

# Living with Arachnoiditis

## Introduction

Arachnoiditis is a rare and painful disorder resulting from inflammation of the arachnoid membrane surrounding spinal cord nerves. Limited research exists on its symptomology, accurate diagnosis, and patient-reported outcomes, hindering effective management and treatment. Artificial intelligence (AI) and cloud computing offer promise in rare disease research, enabling data analysis, pattern identification, and global collaboration. The ACMCRN StuffThatWorks Survey utilized AI and cloud computing to gather the largest patient-reported survey on Arachnoiditis.

The study aimed to assess treatment effectiveness, provide a platform for patient experiences, and improve understanding of the condition. By leveraging technology and patient participation, the study sought to enhance patient care, treatment outcomes, and overall knowledge of Arachnoiditis.

## Methods

From 2021-2022, ACMCRN implemented a series of health-related surveys within their community. These surveys were conducted through the Stuffthatworks health Platform and were disseminated via a combination of targeted social media campaigns and word-of-mouth strategies. There were 1250 respondents.

# FINDINGS

## Top Symptoms



The Top 3 Symptoms:

- Lower Back (N=479)
- Leg Pain (N=458)
- Back Pain (N=431)

Other Common symptoms: numbness, chronic pain, headaches, burning sensation, muscle spasms, electric shock feeling & weakness

## Difficulty Sitting Across Conditions

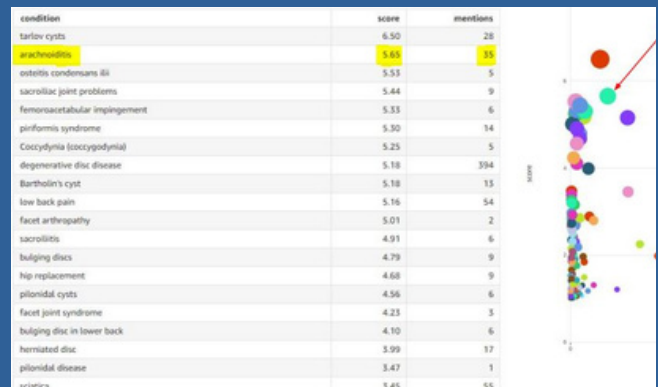


Figure 1. Difficulty Sitting Across Conditions

The report of "difficulty sitting" was highly correlated with Arachnoiditis, and out of 110+ conditions on the Stuffthatworks.health platform, was rated 2nd only to Tarlov Cysts

## Treatment Efficacy/Detriment

Participants were instructed to categorize 34 commonly used Arachnoiditis treatments into one of three groups: those they had TRIED, those they found EFFECTIVE, or those they considered DETRIMENTAL their condition.

The agents that were most commonly cited in the 3 categories are as follows:

**TRIED:** Gabapentin, physiotherapy, pregabalin, and oxycodone

**EFFECTIVE:** naltrexone hydrochloride (28.1% effective) and ketamine (24.8% effective)

**DETRIMENTAL:** epidural steroid injection (38.5% detrimental), spinal injections (31.1% detrimental), myelogram (28.5% detrimental), epidural injections (28.2% detrimental), and surgery (21.7% detrimental)

## Demographics

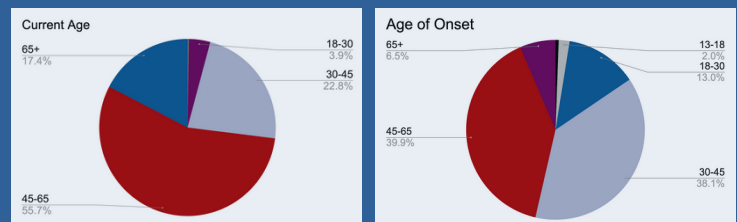


Figure 2. Current age of cohort subjects

A significant majority of respondents were female, white, living in the US and more than half were between the ages of 45 and 65.

Figure 3. Age of onset of symptoms

Over 78% of respondents indicated their symptoms started in adulthood to late adulthood

## Discussion

This early attempt at employing an AI and machine-learning software platform appears to indicate that the traditional burdens of recruitment in Rare Disease may be overcome with the use of virtual software. When combined with the recruitment potential via disease advocacy/support groups, it exceeds past traditional attempts at recruiting a sizeable cohort.

These findings will be expanded upon through the ACMCRN International Arachnoiditis Patient Registry in upcoming studies. Please see more Registry information at [www.acmcrn.org](http://www.acmcrn.org)

