

# PainSTORY: Pain Study Tracking Ongoing Responses for a Year



**MEDIA BACKGROUNDER: PainSTORY**

PainSTORY (Pain Study Tracking Ongoing Responses for a Year) is the first study of its kind to track patients with chronic pain over one year, providing in depth insight into how pain impacts the daily lives of patients and the management of pain in 13 European countries.



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Results from the study show that chronic pain has a significant impact on patients' quality of life, highlighting the need for improved pain management.



Patient 21, France 51-55 yrs old

"There are unbearable days... I have to stop...I feel like crying" Patient 10, Spain 31-35 yrs old

## Despite one year of treatment...

- **Six in ten** patients feel that chronic pain **controls their life**
- **95%** of patients report they are suffering **moderate to severe pain**
- **19%** of patients feel that their **pain is getting worse**

## And yet...

- **64%** of patients believe that they are on the **most appropriate treatment**
- **Over half** feel that **everything possible is being done** to help them
- **Only 12%** are being prescribed a strong opioid medication to control their pain

*"I can't get up out of bed because of pain. I have to plan my life around my pain"*  
Patient 23, Finland, 46-50 yrs old

*"I have treatment, I get worse, I get better and then it gets worse... nothing is long term...no solution is provided, I just feel like I'm going round in circles with nothing being done"* Patient 14, UK, 41-45 yrs old

*"I do not understand why I have to be feeling this way and why I have to be in this awful circumstance. If there are so many people feeling the way I do, how come there is nothing we can do about it?"* Patient 28, Spain, 51-55 yrs old

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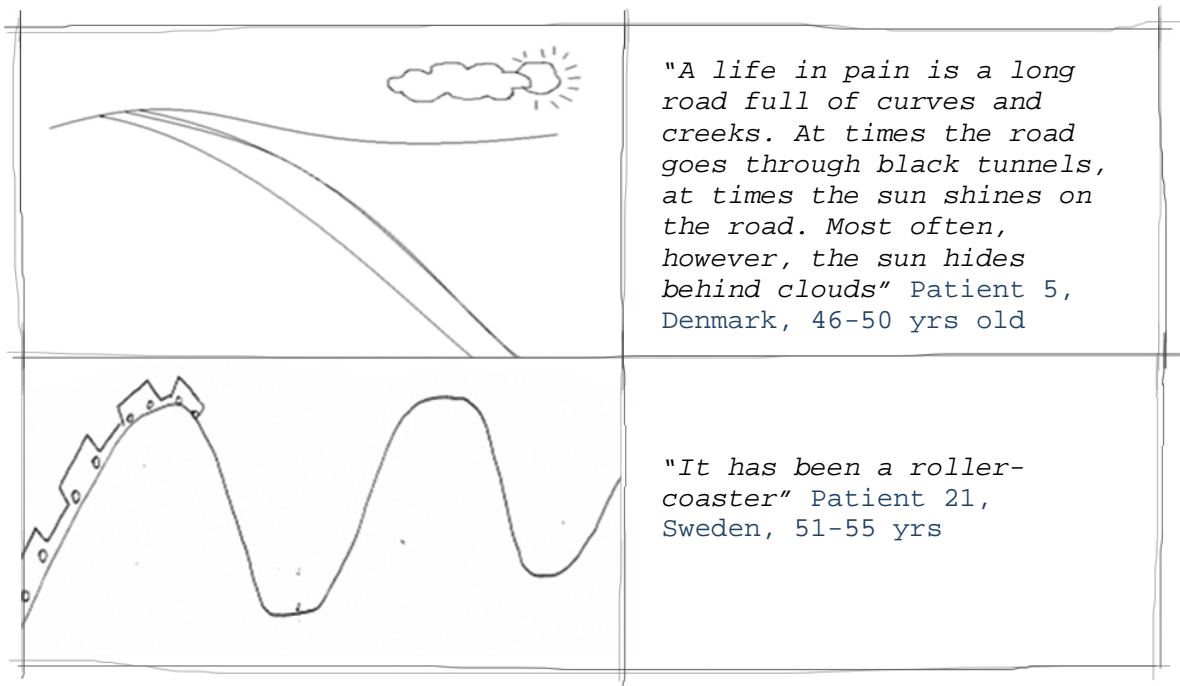
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## A one-year journey through pain

By the end of the 12 month survey, **95%** of patients undergoing treatment reported being in **moderate or severe pain**, with **46%** of this group suffering **severe pain** by the end of the year. For the majority of patients, pain levels had not improved dramatically despite medical intervention for one year.

Although patients' pain remained relatively static throughout the year, daily symptoms of pain fluctuated, leading to frustrating consequences:

*"I can't get up out of bed because of pain. I have to plan my life around my pain"*  
Patient 23, Finland, 46-50 yrs old

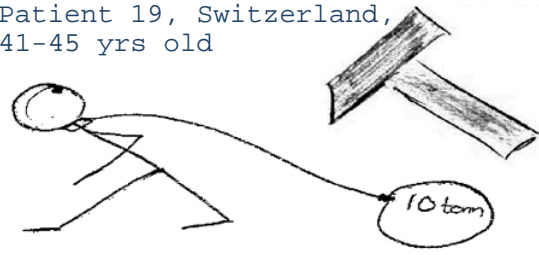


Patients' diaries and illustrations provided a valuable insight into their personal experience of pain. When describing pain, patients most often said that it is an aching and/or stabbing sensation, or something heavy or debilitating.

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<p>Patient 19, Switzerland, 41-45 yrs old</p>  <p>Patient 5, Norway, 26-30 yrs old</p>	<p><i>"It's like the pain you have when you are giving birth and it doesn't stop. It is like a constant physical fight. Sometimes I say 'please help'"</i> Patient 21, France, 51-55 yrs old</p>
	<p><i>"I feel like the pain is too much for me to overcome alone. I feel older because I feel I can't move as freely"</i> Patient 22, Ireland, 18-25 yrs old</p>

## Impact of pain on daily life

The study findings highlight the significant impact that chronic pain has on the daily lives of patients. **Over half** of patients still feel pain has a **'huge' impact** on their daily life at the end of the study with **six in ten** reporting that chronic pain **controls their life**.

**Eight in ten** respondents confirm that their pain has an impact on their **quality of life**, with:

- **64%** reporting problems **walking**
- **30%** reporting problems **washing and dressing**
- **60%** reporting problems **sleeping**
- **73%** of patients reporting problems with everyday activities such as **housework or family/leisure pursuits**
- **44%** **exercising** less because of their pain

Patients also highlight increasing challenges associated with childcare, with **53%** reporting **difficulties in looking after children** at the end of the research compared to **47%** at the beginning.

The survey reveals that pain has a significant impact on patients' ability to work: **65%** worry that their pain will mean they have to **stop work** completely, **38%** claim they have had to **change** the way they work and **33%** have had to **reduce** the hours they work.

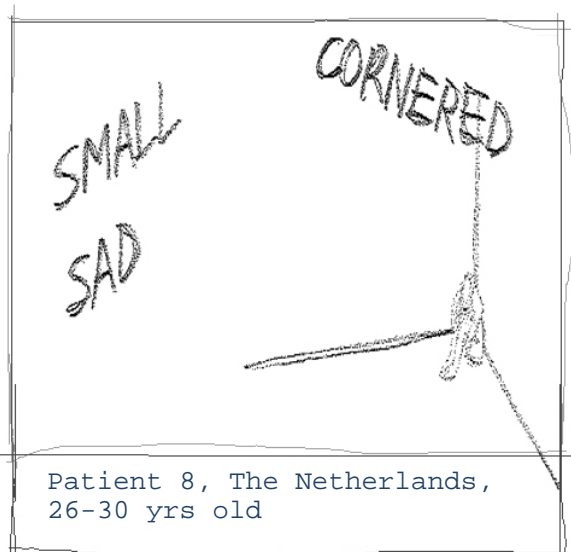
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*"It was difficult to get on with my pain, which was sometimes unbearable. I had to deprive myself of the pleasure of a walk, of shopping around. Moreover, my working life has become more difficult"* Patient 10, Italy, 31-35 yrs old

## The emotional impact of pain



The emotional impact of pain is just as detrimental as its physical impact. Across the year, **44%** of patients report feeling **alone** in tackling their pain and **two thirds** of patients feel **anxious or depressed** as a result of their pain. For **28%** of patients, their pain is so bad that they sometimes **want to die**. Patients report feeling trapped by a pain which may vary in intensity, but continuously affects every aspect of their life.

*"I couldn't interact. The pain trapped me and I couldn't socialise. I felt like a prisoner of the pain"* Patient 1, Spain, 46-50 yrs old

Results also highlight the impact that pain has on relationships with others. **A third** of patients think **people treat them differently** and said they have **fewer friends** as a result of their pain.



*"I close in on myself, I don't want to communicate with other people"* Patient 17, Spain, 46-50 yrs old



*"There is no joy, there is no zest for life. I start experiencing these depressive states"* Patient 4, Poland, 41-45 yrs old

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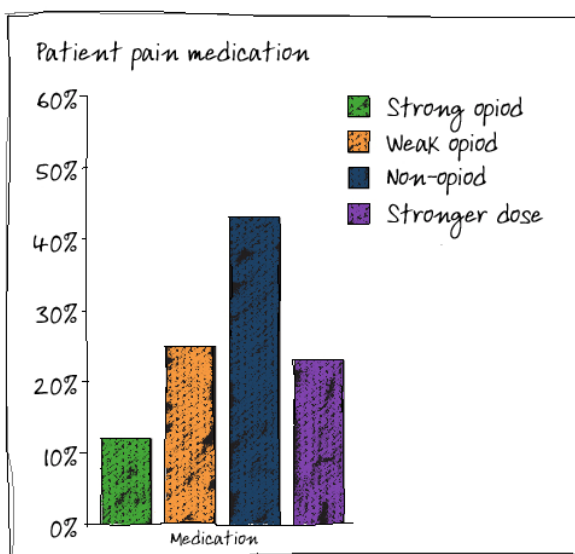
## Patients' experience of healthcare professional teams

The research provides some valuable insights into patients' experience of the healthcare professional team. Even though the majority of patients continued to suffer pain throughout the year, the number of **patients visiting a doctor** declined over the course of the year from **83% at the beginning** of the year to **70% at the end**.

Although **68%** of patients **consistently consulted** a healthcare professional across the year, only **2%** had seen a **pain specialist** consistently throughout the year.

## Patients' experience of pain medication

Despite reporting high levels of pain, nearly half of patients reported that they are happy with their overall pain management, demonstrating an increasing acceptance of pain as a part of daily life.



**83%** of patients are prescribed medication for their pain, but **30%** also have to resort to over the counter (**OTC**) medication to control it.

Despite the fact that **95%** of patients receiving treatment are suffering from moderate to severe pain, only **12%** are being prescribed a **strong opioid** treatment, with **25%** taking a **weak opioid** and **43%** prescribed a **non-opioid** medication. Only **23%** were prescribed a **stronger type** of pain relief over the course of the year.

The survey illustrates **almost half** of all patients report side effects as a result of their medication, the most common of which is **constipation**<sup>1</sup>, experienced by **almost half** of patients, **49%** of whom are receiving treatment with opioids. Although highly effective in controlling pain, opioids can be associated with opioid-induced constipation (OIC).

The research reveals that **26%** of patients taking opioid medication turn to **laxatives** to help relieve their constipation, which may alleviate symptoms but will not address the cause of the problem.

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Results towards the end of the study showed that nearly half of patients were suffering at least one side effect as a result of their prescribed medication:

- **Two thirds** felt **sleepy** and **over half** were **sleep deprived**
- **Over half** felt that their **mood** was affected by their pain
- **31%** experienced **nausea**

When asked about the impact of their side effects, **more than a third** of patients reported difficulties performing **activities** in daily life, whilst **one in five** patients felt that their **side effects have more of an impact on their life than their pain.**

#### One patient's experience of the impact of side effects:

**Tiredness** = falling asleep at the drop of a hat, missing hours in the day

**Wind** = weight gain = depressed, fed up, embarrassed

**Itchy rash** = annoying, drives me crazy

**Forgetfulness** = embarrassed, infuriating, scared, feeling low

Patient 12, UK, 51-55 yrs old

## Recommendations

Commenting on the findings of the survey, Hans Kress, President Elect, European Federation of Chapters of the International Association for the Study of Pain said: "This research presents a unique insight into patients' journey in pain across Europe. It is shocking to observe that one year on, patients are still trapped in an ongoing cycle of pain and a large proportion seem to be losing hope. I urge patients to speak to their doctor if they are experiencing chronic pain or are concerned about side effects and not suffer in silence".

Dr Tony O'Brien, Consultant Physician in Palliative Medicine at Cork University Hospital said: 'This research reveals an alarmingly high prevalence of uncontrolled chronic pain in our communities. This serious public health problem must be addressed as a matter of urgency. Patients suffering pain require comprehensive evaluation and assessment by skilled healthcare professionals. Selected patients will benefit from a supervised trial of opioid medication in order to achieve an optimal level of analgesia, whilst preventing unwanted opioid adverse effects, including opioid induced constipation. The objective is to ensure that patients can experience the best possible quality of life.'

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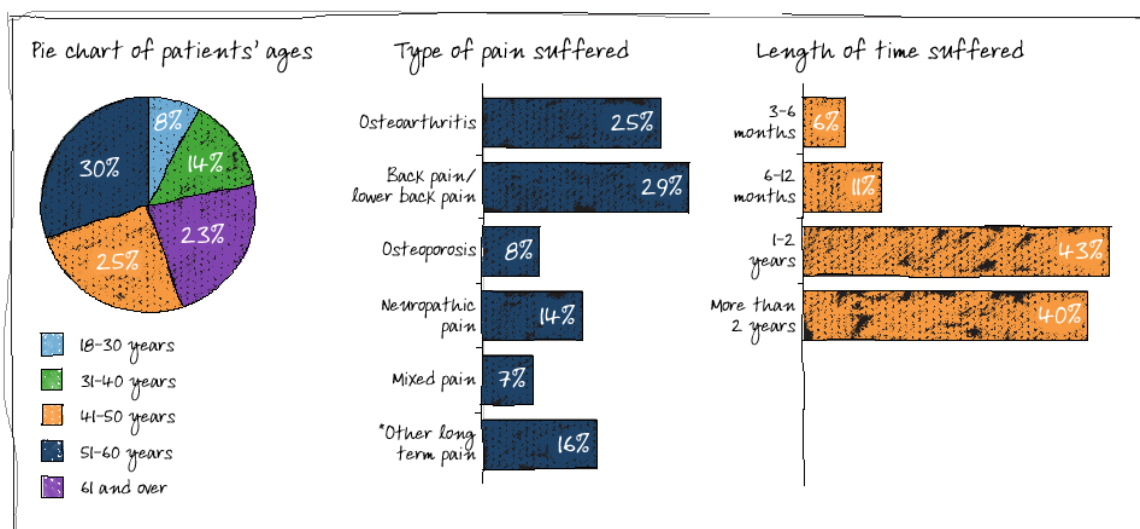
## About PainSTORY

PainSTORY was conducted by an independent market research company in collaboration with a steering panel comprising World Institute of Pain, European Federation of IASP Chapters and OPEN Minds – a group of leading experts across Europe specialising in research and the management of persistent pain – and sponsored by an educational grant from Mundipharma International Limited.

## PainSTORY Methodology

PainSTORY was conducted in the following countries: United Kingdom, France, Germany, Switzerland, Italy, Spain, Ireland, Belgium, Sweden, Denmark, Finland, Netherlands and Norway.

294 patients suffering from non-malignant chronic pain for three months or more completed the survey, with an average daily pain level of  $\geq 5$ -10 on a pain scale at screening stage (where 0= no pain and 10 = the worst pain imaginable) and who had visited their doctor about their pain for the first time in the last two years. At the evaluation stage of the survey, patients' pain levels were ranked as mild (1-3), moderate (4-7) or severe (8-10). All patients were aged 18 or above (see figure below). Patients in the study experienced a variety of pain types including osteoarthritis, back pain / lower back pain, osteoporosis, neuropathic pain, mixed pain and other long term pain (see figure below).



Recruitment processes varied from country to country, and included recruitment via primary and secondary physicians, use of databases, patient associations and advertising in national and regional media.



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The study consisted of four waves of qualitative interviews between April 2008 and May 2009. Interim engagement activities such as diaries and 'life books' were sent to patients between the four waves to provide additional insight. Comparisons between baseline data and subsequent wave results showed how the impact of pain and pain management changed over the course of a year.

In Poland, 25 chronic pain patients participated in one wave of the study, to explore a snapshot view of the current impact of chronic pain and its management in this group of patients.

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