

## **Airing Pain 107: Easing Pain Appointments with the Navigator Tool**

### ***How Pain Concern's Navigator Tool can help focus pain appointments.***

*In 2015 Pain Concern released its report 'Breaking barriers to self-management of chronic pain in primary care', marking the end of the first part of its 'Breaking Barriers' project. Its aim was to highlight the commonly occurring barriers that patients faced during one-to-one appointments with healthcare professionals, and to advance the primary care management of chronic pain.*

*Phase two of the project was to produce a 'Navigator Tool' to break down those barriers and to prepare patients and GPs to allow them to make the most of their appointments. Phase two is now complete, and in this edition of **Airing Pain**, Paul Evans speaks to the researchers, patients, and healthcare professionals who allowed this project to happen.*

*Renée Blomkvist, Pain Concern's researcher heading the project's second phase, explains the established barrier in phase one, as well as the methodology used in preparing the 'Navigator Tool'.*

*Paul speaks to GP study participant Dr John Hardman, who has a particular interest in chronic pain, about his experience piloting the tool and how he found it allowed both patients and GPs to better focus their appointments. We then visit the University of Dundee to hear from the Scottish Government's Lead Clinician on Chronic Pain and member of the research steering group, Professor Blair Smith, who explains his views concerning the role the 'Navigator Tool' could play in helping people conceptualise and discuss their pain.*

*At St. Triduana's Medical Practice in Edinburgh, Lucy and her GP Dr Louise Bailey talk about their experiences using the tool. They discuss how the practice is trying to use supported self-management to further help its patients deal with their pain.*

**Paul Evans** : This is *Airing Pain*, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain and for healthcare professionals. I'm Paul Evans.

**Louise Bailey**: It's a revelation, to use something like this in the consultation.

**Lucy Murphy**: I actually felt my appointment was longer than the normal 10 minutes. I felt that I was given more time.

**Evans**: In 2015, Pain Concern published its report 'Barriers to Self-Management of Chronic Pain in Primary Care'. It marked the end of phase one of its 'Breaking Barriers' research project, funded by the Health and Social Care Alliance and Edinburgh and Lothians Health Foundation.

You can find all the details of the project, including our series of self-management videos at [Pain Concern](#).

Having identified the barriers to self-management of chronic pain in primary care, phase two was to develop and pilot a 'Navigator Tool' to prepare patients and their healthcare professionals for their consultations. This phase is now complete.

Renée Blomkvist, Pain Concern's researcher for phase two, will now remind us of what those barriers identified in phase one were

**Renée Blomkvist**: After interviewing health care professionals, their patients and carers from across primary care they described the barriers as themed around the consultation, patient experience, limited treatment options and organizational constraints. For example, during the consultation, individuals often found that the timing of the self-management discussion, and the communication within this discussion, was challenging. Even though the study found that both parties wanted to discuss self-management, it was something they both found difficult to talk about. Patients expressed that they sometimes wanted to speak about self-management but observed that the healthcare professionals were not up to speaking about it and likewise the healthcare professionals found it awkward to bring this up with patients. The 'Navigator Tool' therefore tries to bridge this perceived gap in communication by preparing both parties for the conversation.

**Evans**: How did you do the research? Who were your subjects?

**Blomkvist:** We wanted to try out the 'Navigator Tool' broadly in primary care. So we used two GPs, two pharmacists and one physiotherapist and they in turn recruited a handful of their chronic pain patients (roughly any patient who had experienced pain for over three months). We instructed the healthcare professionals to ask these patients whether they wanted to participate in the study and we ended up with a sample of thirty five patient participants.

We wanted a randomized control trial structure; this meant that half of the participants would not receive intervention, so that we could compare the results between the two groups. Around sixteen and seventeen patients used the tool.

We administered some questionnaires to them which sought to measure their confidence in pain management, their perceived shared decision-making (how much they felt that the health care professional was enabling to them and letting them share in their decisions) and the consultation quality index; a holistic marker for how enabling healthcare professionals are perceived to be by their patients. We also had a feedback sheet that was specifically feedback about the tool itself asking:

- How easy was it to use?
- Was it too long?
- Which parts did you use?

We asked for specific comments as well:

- How can it be made better?
- What did you like about it?

I also did eight interviews with a random selection of patient participants across the sites and I interviewed all the healthcare professionals as well, in order to get a more in-depth and individualized understanding of what they thought of the 'Navigator Tool' and how they used it.

**Evans:** John Hardman is a GP in Dunbar on the east coast of Scotland. He has a special interest in chronic pain and was one of the GPs involved in assessing the 'Navigator Tool'. So John, explain what the 'Navigator Tool' is?

**John Hardman:** The 'Navigator Tool' a document that is designed to help health professionals and patients to understand the range of treatment options that are available to them, to help them with chronic pain and to help focus the professional consultation in a way

that aids both the professional and the patient in understanding the many complex factors which can contribute to chronic pain problems.

**Evans:** I've got the 'Navigator Tool' in front of me. It starts with a questionnaire, is this to be done by the patient or the doctor?

**Hardman:** The way I've used the tool is to post it out to the patient prior to the consultation, which is different from how most GP consultations work where the patient comes in fresh and describes their problem to us. By posting the 'Navigator Tool' out to the patient this allow them to really think about what's going on before we meet them.

**Evans:** In what way?

**Hardman:** The tool raises a whole range of questions. It starts with some very open questions that ask patients to think about how pain affects them in their life and different elements of their life that it might be affecting. Then, it asks some more focused questions, prompting patients to think about whether they might have other issues surrounding their medication, their mental health or activities of daily living that are impaired by their pain.

**Evans:** Considering how the tool could be used. Suppose I came to you as a patient with chronic pain, would you then say to me: "Right, I've got this form for you – in a week, or a month's time, bring the form back to me and tell me what's on your mind".

**Hardman:** Absolutely. Another option is that some GPs may be able to go through their list of patients, who are coded with chronic pain, identify the ones that might respond well to this tool and send it out to them proactively.

**Evans:** How did it work in the pilot you were involved with?

**Hardman:** I went through a list of patients who I knew had chronic pain problems and selected them to ensure that they met the qualification criteria for the study.

**Evans:** Was the qualification criteria just simply 'if you have chronic pain, then you can take part'?

**Hardman:** It required that participant patients not have severe mental health problems that would preclude them from completing the form and engaging in appointments in a constructive way.

They would not be able to have, for instance, a severe learning disability and they would have to be able to read and speak in the English language to be able to use the tool. But these are all factors that could be overcome if the tool is developed further.

**Evans:** Thankyou GP John Hartman.

Blair Smith is the Professor of Population Health Science at the University of Dundee. He's a consultant in NHS Tayside's Pain Service with most of his clinical career spent as a GP. He was part of the steering group behind the 'Navigator Tool'.

**Blair Smith:** Chronic pain is a very complex condition, it's difficult to understand, let alone to explain and this is true both for patients and professionals. Where I see one of the main roles of the 'Navigator Tool' is in allowing patients time to reflect on how this complex condition affects them in all the multi-dimensional ways, and to give them a structure and language to conceptualize this and allow an understanding of that to the healthcare professional. It work the other way round too, because the time that a GP has to discuss chronic pain with a patient, consulting them is very limited and so maximal time efficiency is beneficial to both parties. The 'Navigator Tool' has the potential to provide that.

If you've got chronic pain, you don't understand precisely what's going on, you are aware that so much is going on and it's all going around in your head. I know this because I've experienced it personally and it's difficult to express or understand. The 'Navigator Tool' enables you to pull these separate entities in and to attach labels to them and also to let you see that these are common things that people who are in similar situations to you experience. Therefore, it's perfectly ok for you to consider them as part of your condition. Then you can begin to formulate your conversation with your healthcare professional.

**Evans:** What sort of things are on the minds of people with chronic pain, before they've been taken into the system, if you like?

**Smith:** My main experience is that they probably *haven't* given it a great deal of thought. People are aware that they have a painful condition and they come to the GP requesting it to be got rid of, without necessarily consider what aspects of it are causing the greatest

problems, what aspects are amenable to being mended and what may be more appropriate to come to terms with, understand and move ahead with managing. The effect of this lack pre-consultation thought is that the patient comes to the GP expecting to get a tablet and go away with their condition 'mended'. Equally, the GP, because that's the easiest thing to do in a ten minute consultation, will very often prescribe a tablet and say "go away", perhaps they might say "come back", perhaps they might not.

I think one of the advantages of the 'Navigator Tool' is that it helps to emphasize that medicines, so-called "painkillers", are only one part of the overall treatment strategy. They rarely cure the problem, they're called painkillers, but they rarely kill the pain. Painkillers don't address all the other important aspects of the pain, for example the psychological, the self-management, the movement, exercise and activity and coming to terms with having a long-term condition. Unless all these things are addressed, whether or not there is painkiller prescribed, the chronic pain is rarely going to improve.

**Evans:** Thankyou Professor Blair Smith. Lucy Murphy has had chronic fatigue and pain for around ten years. Her GP at St. Triduana's Medical Practice in Edinburgh is Dr. Louise Bailey.

**Louise Bailey:** We've done a lot of work in the practice recently thinking about the ways we care for patients with long term conditions. We've looked at all sorts of trying to improve communication with patients in the consultation with patients and really support patients to self-manage their conditions. When the opportunity to be involved with the 'Navigator Tool' came about, it seemed a very natural thing for us to get involved with, it sat well with the ethos of our practice and the way we were trying to support and care for our patients.

**Evans:** So tell me how you use it.

**Bailey:** Well, this was part of a research project so it was done under controlled conditions. Some patients were randomly selected to be issued with the 'Navigator Tool' and they were told to bring that to consultations. We met monthly for normal length appointments within the surgery. Chronic pain patients which were not participating in the study continued to have standard consultations.

**Evans:** So how did you find it to use?

**Bailey:** The document itself is interesting. It has a lot of incredibly helpful, information for patients. I would be a little concerned for some patients whose, health literacy is not quite as good as others as they might find it quite difficult to navigate. Nevertheless it had a lot of useful information. Essentially, where patients came to the consultations and had completed the main page of the document, it really helped set the agenda for the consultation because they'd given thought to what they wanted to discuss prior the appointment.

**Evans:** Lucy, the first part of the 'Navigator Tool' involves you filling out a form...

**Lucy Murphy:** I found that really interesting because it was all the questions that were relevant and it focused my thoughts on exactly what I was coming to the appointment for. So when I was coming to the appointment, I wasn't rambling trying to get across. It wasn't just "Oh, my ankles are really sore this week". Instead, I was homing in more on exactly what was bothering me. Was it that I was unsure about the diagnosis? Was I worried that I was on the wrong medication? It allowed me to look at exactly what I was coming in the doctors to understand.

**Evans:** So it's focused you to come along to the consultation, but were you able to focus on those things before doing this?

**Murphy:** For me, with a long-term condition, sometimes if I get a pain in a different place or a different symptom, I find it quite hard to turn up to the appointment because I feel like "oh it's me, just turning up, being a bit... well *this* has happened now". I actually felt that the 'Navigator Tool' made me focus in on exactly what it was: "right, so that ankle's hurting, *but*, does that mean there's something else wrong? Does that mean my medication's not right? Is this is something I just put up with?" So it allowed me to consider the *reason* for having the appointment.

**Evans:** That's really interesting. I have fibromyalgia as well and it's so easy to go to your doctor and just say "listen, I feel absolutely awful", without actually thinking "what is making me feel awful? How am I awful? Am I just miserable?".

**Murphy:** And "why am I here? What am I asking you to do about it?". Something that came out of this was having a three monthly appointment, which probably isn't good news for the GP, but it was actually quite reassuring that you didn't *have* to have something wrong with

you just to come back and have a five-minute chat about where you were at with your condition.

**Evans:** So you're being treated as a whole person if you like, you don't have to be in a particular state to go to your doctor, it's a continuous process.

**Murphy:** Yes.

**Evans:** That's Lucy Murphy and her GP, Doctor Louise Bailey.

The third part of the 'Navigator Tool' comes under the heading 'Self-Management Options'. Now, the term 'self-management' in itself, if not introduced correctly, could well be one of those barriers to successfully managing one's chronic pain.

John Hartman explains.

**Hartman:** Firstly, we're trying to reframe 'self-management' as 'supported self-management', because a very important aspect this is that you're not on your own, you're doing it with the support of your GP, your physiotherapist, your pharmacist, maybe your counsellor as well and a whole range of different health professionals.

Secondly, broaching the issue of self-management is important. A useful way of doing this is to talk to patients about the obvious thing that patients are often visiting their GP regarding; their drugs, their medicines and how that's helping. For many people who've travelled a long way along the journey of chronic pain management, they might come and see me on a whole range of different drugs and it's usually pretty obvious that a good few of these drugs aren't making any difference at all. Patients are coming in to see me because their pain is bad and they're on a whole bunch of drugs, this pretty much immediately tells me that actually, many of these probably aren't working terribly well.

For many patients, it doesn't take much to have that discussion and say "if all these tablets so far haven't made a difference, we're running out of options, we don't have many other drugs that we can safely try, so what we need to think about are the things that we *know* work". For instance, for chronic back pain, we know that exercise is *the* most effective intervention, far more effective than most drugs.



We know that for most chronic pain, one of the things that really does work is supported self-management, whatever that means for the individual patient and it will mean different things for everybody. So I think framing it in that kind of context, I often see a little light bulb going off just above patients' heads when they realize that actually, there are other things that they could do.

**Evans:** It just seems a shame to me the way you describe it, with patients stacking up on drugs which often don't work, it seems as if self-management should have come *before* that.

**Hartman:** Absolutely, 100%.

**Evans:** Lucy, how did your pain journey start?

**Murphy:** Over ten years ago, I had a flu type illness for over a month, I tried to recover, going back to the gym and things but I just had complete fatigue, I couldn't do anything and so I came along to the GP. She did lots of blood tests and initially diagnosed me with an underactive thyroid, which masked what was really going on. I think it took quite a few months until I got the diagnosis of Chronic Fatigue Syndrome.

**Evans:** How did the management of that start?

**Murphy:** It wasn't a very positive experience. I was simply told I had it, given a printout and that was that really, no more advice than that.

**Evans:** Coming on this trial, or on this research project, was that a changing point?

**Murphy:** I think about a year before, I had been referred to a chronic pain and ME clinic, so that's why I was interested in taking part in this, because I'd already experienced something like it before. I found with the clinic, it was actually talking to somebody, acknowledging the difficulties I was having and them telling me that other people have the same experience as well. That put it into perspective and helped me accept it and start to deal with it more effectively.

**Evans:** Louise, the fact that Lucy had been on a pain management programme, does that mean that she was a member of the converted anyway, preaching to the converted?

**Bailey:** No, I don't think that's necessarily true, because it's a continual process of reviewing and reflecting. What you want to do is try and optimize the quality of life that patients have and I think there were things that Lucy and I had in our consultation, that we discussed, which were very specific to her, her family and her condition.

With some patients that I used the tool with, it actually affirmed the progress they've made and that was a really positive thing, to say "well, actually, we've looked at this and you don't have any concerns in this particular area" and that's really promising.

With one of my patients who was a bit dubious about how helpful it had been, we actually used it as a way to illustrate the progress that she had made in managing her condition. We drew other information out, which I don't think would have come out, without using the 'Navigator Tool'. So that was a very positive and affirming thing, which showed the progress that she had made.

I think Lucy has a huge amount of insight into her condition, but we still managed to look at other areas and consider other things that she might do, which perhaps wouldn't have been drawn out of a standard 10-minute consultation, for which she hadn't prepared in the way she had done whilst using the tool.

**Evans:** Were there patients who it didn't work for?

**Bailey:** The effectiveness for individual patients varies, just as their condition, where they are in self-management, understanding their pain and how best to manage it, varies too. So for some it was, I think, very useful. For some, it was less useful.

As a clinician, I found every contact really helpful. I don't think I have any doubt that for every patient that was engaged in this project, I feel I have a better understanding of their condition and their situation in general, so should they come back in the future to see me, we've gathered a lot more important information than I had before.

One of the great values of my job is continuity and I put a high price on that for my patients. Using a tool like this and then seeing them again, means that you're layering your knowledge and understanding of the patient and their condition, so you can be more effective as a clinician.

**Evans:** The final section of the 'Navigator Tool' is "Goals" and that's where the healthcare professional and the patient agree on the goals are.

**Hartman:** I think that exemplifies the challenge there, because often goal-setting has traditionally been the doctor saying "Well, by next appointment, you've got to do this" but that's not what it's about. Goal setting is about the patient deciding what they want to do, where they want to be, what they want to get out of this and then choosing that as an end point. Then, between the doctor and the patient, working out, "Well, how are we going to get there together?" and deciding something that is realistic and achievable, maybe less than what the patient perhaps expected to achieve in the first place, but which the doctor in their experience thinks: "Yeah, you know we could maybe get there within four weeks or twelve weeks or whatever". Thus setting a goal that is achievable and then working out how to get there.

**Evans:** GP Dr John Hartman.

So, Pain Concern's research project to identify the barriers to self-management of chronic pain in primary care and develop a tool to break down those barriers (that is the 'Navigator Tool') is at a stage where it can be rolled out, albeit with a little tinkering around the edges. Professor Blair Smith.

**Blair Smith:** Ultimately what I would like and part of the education that we would like to facilitate across the whole patient/professional population is that chronic pain isn't necessarily a medical problem. Actually, it's a social problem and it's a psychological problem. What this tool does is, is help people to reflect on that before they come for the ten-minute consultation and it means that some of those previously unrecognized associations, will be recognized, even during the first consultation. It may even mean that if a patient takes this through to its logical conclusion, that they will be able to address some of their most important and challenging issues on their own, without coming to a GP and I would certainly like to see that people who have chronic pain will not necessarily consider the GP as the sole, most important or even the first port of call.

**Evans:** One of the things that came out from the patients results on phase one of the project, which was "Barriers to Supported Self-Management in Primary Care" was that doctors didn't believe them, or at least they think that doctors don't believe them. Now, we've talked about how patients might use this, how would doctors use it?

**Smith:** That's a very good point. I guess there are occasions in which doctors won't believe somebody telling them they're distressed. Though it is perhaps more of a misperception and often a result of, the sense of complicity in seeking and providing analgesia as the most straightforward approach.

It can be difficult for our healthcare professionals to find the language to introduce the concept of self-management, if the patient either isn't, or the GP thinks they're not, ready to engage in a discussion about self-management, because it's a difficult concept to present. Sometimes, the GP might feel that by discussing relationships between pain and modes of thinking or methods of living, that the GP is implying to the patient that it's all in their head. It's a challenging conversation to have at the best of times, but when the consultation time is so brief, it's extremely difficult to have these conversations, to find a common language. That's exactly what this 'Navigator Tool' addresses; providing the common language from the start.

**Evans:** How would you envisage this being rolled out?

**Smith:** One of the things that's clear from what I understand from Pain Concern, is that it's only used by healthcare professionals who have been trained, to some extent, in its use.

**Evans:** Professor Blair Smith.

Here's project researcher Renée Blomkvist again.

**Blomkvist:** The intervention as a whole is actually training for the healthcare professionals and the tool for patients. The training session was preparing the healthcare professionals for the types of questions that the patients would come in with and the types of responses that would facilitate self-management.

**Evans:** In one of your documents, you have terms like, in part of the consultation techniques, "EPE - Elicit, Provide, Elicit, Explore"... what's that?

**Blomkvist:** "Elicit, Provide, Elicit, Explore" - the idea is that if you ask someone on a scale of 1 to 10 "How confident are you in self-management?", then they'll say maybe "2", if they're really unconfident, but then you can ask them why a 2, why not a 1, so there's always something that they know themselves that they're doing well. So, you try and enhance what it is that they already know and then, from what they're already telling you,

you can give them more advice and then that will get the conversation going and you elicit and provide information that way.

**Evans:** So, in layman's terms, I say "I'm miserable". On a miserable scale, I'm 2 out of 10. You would want to know ok, at least he's not 1 out of 10, so could we call that glass half-full and glass half-empty?

**Blomkvist:** Yeah and a lot of people forget that they do have strategies or ways that they are managing their pain, that they are making themselves feel better and they're just focusing on the eight points that are bad, but if you bring the attention to the one point that is *good* that can often help.

**Evans:** Now, I'm obviously talking to the converted here. How do you spread the good news?

**Bailey:** What I now feel using this toolkit in my consultation, is now I need to share this with my partners and for wider use, in a way that is accessible and convenient and easily put within the consultation tools that we have already. So pages from the 'Navigator Tool', I've now saved on the computer, can be printed out if I see a patient with chronic pain, if I want them to come back and give some thought or prepare for an appointment. So that's a very easy way that any GP could allow a patient to go away and think about how the conversation or the discussion will go for a next appointment.

It varies how you use the tool for different patients and one of the things I learned about was that different patients will use different parts of it, in different ways, at different times and so having a flexible tool that you can use for patients when they find themselves in different places or in different situations, adds value to it.

**Evans:** How do your colleagues take that on board?

**Bailey:** Well, I find, as with any clinical change, it's the process of refreshing minds, of discussion and of people using things, of practicing with them. When they get some success with it, that builds confidence and so if there are problems, you identify them and discuss them. We do that with *any* new thing that we implement in the surgery, so I would be hopeful this would be taken up in a similar way.

**Evans:** That's Dr. Louise Bailey.

All the information and resources on the 'Navigator Tool' and the Breaking Barriers project are on Pain Concern's website, which is [www.painconcern.org.uk](http://www.painconcern.org.uk) and you can download all editions of **Airing Pain** from there, as well as from Pain Concern's YouTube and Facebook channels.

Now before I end this edition of **Airing Pain**, I'll just remind you that whilst we in Pain Concern believe the information and opinions on **Airing Pain** are accurate and sound based on the best judgements available, you should always consult *your* health professional on any matter relating to *your* health and wellbeing. He or she is the only person who *knows* you and your circumstances and therefore the appropriate action to take on *your* behalf.

**Bailey:** I've been a GP for over 25 years and the revelation about managing pain 25 years ago was the World Health Organization steps to visualize increasing pain relief, so that you started with paracetamol, anti-inflammatories, codeine and you got stronger and stronger painkillers. As more and more patients have presented with pain, if you adopt that model and you don't recognize the value of the enormous amounts of research that's been done in the management of chronic pain conditions and that the holistic approach to both prescribing, supporting patients and helping patients self-manage, you've absolutely missed a trick.

One of our main jobs as a doctor is to do no harm and what it is really *easy* to do when you see somebody with pain is to give them a stronger painkiller. Actually, I think what the 'Navigator Tool' helped me to do was to look much more effectively at the patient's life, how it was affecting them and how I could specifically support them to make changes.

**Evans:** You and your colleagues are still up against this barrier of 10 minutes for consultation?

**Bailey:** That's exactly right, but the *value* of having a patient who's *prepared* for a consultation and is setting the agenda on arrival, means that those 10 minutes are used to valuably support the patient. The agenda is set by them, not by the doctor and of course when you're managing a long-term condition, it's about what matters to the patient, not the doctor.

**Murphy:** I actually felt my appointment was longer than a normal appointment. I had no awareness it was just a 10 minutes, actually felt I was given more time.

### **Contributors:**

- Dr John Hardman – GP, Navigator Tool study participant
- Professor Blair Smith – Scottish Government Lead Clinician for Chronic Pain, Professor of Population Health Science, University of Dundee
- Dr Louise Bailey – GP, Navigator Tool study participant
- Renée Blomkvist – Pain Concern researcher for the Navigator Tool
- Lucy Murphy – Patient, Navigator Tool study participant

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