



**Supporting Self-Management of Chronic
Pain; a Collaborative Approach Providing
Relevant Tools to Health Professionals
and People with Pain**

**A project to advance the primary care
management of chronic pain**

**Funded by the Health and Social Care Alliance Scotland
and Edinburgh & Lothians Health Foundation**

Position Paper

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❖ THE SELF-MANAGEMENT NAVIGATOR TOOL

Track Record of Self-Management

Pain Concern is a charity which has a track record of promoting self-management activities for people in pain. It organised Edinburgh's Astley Ainslie Hospital's first support group for people completing the pain management programme. Since 1995, it has run a helpline, manned by trained volunteers with personal experience of chronic pain, and published Pain Matters, a paper-based and digital magazine which focused on pain management skills. Pain Concern's leaflets have been continuously in demand by physiotherapy departments and Pain Clinics across the UK, as well as by individuals with chronic pain. Information on its 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, has created over 100 half-hour podcasts (called "Airing Pain") which inform and support people in pain. Evaluation of the podcasts in 2013, found 80% of listeners were helped by the programmes and over 90% said they would recommend them to others. A further qualitative feedback survey was undertaken in 2017 to evaluate the benefits of "Airing Pain;" testimonials from people in chronic pain demonstrated that broadcasting information directly into homes, with podcasts that are available at listeners' convenience thereafter, are helping people in pain, proactively supporting them and reducing their isolation and desperation. There was a sense that the radio shows were filling a gap in service provision and respondents had lots of ideas about how the programmes could be even more useful for listeners in future.

Primary Care and Self-Management

Supported self-management is a recommended intervention for chronic pain (HIS 2014). Effective self-management should enable an individual to reduce the impact of pain on their everyday life (Long Term Conditions Alliance 2008). Clinical guidelines suggest primary care services have a role to play in supporting self-management of chronic pain (SIGN 2013), and since then, the charity has carried out two inter-related projects which have focused on self-management of pain in the primary care setting.

The first project, from 2014-2016, examined the barriers to self-management of chronic pain in primary care. This was a qualitative study using focus groups in locations throughout Scotland. Eighteen focus groups were held with patients and HCPs (healthcare professionals). Fifty-four patients, nine carers and thirty eight HCPs attended the groups (Gordon K et al 2017). A key finding from this study, also known as the Barriers project, was that primary care services needed to be designed to address the barriers identified.

Development of a self-management Navigator Tool

As a result of this first project, over 2016 and until August 2017, a self-management Navigator Tool was developed to help facilitate communications between healthcare professionals (HCPs), with the intention of advancing the primary care management of chronic pain. The initial version of the self-management Navigator Tool was subjected to feedback from people in pain and GPs through an online survey. A survey was completed by ten people with pain and seven GPs (a response rate of 26% and 44% respectively) – Pain Concern (2015). The feedback was generally positive: “as a gold standard I think it is excellent” (GP); “this would be a fantastic tool to use with my GP” (person with pain); all the HCPs interviewed said that they would use the tool and it would be beneficial to help them support self-management: “if we can get it to work then it has the potential to work very well.” Accordingly, an independent agency (Work4Me), was recruited to organise a stakeholder/feedback event in early December 2016. This was held to improve the Navigator Tool drawing out its strengths and weaknesses, and refine the layout of the paper-based part of the intervention in readiness for a feasibility project aimed at testing out use of the self-management Navigator Tool in the primary care setting. Healthcare professionals and people with chronic pain attended and were fully involved in this Stakeholder Event (9 people in pain and 10 healthcare professionals).

Work continued on the design and production of the Navigator Tool, through until August 2017. The process took longer than anticipated because the text of the tool was approved by the Plain English Campaign. This means that the tool has a Crystal Mark and can be understood by a person with a reading age of 11. This is an important addition to the toolkit in line with the national push for taking ‘health literacy’ into account in health provision.

The penultimate versions of the self-management Navigator Tool were shown to the Thistle Foundation, and various stakeholders within Pain Concern gave feedback on drafts; thus the charity was given assurances, and were as confident as they could be, that the final tool would be well received by patients and healthcare professionals, and also, easy to use. Thus, although time consuming, the development phase of the Navigator Tool was essential - to gain face validity for the tool, the interactive document, that was to be used by HCPs and patients during primary care consultations. Such thoroughness was needed to create and produce a professionally credible self-management Navigator Tool of a high standard. The final Navigator Tool used in Pain Concern’s second project is described as follows:

The Navigator Tool is a five-page booklet given to patients with pain prior to their primary care consultation to inform and prepare them for their forthcoming visit. The tool is built around the themes of *Medications*, *Changes to My Life*, *Diagnosis and Cure*, and *The Way I’m Feeling*. The tool contains an instructions page describing its four parts, and how they can be used.

The first part is the ***My Pain Concerns*** form which is divided into four sections, My Medications, Changes to My Life, Diagnosis and The way I’m Feeling, each of which contains statements of 5 common concerns. The patients are prompted to tick ‘agree’ or

‘disagree’ to each statement, and then choose the three most important ones to bring to their consultation.

The following part, *Questions to Ask Your Healthcare Professional*, links each of the concerns with two to three suggested questions, to help patients articulate their concerns.

The third part is *a Self-management Options Grid* which explains common self-management strategies in plain English, which are colour-coded to match the identified concerns.

The last part is *a Goal Setting Sheet* to help patients make a plan of how to action the identified self-management techniques in practice and manage their pain.

The self-management booklet, entitled “The Navigator Tool: Living Well with Pain” (Pain Concern 2017) is available from Pain Concern’s headquarters.

The feasibility of using the self-management Navigator Tool.

Pain Concern’s follow-up project, Bloomkvist et al 2018 - undertaken from 2016 until September 2018 - continued the charity’s interest in self management and supporting people in pain; it examined the feasibility of using the self-management Navigator Tool with a small number of HCPs, and patients with chronic pain, in the primary care setting, within Scotland.

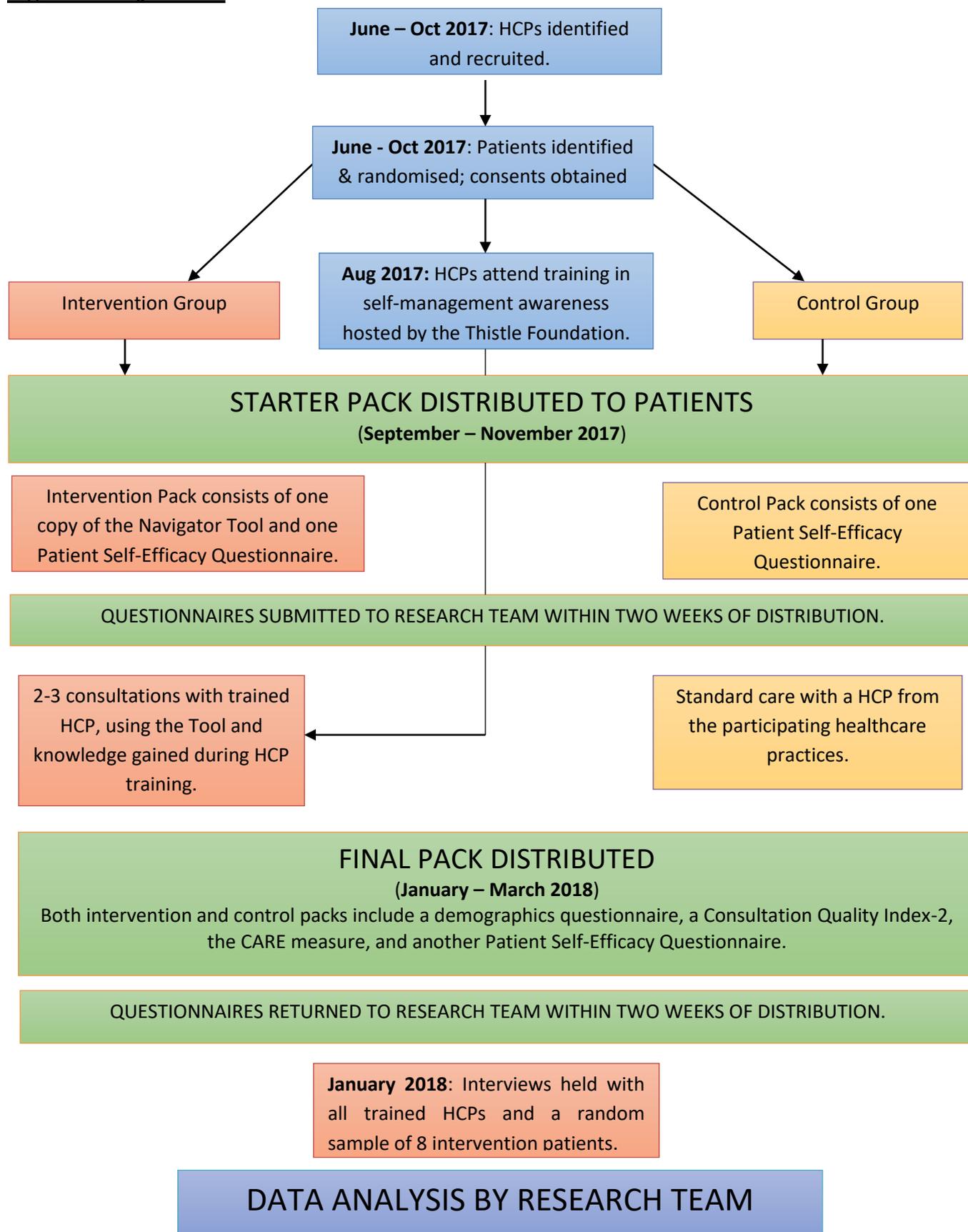
The project was aimed at ‘supporting self-management in chronic pain: a collaborative approach providing relevant tools to healthcare professionals and people with pain’.

It was anticipated that an intervention would be developed and piloted to overcome barriers to people with chronic pain getting support with self-management from primary care. The intervention combined two approaches – training for primary care HCPs and use of the self-management Navigator Tool as an interactive document, for use during consultation – with the HCP and person with pain. Specifically, the aims were to:

- Ensure each Healthcare Professional (HCP) consultation was focused on the concerns which the people in pain wish to discuss.
- Prepare people in pain for their consultation, empowering them to be a partner in their consultation not a recipient.
- Facilitate self-management discussions at the start of the chronic pain journey.
- Encourage adoption of the bio-psychosocial model of healthcare.
- Train healthcare professionals in skills to support self-management and make the best use of their time during the consultation.

By improving the relationship between people with chronic pain and primary care health professionals, the intention was to support, facilitate and promote self-management as a valuable and effective means of reducing the impact of chronic pain on everyday life.

The study was always conceived to be small scale.

Figure 1: Project Plan

Design of the project

As shown in Figure 1: Project Plan, the Navigator Tool was tested in a randomised controlled trial with HCPs and patients, obtaining quantitative data from pain self-efficacy, satisfaction with consultation and participation in decision making measures. Data from control and intervention groups were collected and compared. Qualitative data via feedback forms and interviews assessing the usability of the tool were analysed with a focus on patient satisfaction.

The measurement tools had been used in previous pain studies. The flow chart (Figure 1) summarises the use of the different methods of and timings of data collection, and illustrates the complexity of the project and the organisational demands required to complete it.

Two GPs, a physiotherapist and two pharmacists comprised the five HCPs that finally agreed to take part in the study. To be eligible for the pilot, patients had to be over 18 years of age and have pain for over three months: thirty five patients were recruited into the study; 18 used the Navigator Tool with a HCP. All the HCPs and eight patients who used the Navigator Tool took part in semi-structured interviews which collected information about how the tool improved communications regarding supported self-management during primary care consultations. Fifteen patients also completed feedback forms specifically designed to gather information about what parts of the tool were of most use, their opinion of the toolkit, its impact on their communications and specific suggestions and comments on improvements that could be made to the Navigator Tool itself.

Limitations of the Project

From the outset this project was designed to attempt to link outcomes with inputs i.e. use of the Navigator Tool with measurable benefits to people in chronic pain. Ultimately, the project did not have the conditions sufficient to establish a link with use of the tool and any patient outcomes. The different measures selected for use in this project were easily completed by participants but the quantitative data accrued were too few to be analysed meaningfully, and regretfully, biographical data were not collected to link perceptions of the tool with other variables. The small numbers of HCPs and patients limit the generalisability of the findings. The participants who agreed to take part in this project may have been a self-selecting group; it is unknown how typical the HCPs are compared with others caring for patients with chronic pain, or indeed how typical the patients were of others in that group. The reader must bear these factors in mind when considering the findings presented below.

Nevertheless, the project has shed light on the practical use of the self-management Navigator Tool – in the primary care consultation setting, and on the training that supports its use. The qualitative feedback comments, from HCPs and people in pain (for more than three months),

give an early indication about the value of the self-management booklet; this is essentially a subjective judgment of worth varying with the viewpoints and roles of the evaluators.

Development of Training for Primary Care HCPs

The Barriers project had been advised by leading experts in the pain management field that although HCPs may want to support self-management, doing so effectively in time-limited appointments requires both skills and knowledge in consultation techniques that foster a particular conversation. It was thought that preparing patients for a primary care consultation was not considered enough, and that HCPs needed to be prepared in advance to use the Navigator Tool with patients. A key component of the follow-up project then was to pilot and obtain feedback about such HCP training.

The Thistle Foundation were chosen partners because of their track record and commitment to the adoption of the bio-psychosocial model of healthcare, and work began to develop the HCP training in February 2017; it was focussed on equipping HCPs with consultation skills and knowledge to promote self-management in primary care, covering the following topics:

- The House of Care Model, explaining the different parts of this model and how the Navigator Tool supports this system through introducing pressing self-management concerns early in the pain journey.
- Consultation styles that move away from the medical model of “doctor-telling patient” to patients speaking more than the doctor, to enable Care and Support Planning
- EPE: Elicit-Provide-Elicit – consultation style practice using questions from the tool
- EARS: Elicit-Amplify-Reinforce-Summarise technique
- Agenda setting
- Working with specific questions from the tool to practice the above techniques.

In summary, the final training session (delivered in August 2017) centred on exploring self-management, moving away from the medical model and encouraging people with pain to do the same. It was anticipated that this training would be key to bringing about change in the way chronic pain was managed, as the intention was to advocate the House of Care Model which would offer person-centred care rather than the default of offering medical solutions. Feedback about this training was obtained via semi-structured interviews with the HCPs.

Findings

This project was designed to examine an intervention to overcome barriers to people with chronic pain getting support with self-management from primary care. Specifically, the intervention combined two approaches – training for primary healthcare professionals, and a Navigator Tool (an interactive document, for use during consultation).

Training for Primary Care Healthcare Professionals:

In relation to use of the Navigator tool, the HCPs reported to a certain extent, that the training organised by the Thistle Foundation to equip HCPs in skills to support self-management and making the best use of their consultation time was positive. The interview data suggested

that the training was beneficial to HCPs by allowing them the opportunity to reflect on their own practise, and that the session was well put together. Overall it can be said that HCPs' confidence in raising self-management issues with their patients improved: this aspect of consultations seems to have been enhanced despite HCP's reporting at interview that the training did not provide them with new skills.

Although only a very small number of HCPs were trained about the purpose and use of the Navigator Tool, they made suggestions about future training: they wanted more specific guidance on the self-management Navigator Tool, and clearer instructions on how to use it. A few HCPs also desired follow-up, and suggested that peer support during use of the tool would have been useful to share ideas and experiences or to have follow-up sessions to share best practice to develop skills.

The benefits of the Navigator Tool:

This latest project done by Pain Concern provided a valuable insight into the use of the Navigator Tool in primary care and identified how self-management for people with chronic pain can be improved. It found that the benefits of the self-management Navigator Tool are that it helps people in chronic pain and their HCP to:

- see the bigger picture of the pain condition;
- facilitate engaged, efficient consultations;
- highlight a range of self-management strategies; and
- facilitate encouragement, planning and hope.

It is clear from the feedback comments that the tool helps deliver more person-centred care, and, with the caveat that the numbers in this project were small, the pilot found that some patients were enthused by using the Navigator Tool and found it helpful to reframe how they saw their chronic pain. Patient accounts suggest that the experience of using the tool resulted in a more holistic consultation and topics not raised before were brought to the HCP's attention. Consultations were seen as more focused and conducive to relationship building by both HCPs and by patients, and helped the HCP take stock of a patient's progress, often focus on the positives, and signpost appropriate services more quickly.

Application of the Navigator Tool by the HCPs:

Each HCP adopted a different style of using the Navigator Tool: the physiotherapist consistently followed the structure of the tool for each patient; one of the pharmacists photocopied parts of the tool (for use with patients not in the study). Of the two GPs in the project, one used the tool to prepare in advance for patients, the other, used the Navigator tool flexibly to guide their consultation discussions. The tool then was variously used by them. Some HCPs suggested that the parts be separated to allow relevant parts to be given to the right patients.

Not all HCPs valued the tool unreservedly; it was stated that the tool could be a distraction and that it was challenging to fit it into the consultation time. Interviews with HCPs indicated that goal setting was already part of routine practice at some of the sites, so the use of goals may not necessarily be prompted by use of the tool.

Application of the Navigator Tool: people in pain:

In relation to using the Navigator Tool, the patients did not all use the tool at home, as intended, to prepare them for the primary care consultation. In some consultations, the HCP's guided their patients in use of the tool. Nevertheless, 11:15 patients who completed 'patient feedback forms' said they had been given comprehensive information to use the tool, and, that it provided them with information that they could use at consultations to talk about their self-management. Importantly too, just over two thirds of patients reported that using the tool improved their communication with their HCP with over half saying 'very much so'. All but one patient reported the tool easy to use, ½ claiming 'very much so'.

The answers from the 'Patient Feedback Forms' (completed by 15 patients in the project) indicate the value of different parts of the Navigator Tool to people with chronic pain. It showed that the ***My Pain Concerns Form*** was the form most frequently used during consultations (14/15), closely followed by ***the Goal Setting Sheet*** (13/15). The ***Questions to Ask My HCP*** part of the tool, was also frequently used (10/15) and just under half of the patients, (7/15), reported use of ***the Options Grid***.

What were the patients' attitudes towards the Navigator Tool's length, ease of use and content? Two thirds of participants reported that the length of the tool was "just right". The interview comments suggested that some parts of the tool seemed lengthy (such as the Options Grid) while others seemed too simplified (like the Pain Concerns form). The tool was not always seen as necessary e.g. patients satisfied with their medication, whose pain did not impact on their daily life, or who already had good communications with their HCP. Not all the eligible patients then - with pain for over three months - found the tool useful.

Conclusions and next steps

It is noteworthy that the HCPs and patients in this project found use of the self-management Navigator Tool in primary care consultations beneficial (see above). The result was more person-centred, holistic care provision which was positive, efficient, targeted and timely.

The place of self-management training and the use of the Navigator Tool are stimulating discussion and debate within the pain community and amongst self-management proponents in the third sector. The early indications are that the tool has the potential to change the perceptions and practises of primary care clinicians and empower people in chronic pain. Different patients found different parts of the Navigator Tool useful and the project obtained feedback about the usefulness of the different parts of the document from the patient perspective. In conclusion, the HCPs advocated that different parts of it could be used for different patients. The tool then, if used flexibly, was seen to be helpful and could make a positive difference to the patients with chronic pain presenting to primary care.

As a result of this project, dedicated resources for people in chronic pain have been created by Pain Concern and these fill gaps in the material and tools available to enhance the self-management approaches available to people in chronic pain in the primary care setting. An 'Airing Pain' radio programme and podcast has been produced on the value of the tool from the perspective of the participating HCPs and patients. Videos to accompany the tool have been created and additional information on its website - about conducting a good consultation

- will undoubtedly help encourage people with pain to successfully manage their life through overcoming barriers to obtaining the best help from their doctors, and primary care HCPs.

Discussion is ongoing with experts in the pain management community about the way ahead. The use of the self-management Navigator Tool and option of putting it in downloadable format for patients and HCPs to use as they wish, without formal training, is being explored. The challenge will be to maintain a dialogue with users to capture data in future about how the tool empowers people in chronic pain to constructively interact with HCPs to meet their needs, enhance their health literacy and abilities to self-manage their pain. The self-management toolkit is at the stage of readiness for further testing. Such work is needed to ascertain if the Navigator Tool could actually be transformational in primary care, and make a major difference to the care of people with chronic pain.

Feedback Received

Feedback received from HCPs and patients using the tool

Enables HCPs and patients to see the bigger picture of the pain condition:

“From a medical perspective we’ve got to work reasonably hard to help patients to understand that there is a psychological element to pain, just simple concepts like that are hard to get across sometimes. But I think the tool quite effectively did that on its own.” [GP]

“...opened up areas that might not naturally come up in a routine consultation” [GP]

Highlights a range of self-management strategies:

“I felt that the patients were taking ownership of the tool. So even though I’d been to these motivational interviewing courses that were all about how it’s you as the HCP leading the patient, I felt they were leading me.” [pharmacist]

“...one lady is speaking to her boss and managing it herself that way; another lady is going to our community link worker to get help with benefits and money; the other guy has moved to go to the pain service, which is group work which he wouldn’t have cared about until we made a bit of progress.” [GP]

Elicits positive emotions:

“...instead of me thinking of all the negatives, I’m thinking of all the positives” [person with pain]

“...helped me see how much I had come on” [person with pain]

"Rather than worrying whether I was wasting my GP's time, this allowed me to talk about my issues with pain." [person with pain]

Leads to engaged and efficient consultations:

“In some ways the tool is a victim of its own success in that it draws out some of the more difficult things that are relevant to chronic pain and it’s always going to be virtually impossible to constrict those to just a 10 minute appointment [GP]

“It’s a revelation to use something like this in the consultation” [GP]

“It enabled me to think through what I actually wanted to discuss at the appointment. Also in looking through my completed forms with the GP it helped us both see what my concerns were” [person with pain]

I actually felt that my appointment was longer than it usually is. I had no awareness that it was just 10 minutes. I felt that I was given more time” [person with pain]

Feedback received from Pain Concern’s Research Steering Group

“Long-term pain causes so much distress and disability in Scotland today that it’s difficult for people working in the health service to know how to manage it. We use a lot of potentially harmful medicines, and prescribing is often the focus of treatment, for patients and professionals. But the drugs don’t always work and are rarely the only answer. The Navigator Tool - which was piloted in this study - can help patients to understand all the different ways in which pain affects them, and therefore all the ways in which they can be helped or can help themselves. It also allows their healthcare professionals to get a quick, in-depth snapshot of the most important areas to address. Most importantly, it allows an informed and realistic conversation about how we as doctors and pain specialists can work together to improve life with pain.” – Professor Blair Smith

“This report reads really well and a huge congratulations. What come across is a huge amount of positivity especially when you compare it to the dysfunctional consultations described in the original work [Barriers to Self-Management in Primary Care].” – Dr Graham Kramer

The Steering Group Membership:

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Heather Wallace MA (hons), Trustee, Pain Concern (until January 2018)

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