pcori
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Social Media and Research Toolkit (SMART)
GLOSSARY OF TERMS

1. ArthritisPower ™ [also known as AR-PoWER Patient Powered Research Network (PPRN)]
Created by CreakyJoints®, the online, non-profit, arthritis patient support community with more than 100,000 members, in collaboration with the University of Alabama at Birmingham, ArthritisPower is the first ever patient-led, patient-generated, patient-centered research registry for arthritis. ArthritisPower is part of PCORnet. Using a web-based and mobile application, and focusing on rheumatoid arthritis as well as other musculoskeletal conditions, the goal of ArthritisPower is to collect health data from tens of thousands of arthritis patients to support future research to compare treatments, identify new ones, and, perhaps, find elusive cures. ArthritisPower includes a committee of Patient Governors living with various forms arthritis who identify research needs for study development and prioritize research requests from the CreakyJoints patient community around the world. To learn more, visit www.ArthritisPower.org.

2. CreakyJoints (CJ)
CreakyJoints, part of the not-for-profit Global Healthy Living Foundation, is a dynamic education, support, advocacy, and patient-centered research organization for people with all forms of arthritis and rheumatic disease. Co-founded in 1999 by arthritis patient Seth Ginsberg, CreakyJoints has grown to a community of more than 100,000 patients and their families in all 50 states, Western Europe, South America and Australia. For more information and to become a member, visit www.CreakyJoints.org.

3. Comparative Effectiveness Research (CER)
A kind of research that focuses on developing new evidence for comparing the effectiveness and safety of different clinical options to see which ones work best for different people

4. Patient-Centered Outcomes Research Institute (PCORI)
PCORI is an independent nonprofit, nongovernmental organization located in Washington, DC and authorized by Congress in 2010 as part of the Affordable Care Act to support patient-centered outcomes research. The mission of PCORI is to help people make informed healthcare decisions and improve healthcare delivery and outcomes by producing and promoting high-integrity, evidence based information that comes from research guided by patients, caregivers, and the broader healthcare community.

5. Patient Centered Outcomes Research (PCOR)
PCOR is a way of doing research that addresses the questions and concerns most relevant to patients. It involve patients, caregivers, clinicians, and other stakeholders in the research process

6. Patient-Centered Clinical Research Network (PCORnet)
PCORnet is a large, highly representative, national network for conducting comparative effectiveness research. It fosters a range of observational and experimental research by establishing a resource of clinical data gathered in a variety of healthcare settings, including hospitals, doctors' offices and the community. PCORnet is made up of two kinds of individual partner networks— Clinical Data Research Networks (CDRNs) and Patient-Powered Research Networks (PPRNs).

facebook/creakyjoints   515 N. Midland Ave., Upper Nyack, NY 10960-1205   @GHLForg
                          +1 845 348-0400 • +1 845 348-0210 fax   @creakyjoints
                          www.ghlf.org • www.creakyjoints.org

7. Patient-Powered Research Networks (PPRN)
PPRNs are research networks that are operated and governed by patient groups and their partners to focus on particular conditions or communities of interest. There are twenty PPRNs in PCORnet.

8. Patient-Reported Outcomes Measurement Information System (PROMIS)
PROMIS is a set of person-centered outcomes measures that evaluate and monitor physical, mental, and social health in adults and children that was developed by the National Institutes of Research (NIH). It can be used with the general population and with individuals living with chronic conditions.

Relevant Social Media Terms

1. Social networking sites
Social networking sites are online communities where people can interact with friends, family, coworkers, acquaintances, and others with similar interests. Most social networking sites provide multiple ways for their users to interact such as chat, email, video, voice chat, file sharing, blogging, and discussion groups (i.e. Facebook).

2. Facebook
Facebook is mainly used by people who want to connect with family and friends. It is a place to talk about people they know and interests that relate to their life.

3. Post
A Facebook post is content that you load and comments that you make on a Facebook page.

4. Twitter
Twitter is a micro-blogging platform, where short status updates are posted about stories, ideas, opinions, news; anything that is of interest.

5. Tweet
A tweet is a Twitter message, which by definition must be no more than 140 characters.

6. Hashtag
The # symbol used in front of keywords to index and make the topic of a tweet searchable.

7. Handle
A handle is the unique user name selected by a Twitter user. It is designated by an "@username" identifier.

8. Twitterview
A Twitterview is a combination of the terms Twitter, a popular microblogging platform, and interview. It is a type of interview for which the medium restricts the interviewer and interviewee to short-form responses.

facebook/creakyjoints   515 N. Midland Ave., Upper Nyack, NY 10960-1205   @GHLForg
+1 845 348-0400 • +1 845 348-0210 fax   @creakyjoints
www.ghlf.org • www.creakyjoints.org