

Cluster Headache Questionnaire: A New International Study



Study Title: Cluster Headache: Investigating severity of pain, suicidality, personal burden, access to effective treatment, and demographics among a large International survey sample.



www.clusterheadache.center

If you have been diagnosed with Cluster Headaches and are at least 18 years old, you are invited to complete this important survey. This study will provide important research data and help advance future research and advocacy.

Despite numerous descriptions in the literature suggesting Cluster Headache is among the most painful medical conditions, it has been difficult to measure and describe with precision the severity of the pain that occurs during an attack.

Our study focuses on the following questions:

1. Severity of pain
2. Prevalence, severity, risk factors, and protective factors of suicide
3. Personal burden (impact on relationships, work, and daily living)
4. Effectiveness of treatment as well as obstacles
5. Psychological impact



UNIVERSITY of 
West Georgia.

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A New International STUDY
Clusterbusters® is pleased to announce the launch of a very important research study:
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personal burden, access to effective treatment, and demographics among a large International survey sample.
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The Cluster Headache Questionnaire (CHQ) is a survey consisting of 144 possible questions, translated in 10 languages, about your experience with Cluster Headache attacks. The survey is interactive which means it will display certain questions depending on earlier responses. Some of these responses include space for you to describe in your own words certain features or aspects of this condition. You can access this survey from a computer, tablet, or smart phone.

This link is anonymous. The only identifiable information collected will be your IP Address which will be de-linked. At the end of the survey, you will be given an option to provide us with your contact information. You may decline to provide us your information and your response will still be recorded. As custodians of your personal information, we will not release your contact information to anyone for any reason, your contact information will be encrypted, and any identifiable information will be de-linked, deleted, or destroyed upon completion of our research.

Reason for Study:

Existing accounts are well known among Cluster Headache patients and knowledgeable physicians. However, despite numerous descriptions in the literature suggesting Cluster Headache is among the most painful medical conditions, it has been difficult to measure and describe with precision the severity of the pain that occurs during an attack.

Methodology:

Recognizing the compromises, need to prioritize, and trade-offs inherent in developing this type of survey, we will not be able to investigate everything of interest. Consequently, our aim is that the survey will take less than two hours for most people to complete. The survey is interactive meaning it will vary based on some responses that trigger/open additional questions.

Despite the numerous statements regarding the severity of pain, the existing literature seems rather anecdotal and inferred. Consequently, we will be asking specifically if this is the worst pain each subject has experienced and elicit their subjective comparison with other painful experiences. We should have a sufficiently robust sample size to gather data from people who, in addition to Cluster Headache, have also experienced such conditions as kidney stones, childbirth, gunshot wounds, migraine, pancreatitis, shingles, etc.

Pain:

Describing patients during a Cluster Headache attack, Horton (1939) reported, "Their pain was so severe that several of them had to be constantly watched for fear of suicide. Most of them were willing to submit to any operation which might bring relief."

In a recent study, Rozen noted, "Very alarming is that 55% of the US cluster headache population has had suicidal thoughts while 2% have tried to commit suicide (2012). Rozen (2002) states, "There is no more severe pain than that sustained by a cluster headache sufferer and if not for the rather short duration of attacks most cluster sufferers would choose death rather than continue suffering."

Other Constructs:

Beyond attempting to clarify the nature and severity of pain, the CHQ will gather additional data on demographics, suicidality, access to effective treatment, attitudes toward existing and potential devices and procedures, Fear of Pain, impact on Quality of Life (QoL), disability, and personal burden.

This study is a collaboration between Clusterbusters® and Larry Schor, PhD Professor of Psychology at the University of West Georgia with additional support generously provided by Autonomic Technologies™.