

# HARNESSING ARTIFICIAL INTELLIGENCE/MACHINE LEARNING IN RARE DISEASES: LIVING WITH ARACHNOIDITIS:

An International Study by the Arachnoiditis & Chronic Meningitis Collaborative Research Network (ACMCRN)

## 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.

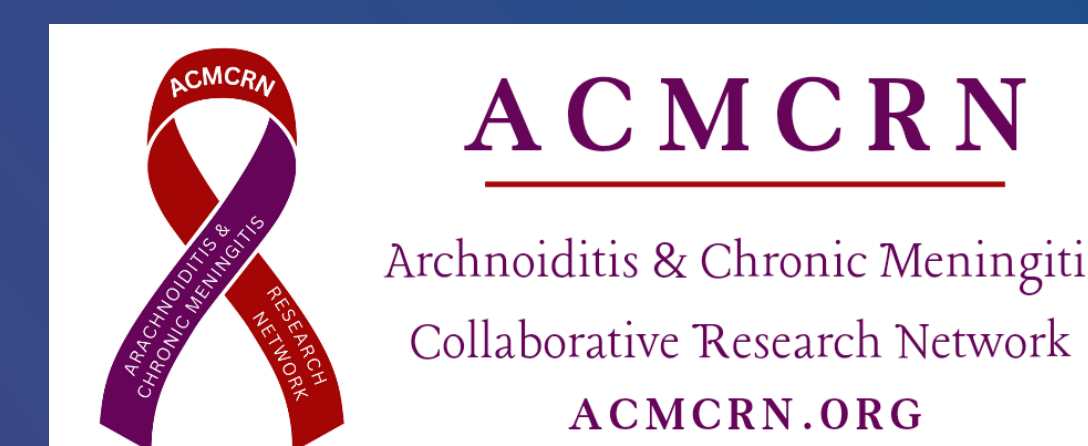
These surveys were conducted through the StuffThatWorks health platform and were disseminated via a combination of targeted social media campaigns and word-of-mouth strategies.

There were 1,250 respondents.

## 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)



## TOP SYMPTOMS

THE TOP 3 SYMPTOMS:

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

OTHER COMMON SYMPTOMS:

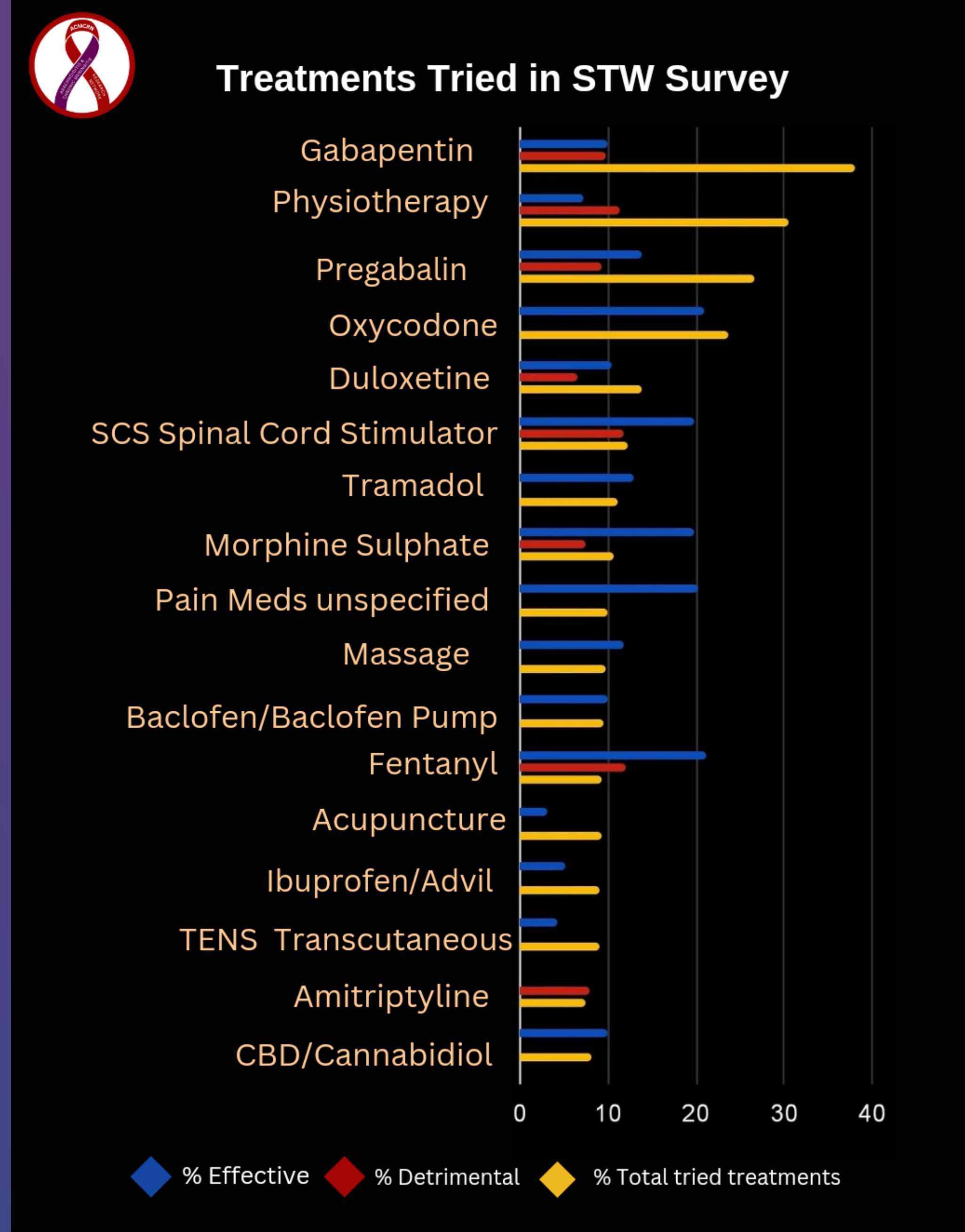
- Numbness, Chronic Pain, Headaches, Burning Sensation, Muscle spasms, Electric Shock Sensation & Weakness

## FINDINGS

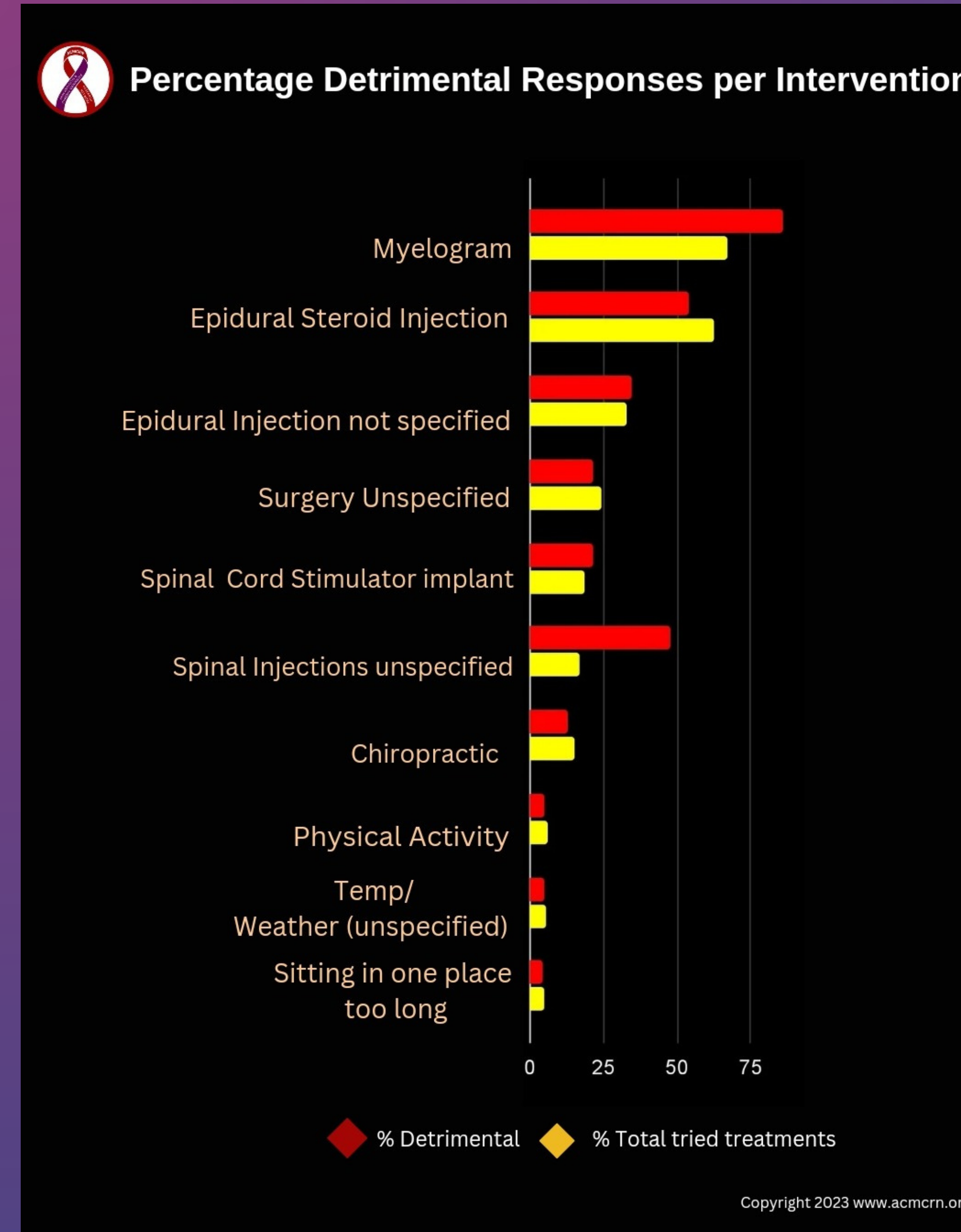
### AGGRIVATING FACTORS



### TRIED TREATMENT



### DETRIMENTAL TREATMENT



### STW CONDITION COMPARISON

