit of the charity and of its partner, NHS Forth Valley Pain Management Services, that they were able to run an effective and professional, and targeted helpline service so quickly.

## **1.2. Staffing and Recruitment for the Forth Valley Helpline:**

Pain Concern was able to achieve the short timescale because of the experience of the People and Operations Manager, (SM). Until notification of the project funding, SM had run its historical helpline, and had overseen the 2022 Winter Funded project. Accordingly, lessons were learned from the latter, and SM was able to meet the management demands of setting up the dedicated helpline at speed, and to ensure that it functioned efficiently from the start.

It should be emphasised too, that SM's expertise, combined with an ability to use Pain Concern's existing platforms, and tried and tested systems and processes, meant that SM was able to use a current pool of trained and experienced national helpline staff plus the charity's wide range of already-developed resources and support information on pain.

Two existing volunteer Pain Concern telephone call handlers were approached to take part in the project: these individuals had already been vetted, had a good idea of local pain management services, and of Pain Concern's resources. A third call handler, who had been involved in the winter funded project, was also identified for the NHS Forth Valley project; this individual was aware of the documentation to be used during calls, but, for all three, their performance was known by SM. Three individuals were appointed then into the role for the duration of the project, and they received payment for their work.

In terms of HR governance, SM was familiar with the person specification for the role, and she particularly selected operators who had their own personal lived experience of chronic pain, and were former patients of a pain management programme; these qualities were in addition to their ability to communicate well by phone, and empathise with people in pain.

The three staff were contracted to work for 20 hours per week, on fixed term contracts; two call handlers were available for set times to run the telephone helpline, and this arrangement worked well. They have now returned to their roles as volunteers with Pain Concern.

## **1.3. Facilities and Equipment:**

The project targeted people from NHS Forth Valley but the call handlers worked remotely from home for the duration of the project. The resources and information material issued to callers were collated and posted out from Pain Concern's headquarters in Edinburgh at the request of the helpline call handlers. No additional equipment required to be purchased to support the remote working undertaken in this project.

Pain Concern's helpline telephony services are provided by BT and their service contract and current infrastructure enabled additional the new dedicated line to be switched on easily. Testing of the line was done in January and there were no technical problems with the system when it went live.

## **1.4. Training:**

Bespoke training was created for the telephone call handlers and delivered jointly by SM and the lead physiotherapist in NHS Forth Valley. The training covered the following:

- Up-to-date Information about the organisation of NHS Forth Valley's Pain Management Services, an especially valuable was the information needed by the call handlers about Forth Valley's local charitable and support networks.
- The helpline call handlers, in line with the recommendations contained within the Framework for Recovery of NHS Pain Management Services, were provided with simple self-management advice, around understanding pain, activity management, and dealing with emotional distress, with the aim of preventing further decline in function whilst on the waiting list.
- The helpline call handlers were trained to use Pain Concern's *Self-Management Navigator Tool* with callers (see Appendix 2).
- The helpline call handlers were also informed about the evaluation plan and the importance of recording information during the process of call handling - a key part of the data collection which was integral to this project.

### **1.5. Management and Supervision:**

In terms of internal governance, oversight of the project was undertaken by weekly contact of the Pain Concern's CEO, Treasurer and with SM, and regular reports were provided directly to the Board of Trustees. Problems emerging were dealt with as they arose, with NHS Forth Valley's contact person if necessary e.g. callers were slow to use the helpline facility at the start and it was decided to mailshot those on the waiting list (see below and Appendix 3).

An important aspect of governance peculiar to this project was that the charity and the NHS Board, put a 'data sharing agreement' in place (see Section 2.1, below). This was done before the project started so that both were clear about the handling of confidential, sensitive information during the project. It is to the credit of Forth Valley and Pain Concern that such practicalities were worked through in anticipation of the project and before problems arose.

A key functionality of the BT system is that a supervisor can listen into conversations remotely (like a call centre). Previously, supervision and support of the Helpline Call Handlers was carried out by SM using this facility but this time, call handlers were experienced helpline operators; one of them had worked on the 2020-2021 Winter Funded helpline. For this project, SM contacted the call handlers after every shift, and the latter contacted SM if any problems or issues emerged e.g. the need to escalate callers.

It is worth mentioning that Pain Concern's staff and volunteers have access to counselling services as a back-up if anyone is distressed by a call. This means that the call handlers could be properly debriefed if necessary. One call handler took advantage of a counsellor-led session, perhaps reflecting the high call volumes experienced by the call handlers in this project (compared to the 2022 Winter Funded project). Listening into lengthy calls was not considered the best use of SM's time, and not seen to be necessary by the oversight group. Monitoring of calls post each shift was felt to be adequate, and SM checked emails to ensure the delivery of a professional service and, good teamworking existed throughout the project.

## 2. Process:

### 2.1. Timeline for the Project:

The timescale for the project was as follows:

**January:** BT additional line activated / recruitment of operators and joint training of helpline call handlers with staff from NHS Forth Valley and Pain Concern.

**February:** Flyer produced for the project and circulated to NHS Forth Valley hospitals, physiotherapy and GP Clinics in the geographical area – to stimulate calls.

**January to end of April:** NHS Forth Valley Waiting List Helpline live and ongoing collection of outcome data. Text messaging by Forth Valley for the project duration.

**April / May:** Data and report writing of the project.

### Co-Working: Pain Concern and Forth Valley:

This project has been an excellent example of co-working between the NHS and the third sector. Its success has built on Pain Concern's expertise and intelligence in relation to running a telephone helpline and its readily available pain management resources. NHS Forth Valley had confidence in the latter, and they were able to use their track record and experience of communicating with patients on their (pain) waiting list patients.

Calls to the helpline were slow at the beginning despite NHS Forth Valley texting everyone on the waiting list about the existence of the helpline at the end of January. Accordingly, Pain Concern and Forth Valley conferred about how they could encourage use of the helpline. Together they decided on the creation of a simple leaflet promoting the service. The flyer was a simple leaflet with ten top tips to help people on the waiting list which advertised the telephone number to get help from Pain Concern. The flyer (see Appendix 3) was sent to local GPs, pharmacists and link workers in NHS Forth Valley in late January, as well as to other services e.g. rheumatology, orthopaedics and physiotherapy. Pain Concern continued raising awareness through social media and both throughout the project's life, attended local events and conference hosted by NHS Forth Valley.

In February, Pain Concern could see that people had phoned the helpline but had not left a message. After conferring with the Helpline Partnership, the Information Commissioner, and the Caldicott Guardians, it was decided that, although not infringing GDPR regulations, it would be an invasion of privacy to call back a number, unsolicited. In March, the Health Board sent out letters to waiting list patients: this was thought to be an acceptable response, emphasising the availability of the dedicated telephone number to help people on the pain waiting list (see Appendix 4). Similar letters were sent out to services who had referred the patient to the pain management service. There was an immediate rise in uptake and use of the helpline. The leaflets (with the NHS and Scottish Government logos), combined with the letters seem to have lent legitimacy to the worth and value of patients phoning Pain Concern.

## 2.2 The Nature of the Project:

When the project started NHS Forth Valley had a waiting list of 850 new and returning patients on the waiting list for Out-Patient Pain Management consultations, and pain management programmes. The aim of this project was to work with NHS Forth Valley to encourage the use of Pain Concern's Telephone Helpline. NHS Forth Valley was chosen as Pain Concern's partner because, unusually in Scotland, had a mechanism to communicate with their patients on the waiting list, via texting.

Collaboration with this Health Board meant that they could promote awareness of Pain Concern's dedicated helpline; it would be operational for up to 20 hours per week and callers could leave messages outside opening hours or send an email to a dedicated email account. The intention was, short term, to provide pain education and emotional support to these patients, and additionally emphasise what to expect from the Forth Valley Pain Services. The expectation was that patients would be better prepared for their Out-Patient appointments with the specialist pain management services.

Previous work within Pain Concern has shown that a dedicated helpline for waiting list patients can lead to the following outcomes:

- People feel empowered to tackle the broader problems of daily living.
- People feel empowered with supported self-management advice including signposting: providing information about understanding pain, activity management and dealing with emotional distress to prevent further decline in function.
- People are better able to make the best use of NHS pain services when they leave the waiting list.

Every time a caller contacted Pain Concern's dedicated telephone helpline the team provided:

- Emotional and practical support, and an information pack from NHS Forth Valley.
- A copy of Pain Concern's *Self-Management Navigator Tool* (see Appendix 2)
- Appropriate Pain Concern Leaflets (see Appendix 6)
- Details on how to join Pain Concern's online community forum
- A free subscription to Pain Matters magazine.

A standard email was sent to callers confirming what information was going to be sent to them, and sending the material was actioned by a volunteer in headquarters office. The information pack contained details of local support and services in NHS Forth Valley.

The return wait time in NHS Forth Valley for pain management services is approximately two years and equipping patients with ways of dealing with their pain in the interim was crucial. Long term, the NHS Forth Valley clinicians plan to determine if patients' contacting the helpline had helped them and impacted on their experience of waiting to see a specialist.

### **2.3.Data Collection:**

For its Winter Project in 2022, Evaluation Support Scotland (EES) had enabled Pain Concern to develop an evaluation plan (see Appendix 5) and which allowed the charity to get feedback from those who had accessed the helpline. ESS were instrumental in helping SM devise the recording system to enable the call handlers to collect contemporaneous data about outcomes during calls. This allowed data collection by the call handlers systematically as calls were happening. Call handlers were also required to complete a record and documentation for each caller immediately after a call.

For the NHS Forth Valley Project, data collection procedures were streamlined and simplified, having learned lessons from the experience of the Winter Funded Project. The number of records to be completed was reduced from the previous project, and the descriptors of the documentation rationalised. In summary then, three (rather than five) different methods of data collection were used to gather information about Pain Concern's telephone Helpline: a caller feedback form and, the outcome measurement and indicators record, capturing casual moments and observations of the call handlers.

The approach to data collection, importantly, offered a structure around the call handling to focus on the outcomes of the project, and furnished Pain Concern with information about the impact of the helpline for people in pain. All the call handlers were experienced in taking calls from people in pain, and they all used familiar phrases and took a standardised approach to dealing with conversations.

SM took an overview of the project to check that the data and records completed were appropriately collected for the evaluation. Before callers were escalated to NHS Forth Valley, the need for this was discussed with SM and the call handlers talked to the NHS Forth Valley contact person directly – this system worked well.

### **3. Data Analysis and Results:**

The Evaluation Plan allowed both quantitative and qualitative data to be collected.

Quantitative information was collected about the numbers of callers who used the helpline. The methods largely accrued qualitative information about the value of the service; these allowed case studies to be constructed and feedback comments to be collated which illustrate the benefit of the helpline to individuals with pain on NHS Forth Valley's waiting list.

#### **3.1.Quantitative Data and Results arising from the Project:**

In summary, 17% of NHS Forth Valley's pain waiting list contacted the helpline, five were escalated for urgent attention. For the duration of the project – 12 weeks long, the helpline received a total of 130 calls. 1750 texts were sent out by NHS Forth Valley to (pain) waiting list patients over the duration of the project. Texts went out weekly to patients, to 100 new and 100 return patients. By the end of the project then, all patients had been texted twice.



Over three times the number of calls were received compared to the Winter Funded Project in 2022, (when 42 ‘were assisted’ calls meaning that the helpline operators spend considerable time with the callers supporting them in line with the project goals). The fact that so many more patients contacted the helpline suggests that the combined communications, from both NHS Forth Valley Health Board and the charity, was an important influence on callers to use Pain Concern’s telephone helpline service – giving the latter a resounding endorsement. The following table summarised the monthly activity that took place in relation to the project:

<b>Date</b>	<b>No of texts sent</b>	<b>Text to new or return</b>	<b>Total no of calls received</b>	<b>Total no of SU spoken to</b>	<b>Total no of emails received</b>	<b>Total no of contacts received into the Helpline</b>	<b>Total no of contacts handled by Helpline Team</b>
<b>Jan/Feb</b>	550	split between new and return	16	6	4	20	10
<b>March</b>	300	split between new and return	99	46	10	109	56
<b>April</b>	900	split between new and return	15	14	3	18	17
<b>Total</b>	<b>1750</b>		<b>130</b>	<b>66</b>	<b>17</b>	<b>147</b>	<b>83</b>

As well as the calls received, 17 additional emails were also sent by the call handlers; this represents extra work and further help and information which was offered to callers. The call handlers in total dealt with 147 contacts. These took roughly 30- 40 minutes. The call handler who had been involved in Pain Concern’s winter funded helpline stated that she felt callers, this time round, were “more purposeful in their conversations.” This comment may be testimony of the communications sent to patients which explained the role of Pain Concern’s helpline as “a service” which could provide “information about Forth Valley’s Pain Management Service, and signpost patients to resources.”

Replication of Pain Concern’s Winter Funded telephone helpline and focusing on one geographical area has allowed additional data to be collected about ‘new or returning’ waiting list patients. 80% of the callers were new patients i.e. new patients to the Pain Waiting List; 10% were return patients (data for 10% was not captured). It is known that 28% of these patients had had been waiting for pain management service for over 12 months.

A major benefit of co-working with a specific NHS Health Board partner was that callers could be escalated to the Forth Valley Pain Team. Five callers were so highlighted to the Health Board – all were very distressed and, the call handlers had concerns about the caller’s mental health and well-being; all the latter consented to this course of action. Of these callers, three were sent resources by Pain Concern to help them manage their pain. 3;5 of these were new patients who had been waiting more than twelve months on the Waiting List.

### **3.2.Contact Volumes and feedback:**

81% callers had a low tone at the beginning of the call but by the end, 69% had improved, indicating that they were calmer and less upset at the end of the call, compared to the beginning. This is an indicator that the helpline conversation had a positive impact on callers – a finding confirmed by the fact that 70% of callers stated that they felt more positive after speaking to call handlers, with 77% of callers thanking the call handlers for listening to them. 65% said they felt better prepared for their healthcare appointment and 74% of callers received additional resources from Pain Concern.

### **3.3.Qualitative Data and Results arising from the Project:**

Comments from the call handlers give an insight into those using the telephone helpline. They stated that many callers felt quite distressed about their situations and contact details for the Samaritans and information on Breathing Space were given out on many occasions.

The call handlers thought that many callers were very appreciative of the support provided and thanked the helpline staff member. Many stated that they felt “not just listened to but understood” and, were grateful that there was a service there for people with pain staffed by people who understand pain. Many of the callers mentioned feeling very alone, “not listened to by others, overwhelmed and that talking can never take the pain away, but no one else could help.” Callers were pleased that there was” someone to speak to and felt they were less alone, able to speak freely and able to call back if they had any other questions.”

Many were relieved that there was help out there - as they weren’t aware of what was available and were struggling to find someone that understood. Services users were thankful for having someone supportive to speak to and share their pain with, when they did not know where else to turn to and that they had been validated.

Many service users mentioned a lack of understanding when it came to their experiences of healthcare appointments and healthcare staff. Some people however had already looked at the Pain Concern website, listened to Airing Pain and found the information provided, really helpful.

Judging by the reaction of callers to the information provided by the call handlers the latter thought that the advice provided often gave service users “lightbulb moments of finding new ways to manage and understanding pain more.”

The call handlers stated that issues such as medication, financial information and concerns about medical conditions that then impacted their pain management were raised but although many callers did not want to talk any further, they were grateful that resources could be sent out to them. Testimonials by email from callers provide qualitative feedback and sum up the value of the telephone helpline service: “Wow! This really is a fantastic help, as was our discussion yesterday. I am extremely grateful to you – thanks very much” and “Thank you so much for all these links – I will take my time going through all that you have suggested.”

#### **4. Outcomes.**

This project is exceptional in that it is an example of a charity and NHS Board working together to reduce waiting lists and focus on efforts to help patients deal with this. NHS Forth Valley have been open in their sharing of information, and both have worked hard to capture data that illustrates how a helpline and a charity with a track record of dealing with people in pain can improve outcomes for patients.

The expected outcomes of the creation of the National Telephone Helpline were that people in chronic pain – on the waiting list for specialist NHS Pain Management Clinics would:

- People feel empowered to tackle the broader problems of daily living.
- People feel empowered with supported self-management advice including signposting: providing information about understanding pain, activity management and dealing with emotional distress to prevent further decline in function.
- People are better able to make the best use of NHS pain services when they leave the waiting list.

All of the above outcomes have been achieved as demonstrated by the feedback comments from the callers and data captured by the call handlers.

#### **5. Changes to original proposal:**

The main change to the original proposal is that NHS Forth Valley’s data from clinicians about the referrals, and the impact about the value of Pain Concern’s telephone helpline, from the clinician perspective, will not be available until 2024. The funding body are aware of this. As referred to above, in Section 2.2, this delay is related to the lengthy waiting times that currently exist in NHS Forth Valley. This means that most of the feedback about the helpline, its call handlers, and resources will not be available until patients are seen.

Appendix 7 shows the Clinician Evaluation Form that has been developed for the project, and the intention is clinicians will complete this to get feedback about Pain Concern’s Helpline resource once they start seeing the patients. The contact person in NHS Forth Valley however gave Pain Concern the following feedback recently from a waiting list patient:

Just had some lovely feedback from a patient who wanted to let you know how grateful they were for the support. They said it was "brilliant" and the first time they felt someone had understood. They also found the tips really helpful.

They clearly mentioned it to other departments too, this was stated in her ortho letter: "although they have not been seen directly by an NHS Pain Clinic they were given a telephone to speak with someone from Edinburgh and the website from Pain Concern and says the person they spoke with was very helpful and gave them a lot of tips and information over e-mail and they are quite happy with it so far."

## **6. The Impact of the Project:**

This project has been an excellent example of joint working with a Health Board and the third sector. The aim was to provide pain education, emotional support and a clear explanation of what to expect from one geographical area, and to prepare patients better for their Out-Patient appointment with NHS Forth Valley's specialist pain management services.

This project explored the value of the provision of a telephone helpline service which targeted people in pain waiting for appointments with Pain Specialists in NHS Forth Valley Health Board. The co-working was evident from the start in the preparation for the project, but the partnership and co-working has had ongoing clear benefits.

This project has been unique on several fronts. Firstly, a helpline resource is available as a source of help to people without access to computers and IT systems. This conclusion is evidenced by the callers who thanked Pain Concern for the help received, and those who expressed gratitude to the charity for the resources received. Callers particularly appreciated having someone to reach out to who listened to their experience of suffering with pain.

Secondly, this project is unique in that it has provided immediate feedback from users about the benefits of a helpline service in terms of callers' management of their pain.

Thirdly, the feedback indicates that the call handlers with their lived experience of pain management clinics and insight into pain treatments seems to have provided 'added value' to the service as callers felt 'understood' and 'less isolated and alone. The following quote from a call handler indicates too the benefit of the project to the call handlers themselves:

"Working on the helpline has been a wonderful opportunity to work directly with service users and understand that, whilst we can't provide a cure for the pain, even the smallest amount of information, new resources or suggesting techniques that they may not have tried yet, can make such a big difference. I have also been able to expand my communication and interpersonal skills which is going to be invaluable when it comes to applying for jobs".

The project has highlighted that NHS Forth Valley's system of texting patients on waiting lists, combined with the production of leaflets, and letters sent from its Specialist Pain Service, lent legitimacy to the project run by a charity (who was previously unknown by many callers). The letters also mentioned that the project was funded by the Scottish Government. Undoubtedly, this approach encouraged patients to use telephone helpline.

### **6.1.Immediate benefits of the project:**

There were four immediate benefits achieved for those with pain on the waiting lists.

1. First and foremost, the close collaboration between NHS Forth Valley and the team was extremely helpful and worked well throughout the project. This relationship resulted in five patients being escalated to the Health Board Specialist Services to receive care. As a result of the co-working, Pain Concern and the Health Board did joint presentations to local groups with NHS Forth Valley, informed participants about the helpline, answered questions on pain management, and Pain Concern issued resources and information about their educational and support materials. This double act was considered invaluable. In reality then, the reach of the project (promoting the existence of the charity and advice about pain management) extended far beyond the creation of a helpline for waiting list patients, and out to people in the local area.
2. Secondly, callers to the helpline received immediate relief: they spoke of feeling believed, listened to and understood, and the receipt of support and information on self- management of pain was clearly helpful (see Section 3.3).
3. And finally, the ‘caller feedback’ form data indicated that callers using the helpline felt better prepared to make the best use of NHS services while they were waiting for their appointment and better able to use the specialist service, once seen.

### **6.2.Medium term benefits of the project:**

As mentioned above, good relationships have been established between Pain Concern and NHS Forth Valley pain management services and both have consolidated their presence with local groups. The wider community is now aware of the pain resources and support available from Pain Concern e.g. the online community forum, its historical helpline run by volunteers, and the wide range of ‘Airing Pain’ podcasts. The project then has extended Pain Concern’s networking and broadened their engagement with local groups: thus, the charity has acquired increased awareness of people on the ground in one geographical area. This information will help people from NHS Forth Valley (and neighbouring towns) who contact the charity. Pain Concern has a better knowledge of the services in primary and secondary care, and how they link up and this information too will be valuable when the call handlers return to volunteering in the historic Pain Concern helpline supporting people in pain and their families. Given the waiting lists for pain management programmes are lengthy this knowledge acquisition is valuable going forward.

### **6.3.Long term benefits of the project:**

As the previous Winter Funded Telephone Helpline demonstrated, it is clearly beneficial to use staff with lived experience of pain, and this requirement will remain as an essential experience for the helpline support offered by Pain Concern.

NHS Forth Valley’s Pain Management Services are to be applauded for being receptive to working with Pain Concern. They have demonstrated a vision and commitment to helping patients with pain

long term, and while on the waiting list. Importantly, a productive working relationship has been established that can help pain patients in the months and years to come.

Supported self-management and better communications between GPs, patients and pain specialists is key to long term pain management. This is the essence of what Pain Concern offers, and the resources available from the charity are now better known by the specialist pain services. Hopefully by word of mouth, consistent messages will be given by local groups and the NHS about the value of Pain Concern's resources to those who can benefit from them. In parallel Pain Concern has acquired up-to-date knowledge and information about NHS Forth Valley's Pain Management Services.

## **7. The Lessons Learned:**

Compared to the Winter Funded Project in 2022, SM was provided with more support to do the data analysis and final report writing. ESS were tremendously helpful to Pain Concern in conceiving the evaluation plan for the project, and SM and the call handlers were comfortable with the data collection methods used, successfully collecting feedback on the worth of the telephone helpline and, and feedback confirms that the calls have helped patients prepare for out-patient appointments.

The joint working and collaborative relationships established with NHS Forth Valley have taken Pain Concern's helpline to a different level allowing consistent messaging to be given to pain sufferers about the support available to pain sufferers.

## **8. Future work to promote improved self-management of chronic pain.**

The existence of the telephone helpline has not only given higher profile to Pain Concern to sufferers of chronic pain but the partnership working with NHS Forth Valley has promoted the charity, and the long term help it can provide, within a geographical area. The co-working with NHS Forth Valley lent legitimacy to Pain Concern and the existence of the resources it offers.

Almost 20% of NHS Forth Valley's pain waiting list patients contacted Pain Concern's helpline – both new and return patients - over three times the number of calls made to the 2022 Winter Funded Project. The fact that so many more patients contacted the helpline suggests that the communication from NHS Forth Valley Health Board was an important influence on callers to use the telephone helpline service. Texting took place for the duration of the project, but flyers and letters also informed waiting list patients about the helpline and its value. An additional unforeseeable element of the project was the joint presentations done by the contact person in NHS Forth Valley with SM to local groups. These will have undoubtedly succeeded in promoting Pain Concern and its resources to a wide network of people not just for this project but longer term. This work was demanding of SM and in future a supervisor should be funded to listen into calls and provide further team support.

It is difficult not to argue that if this helpline service had been funded for longer, more patients would have benefited from Pain Concern's call handlers, and the resources available to them.

The outcome data demonstrates that the helpline services made a difference to their callers' lives and helped them consider how to maximise the contact that they would have in future with the NHS pain specialists and their GP appointments. More funding for a longer project would have allowed Pain Concern and NHS Forth Valley to do more work with waiting list patients and might even have reduced demands on the primary and secondary care services.

Long term funding to Pain Concern is needed to create its 'Airing Pain' podcasts and revise and updates its resources for pain sufferers.

Specifically, in relation to the provision of another Pain Concern telephone helpline service, long term funding is needed to enable call handlers to be paid to run it. The feedback from the call handlers, and the callers, demonstrate without a doubt that the 'lived experience' of pain management programme and enduring pain, their knowledge and insight into the practical benefits of Pain Concern's resources, was especially valued by callers.

The findings of this project will be presented at future conferences to encourage all Health Boards to text patients on pain waiting lists and highlight the existence of Pain Concern, its historical helpline, and the wealth of other resources it has to offer.

## **9. Conclusion.**

This project has delivered on its original proposal and successfully created a dedicated telephone helpline for people in pain – on the waiting list for specialist NHS Pain Management Clinics in

NHS Forth Valley. Apart from feedback from the Clinicians about the service, all the expected outcomes of the project were achieved:

- People feel empowered to tackle the broader problems of daily living.
- People feel empowered with supported self-management advice including signposting: providing information about understanding pain, activity management and dealing with emotional distress to prevent further decline in function.
- People are better able to make the best use of NHS pain services when they leave the waiting list.

If the project had lasted longer, it would have had a greater impact, and helped more patients on NHS Forth Valley's waiting list for pain management services.

In addition to replication of innovative methods to obtain feedback from callers about a telephone helpline, this project has been unique on several fronts. Firstly, it has been a resource available as a source of help to people without access to computers and IT systems.

Secondly, it has provided immediate feedback from callers about the benefits of a helpline service in terms of callers' management of their pain. Thirdly, the project has confirmed that call handlers with their lived experience of pain management and insight into pain treatments have provided added value to the service. Last but not least, 5 callers were seen more quickly by the Health Board as they were so distressed call handlers were concerned about them.

This project has been so successful because of the co-working and collaboration with NHS Forth Valley. Thanks are extended to them for having the foresight to agree to partner with Pain Concern and work together to help patients in their pain management waiting list. The openness of NHS Forth Valley to share information about their waiting lists and agree to publicising outcomes relating to their new and return patients has been fundamental to the success of this project. Additional benefits of the project have accrued from joint work that was done with Pain Concern in terms of publicising Pain Concern's resources, and the charity gaining insights and knowledge about local groups and primary and secondary care services.

Special thanks to Sigrun Groves-Raines for her tireless and positive commitment to the project.

**Dr Linda Pollock, Primary Care Consultant, Smeaton House, Inveresk, EH21 8PR**

**Contact: [linda.pollock5@btinternet.com](mailto:linda.pollock5@btinternet.com) Or 0131 665 2940**



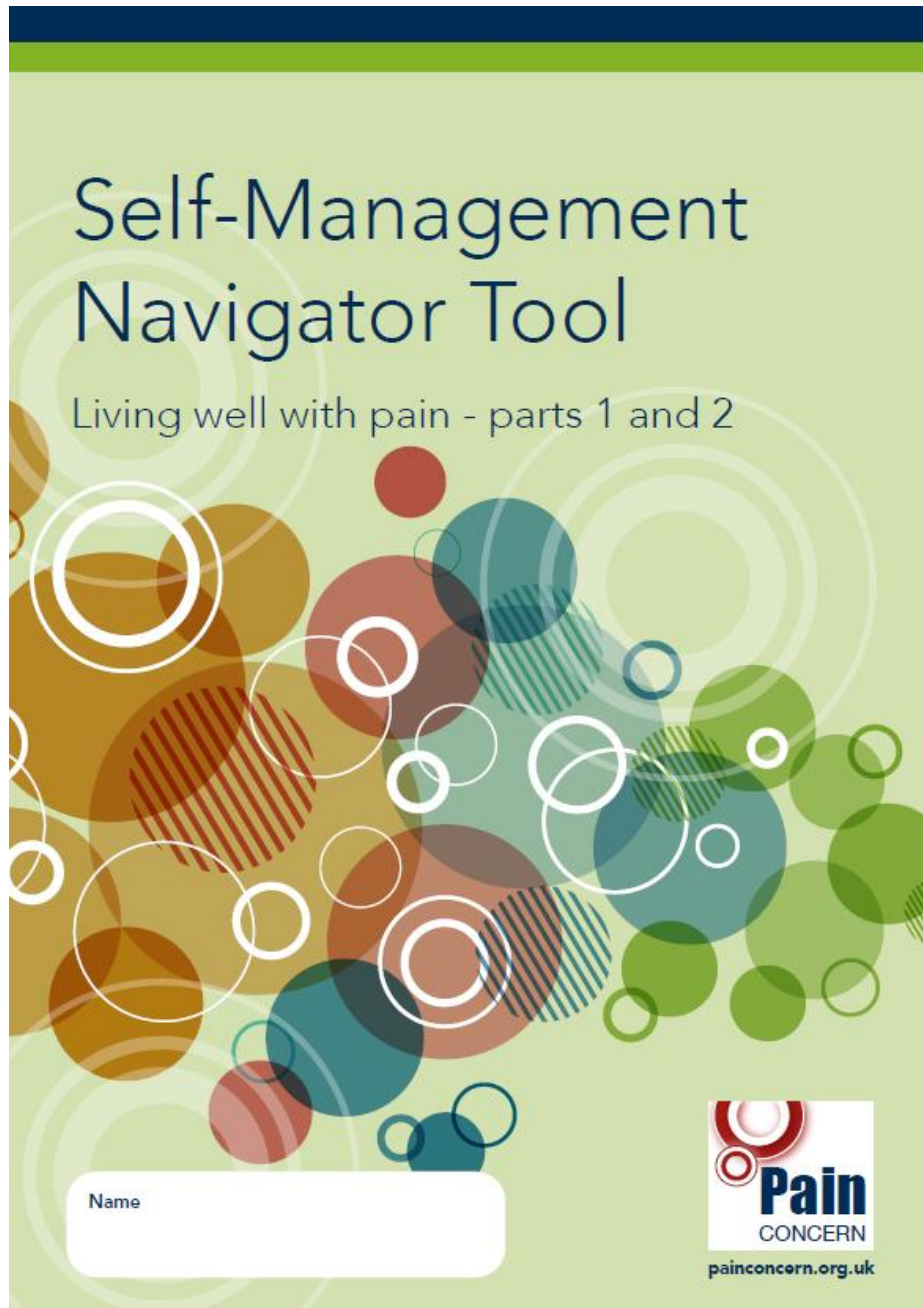
Appendix 1:**FINAL ACCOUNTS FOR THE PROJECT****Pain Concern NHS Forth Valley Waiting Times Helpline Project**

	<b>BUDGET</b>	<b>ACTUAL</b>
Helpline call handler's payment	£4,000	£2,321
Phone, printing, distribution, marketing, publicising results	£1,900	£3,249
Administration	£1,000	£1,030
Helpline supervisor's salary	£3,000	£3,300
Independent Evaluation	£1,200	£1,200
<b>Total</b>	<b>£11,100</b>	<b>£11,100</b>

Appendix 2:

**THE SELF-MANAGEMENT NAVIGATOR TOOL**

**(SENT TO ALL CALLERS THE TO HELPLINE)**



Appendix 3:

**THE FLYER CO-PRODUCED FOR THE PROJECT**

## - TO STIMULATE USE OF HELPLINE

# IN PAIN?



## ON THE WAITING LIST FOR THE PAIN MANAGEMENT SERVICE? NEED HELP RIGHT NOW?

### We will:

- listen
- support

### We can help you:

- ways to live well with pain
- resources that matter to you
- what to expect at your appointment

'I feel listened to and understood.'  
- Patient

Phone

**0131 563 9011**

Email

**support@painconcern.org.uk**

A confidential helpline and email service provided by Pain Concern in collaboration with NHS Forth Valley Pain Management Service.

Pain Concern is a registered charity no. SC023559, company limited by guarantee SC546994

### Understanding

Knowing about your pain reduces concern, increasing your confidence in movement

### Activity

Physical exercise and stretching can help keep pain under control

### Help

Letting people know how to help makes them feel useful, as you do when you help others

### Relaxation

Practising relaxation techniques eases stress and may reduce pain intensity

### Enjoying life

Socialising and making time for enjoyable activities puts pain in the background

### Pacing yourself

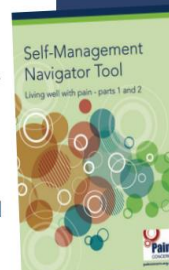
Setting goals, taking rests and breaking tasks into bitesize chunks avoids flare-ups and helps you build up steadily to doing more

### Negotiate

Negotiating with the pain and making appropriate adjustments works better than fighting against it

### Be kind to yourself

Consider if you expect more from yourself than you expect of others



### The Self-management Navigator Tool

A tool to help you and your healthcare professional talk through your concerns and possible solutions

### Airing Pain

radio | podcasts | transcripts  
*Listen or browse through the transcripts*

### Pain Matters magazine

print | digital  
*All about pain and how to live well with chronic pain*

### Helpline

phone | email  
*Information, support or just a listening ear*

### Online community

*A space for people in pain to connect with each other*

### Pain education

Check out our pain education resources at [www.painconcern.org.uk](http://www.painconcern.org.uk) or ask us to post you, free of charge, a set of pain education leaflets



Pain Concern  
62-66 Newcraighall Road,  
Edinburgh EH15 3HS  
T: 0300 102 0162

### Appendix 4:

## NHS FORTH VALLEY LETTERS SENT OUT

## - TO STIMULATE USE OF HELPLINE

**Dept of Anaesthesia & Pain Management**  
**Advanced Physiotherapy Practitioner:**  
**Sigrun Groves-Raines**  
Tel: 01324 567832

Forth Valley Royal Hospital  
Stirling Road  
Larbert  
FK5 4WR



March 2023

Dear Colleague,

*Support for wait list patients with chronic pain*

Please find enclosed flyers and a poster about a helpline and email service. This service is for new or return patients currently on Forth Valley Pain Management waiting list. The helpline is being run by the charity Pain Concern, and is funded by the Scottish Government.

Pain Concern can provide information about the Forth Valley Pain Management Service, and signpost you to resources whilst you are waiting.

Please pass these on to relevant healthcare professional in your practice (doctors, nurses, physiotherapists, podiatrists, occupational therapists) to distribute to appropriate patients.

Yours sincerely

Sigrun Groves-Raines  
Team Lead Pain Management Physiotherapist  
Falkirk Community Hospital

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**Dept of Anaesthesia & Pain Management**  
**Advanced Physiotherapy Practitioner:**  
**Sigrun Groves-Raines**  
Tel: 01324 567832

Forth Valley Royal Hospital  
Stirling Road  
Larbert  
FK5 4WR



March 2023

Dear Patient

*Support for wait list patients with chronic pain*

Please find enclosed a leaflet for a helpline and email service for Forth Valley Pain Management patients who are currently waiting for an appointment.

This is being run by the charity Pain Concern, and is funded by the Scottish Government.

Pain Concern can provide information about the Forth Valley Pain Management Service, and signpost you to resources whilst you are waiting.

We know that waiting for pain management support is hard and urge you to seek help from Pain Concern. Contact details are on the enclosed leaflet.

Yours sincerely

Sigrun Groves-Raines  
**Team Lead Pain Management Physiotherapist**  
**Falkirk Community Hospital**

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## Appendix 5:

# THE EVALUATION PLAN

Forth Valley Helpline Evaluation Plan



<b>Outcome (change or difference you want to make)</b>	<b>Indicators (how you know the outcome is happening)</b>	<b>Methods (how to collect information about the indicator)</b>	<b>Who will do this</b>	<b>When and where info will be collected</b>
1. People feel empowered to tackle the broader problems of daily living.	Improved Tone of voice	Observation via Caller feedback record	Helpline Team	Teams Make a note at the beginning and end of call for Mood
	Mood – SU mood sounds more positive and hopeful.	Observation via Caller feedback record	Helpline Team	Teams Make a note of this at the beginning and end of the call
	Pace of Speech is calmer and slower	Observation via Caller feedback record	Helpline Team	Teams Make a note at the beginning and end of call
2. People with chronic pain (and carers) feel listened to and believed.	"Thank you for listening"	Capturing casual moments via Caller feedback record	Helpline Team	Teams During the phone call
	"I feel believed"	Capturing casual moments via Caller feedback record	Helpline Team	Teams During the phone call
	"Feelings of hopelessness"	Capturing casual moments via Caller feedback record	Helpline Team	Teams Collected at the beginning and end of the call
3. People feel empowered with supported self-management advice, including signposting;	Number of requests for information and resources received	Caller feedback record	Helpline Team	Teams Collected any time resources are sent to service users.

## Appendix 6

# THE PAIN CONCERN LEAFLETS / MATERIAL – EXAMPLES SENT TO HELPINE CALLERS





Appendix 7:

## NHS FORTH VALLEY PAIN MANAGEMENT CLINICAL FEEDBACK FORM

Pain Concern's Helpline for Forth Valley Pain Management Waiting List Patients

Project outcomes are:

- People feel empowered to tackle the broader problems of daily living. ·
- People feel empowered with supported self-management advice, including signposting; providing information about understanding pain, activity management, and dealing with emotional distress; with the aim of preventing further decline in function ·
- People are better able to make the best use of NHS pain services when they leave the waiting list

<b>Patient's Initials</b>	<b>New or Returning Patient (please circle)</b>	<b>Contact with Pain Concern's helpline Yes/No</b>	<b>Did contacting Pain Concern BENEFIT the patient - explain?</b>	<b>Would the patient recommend the helpline Yes/No?</b>
	<b>New or Returning</b>	<b>Yes/No</b>		<b>Yes/No</b>
	<b>New or Returning</b>	<b>Yes/No</b>		<b>Yes/No</b>
	<b>New or Returning</b>	<b>Yes/No</b>		<b>Yes/No</b>
	<b>New or Returning</b>	<b>Yes/No</b>		<b>Yes/No</b>
	<b>New or Returning</b>	<b>Yes/No</b>		<b>Yes/No</b>
	<b>New or Returning</b>	<b>Yes/No</b>		<b>Yes/No</b>
	<b>New or Returning</b>	<b>Yes/No</b>		<b>Yes/No</b>
	<b>New or Returning</b>	<b>Yes/No</b>		<b>Yes/No</b>
	<b>New or Returning</b>	<b>Yes/No</b>		<b>Yes/No</b>

JANUARY 2023