



**Pain Alliance
Europe**



How Europe's Chronic Pain Patients are affected by the COVID-19 pandemic?

PAE SURVEY - SHORT REPORT



Short report - Pain Alliance Europe - an in-depth Survey of Covid-19 and Chronic Pain

The COVID-19 pandemic has had an influence on people with chronic pain just as it has had on everyone in society. We saw this before in the results of the Pain Alliance Europe's survey which was conducted in early 2020. Now with this new and in-depth survey, we have looked more deeply into this subject to find out if there are more noteworthy points to consider.

In this first, short report, we are only highlighting some of the most standout results. The long report that follows will go into more detail.

As we know from past research, the management of chronic pain is based on a bio-psycho-social model. This means that all three elements should be addressed at the same time in order to achieve the best possible care. This survey shows that we are a long way from that. So, there is a lot more work ahead of us.

Some of the first results arising from this survey:

We had 970 replies to the survey which was available in 7 languages: Bulgarian, Dutch, English, French, German, Italian and Spanish. The number of valid answers varies from question to question. Each percentage that we present in this report is referring to the total number of valid answers for that particular question. This number is presented in parentheses.

85.74 % respondents were females and 13.79 % males. (631)

The top three physical conditions that respondents suffered were (953)

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| 1) Fibromyalgia | 34.94% |
| 2) Arthritis, osteoarthritis or other rheumatic diseases | 10.49% |
| 3) Complex regional pain syndrome (CRPS) | 8.50% |

Medication:

79.75% (from 948) were using medication. 93.09% (752) was prescribed and 24.73% (752) was OTC (over the counter) medicines. This means that several respondents were using both OTC and prescribed medication.

25.75% (804) said they think medication is harder to get now.

9.44% (805) reported being afraid to take prescribed medication and 12.11% (809) to take OTC medication.

Top three obstacles or delays reported by respondents: (811)

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| 1) Appointments with healthcare professionals | 67.69% |
| 2) Treatment / interventions | 33.66% |
| 3) None of the suggested | 19.48% |

Top three reasons given by patients for cancelling appointments themselves: (805)

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| 1) Not relevant (i.e. they had no appointment) | 59.13% |
| 2) Don't want to tire them (healthcare professionals) | 10.68% |
| 3) Afraid to go to hospital | 9.69% |

Access to healthcare / services:

Almost half replied finding it 'difficult' to 'more difficult' to obtain healthcare / services.

Top three sources of the patients' pain management: (810)

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|-------------------------|--------|
| 1) GP /family doctor | 50% |
| 2) Self management | 38.77% |
| 3) Not getting any care | 16.05% |

Top three responses to the question of how frequently they were getting therapy: (803)

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| 1) Not relevant (had no therapy) | 37.86% |
| 2) 1-5 per year | 26.15% |
| 3) Once a wee | 12.08% |

Before COVID-19, the top three choices given regarding quality of life (QoL) (from a scale where 0 was no QoL at all and 10 which was excellent - comparing before and during the pandemic:

Top 3 scores re QoL: before the pandemic: (803)			Top three QoL during: (800)	
On a scale of	5	19.68%	4	18.25%
0-10	6	19.68%	5	17.25%
	7	19.05	6	10.00%

The average rating given by the respondents to their QoL before the pandemic is 6.61 which can be considered a satisfactory quality of life. 50% of the respondents estimate that, the level of the quality of life, before the pandemic was between 5 and 8.

Now, during the pandemic the average rating for the quality of life has gone down to 5.15 points and 50% of the respondents had rated their quality of life between 4 and 6 points.

Mood: 2 out of 3 stated their mood was worse to much worse. (803)

Pain intensity: 1 out of 2 stated their pain intensity was 'worse' to 'much worse'. (801)

Pain interference: 3 out of 5 stated now the degree to which pain interfered in their lives was 'somewhat' to 'a great deal'. (801)

Sleep disturbance: 1 out of 2 stated sleep was 'worse' to 'much worse'. (800)

Top three psychological problems caused by the pandemic: (801)

- 1) Anxiety (50.19%)
- 2) Worry (35.46%)
- 3) Insomnia (27.22%)

The ability to speak about these problems with someone: almost 3 out of 10 reported they were not able to speak with anyone about their problems. (796)

Top three choices given by those who were able to speak to someone: (490)

- 1) Family member 41.02%
- 2) Specialist HCP 27.55%
- 3) GP/family doctor 14.69%

Top three worries that were reported re the pandemic itself: (802)

- 1) Loved on becoming infected 53.62%
- 2) Not seeing family / friends 48.00%
- 3) Catching the virus 44.64%

When asked “have these worries increased as the pandemic continues?”: 77.36% answered yes. (795)

Experiencing stigma re having chronic pain: (797)

32.50% said yes, 56.34% said no and 11.17% don't know

Asked if this experience of stigma had increased: (796)

32.29% said yes, 47.11% said no and 20.60% don't know

89.56% reported that their social life had been disrupted. (795)

Top three disruptions to their lives were regarding:

- 1) Close family contacts 23.38% (663)
- 2) Social clubs 17.10% (661)
- 3) Active sports 13.14% (662)

Top three missed social events: (607)

- 1) Birthdays 70.68%
- 2) Others 32.62%
- 3) Funerals 31.30%

Top three challenges to living with chronic pain: (634)

- 1) Underestimation of pain by healthcare professional 47.79%
- 2) Inadequate treatment 36.91%
- 3) Difficulty of accessing correct information re pandemic 29,65%

Regarding exposure to COVID:

18.8% (of the 633 respondents) said they thought that they had been **exposed** to the coronavirus.
46.76% (from 633) had been **tested**, and 7.15% (from 629) had been **diagnosed** with the virus.

54.34% said would take the vaccination when it became available, 11.53% said they would not and the others were not sure. (633)

1 out of 3 thinks or strongly believes that they are more likely to catch the virus. (633)

3 out of 5 are unsure or not confident that their healthcare systems are able to cope with their health issues. (634)

In summary, this survey again indicates that people living with chronic pain need a holistic approach to their treatment. We have seen an increase in the intensity of their pain, the interference that pain makes to their lives, and sleep disturbance. We see a decrease in people's mood. We see the disruption in their social lives, and we observe that nearly 1 out of 4 has no one to speak to about all these things.

We have seen that the top three problems reported are strongly related to each other: anxiety, worries and insomnia. It is therefore very logical that the overall quality of life has decreased by over 40%.

Conclusion:

The COVID-19 pandemic has had and is still having a great impact on the quality of life of people living with chronic pain.