

Global Healthy Living Foundation 515 North Midland Avenue Upper Nyack, New York 10960 USA +1 845 348 0400 +1 845 340 0210 fax www.ghlf.org

CreakyJoints Presents

Pain Explained: Where to Start - Finding Reliable Information (Part 3)

Understand where to find reliable information

With the advancement of technology and Dr. Google at your fingertips, the internet has been saturated with a lot great information along with a slew of misinformation. This can put users at risk especially when you are searching for answers regarding your health. It is understandable that when you are in pain your first instinct may be to type in your symptoms and try to understand the cause of your pain.

What then is the best course of action? Here are a few things to consider when looking for information.

First of all, it is not a bad idea to become more informed and educated about pain and your treatment. The critical thing is to find reliable, or "evidence-based information" or information from "evidence-based research". This is information based on evidence that has been thoroughly reviewed in medical research. The goal is to try to become a "critical consumer of research" – which simply means you are able to identify reliable information based on science, versus unreliable information which may be from hearsay or word of mouth. It is important that information is evidence-based even when it includes the person-lived experience perspective.

For example, the <u>Patient-Centered Outcomes Research Institute (PCORI)</u> is a non-profit organization that supports studies that can help patients and caregivers make better-informed healthcare choices by engaging in research that is meaningful and relevant to patients and other interested parties. PCORI's goal is to support research that will provide reliable, useful information to help improve patient care and outcomes.

For many, reading research can be confusing. With reliance on complex language like "p-values" and "statistical significance", or "sample sizes" and "generalizability", reading and using research may often seem like an impossible task. But the good news is that it is not the only way to learn about evidence-based information.

Patient-centered research aims to ensure that research findings are presented in a format that is relevant, easy to understand and use. Patients may begin by looking at the summary or highlights of the research they find most interesting. Even if you're not a scientist, you might be





able to gather information from a study abstract's conclusions or study summary. PCORI sends regular emails highlighting results of their funded studies, in language that is easy to understand, with the aim of helping you and the patient community better understand what is new and recently discovered in the world of research.

What is new in the way research is being done? Let's consider the big picture.

Over the past few decades, the landscape of how research is done has undergone a fascinating transformation. It has become more patient centered. Researchers, clinicians and public health experts are now more aware of the path to understanding the needs of their patients, ensuring that treatment approaches are developed in the best interest of the patient. If patients are to be engaged then they must be able to access and understand their current research and information around diagnosis, management and treatment.

When we learn what is important to patients, researchers can develop more studies and clinical trials that are patient-centered, in order to gain more insight and in order to design studies that are relevant to patients.

For instance, we now know, from including input from people with inflammatory arthritis in research, that emotional health plays a major role in effecting the patient's experience of pain, in addition to physical health. Over time researchers have begun to incorporate the evaluation of emotional health into our treatment plans.

But we still have a lot of work to do. There are many research areas that are unexplored. For example, CBD (cannabidiol) is a hot topic, but there isn't a lot of research out there. Well, what does the lack of research mean for treatment?

In a study conducted by our research team here at the <u>Global Healthy Living Foundation (GHLF)</u>, we learned from our <u>CreakyJoints</u> community that more than half of arthritis patients have tried medical marijuana or CBD products for a purpose they perceived as medical, and 90% reported that it helped alleviate their symptoms. Pain and sleep disturbance were the main symptoms participants sought to relieve with these products and many used them in place of prescribed or over-the-counter medications.

While this is significant, it is also important that further research be done on these topics to understand the short term and long-term effects of any intervention or treatments. As W. Benjamin Nowell, Ph.D., Director of Patient-Centered Research at CreakyJoints and an ArthritisPower notes, "...In addition to various differences between state and federal laws which regulate medical marijuana, there is also a significant absence of high-quality evidence about the safety, effectiveness, and appropriate dosing."

As critical consumers of research and as patients managing chronic pain, it is always important to consider what we read, even if it's evidence-based research, it may require further





exploration of how the study was conducted and in whom. Therefore, it is key to bring your questions and concerns into your treatment discussions with your doctor.

It is also important to note that there is no one-size-fits all for evidenced-based research. There are times when evidence-based research does not provide information about a specific topic or conducting it might involve risks. For example, the research on the best approach to nutrition and inflammatory arthritis is not conclusive. That is why it is imperative to consult with a medical professional about the best approach for you.

Likewise, as you learn about treatment options and studies covered in our *Pain Explained* series, remember to keep an open mind about what the science is telling us. Not all of these approaches may be right for you and only you and your doctor can decide what is best.

Thank you for listening and we hope you found this information helpful. Remember to take the one question quiz to receive your free resources, including information on how to access PCORI, other evidence-based websites, and other helpful tools.



