

## PD57 Patient Involvement In The Development Of Clinical Practice Guidelines For Rare Diseases: A Systematic Literature Review

Anabel Granja Dominguez ([anabel.granja@juntadeandalucia.es](mailto:anabel.granja@juntadeandalucia.es)), Carmen Martín-Gómez, Rocío Rodríguez-López, Lourdes Gonzalez-Bermudez and Juan Antonio Blasco-Amaro

**Introduction:** One obstacle to the development of clinical practice guidelines (CPGs) for rare diseases (RDs) is the lack of scientific evidence. This can be partially overcome by involving patients in the development of CPGs. Our aim was to develop a process for involving patients with RDs in all stages of CPG development to ensure that their needs and expectations are addressed.

**Methods:** A literature search was conducted in the MEDLINE, Cochrane Library, and Embase databases and the websites of the European Organization for Rare Diseases, the National Organization for Rare Disorders, and INAHTA. Eligible articles reported methods for involving patients in CPGs, other clinical decision support tools, and research studies. A fit-for-purpose data extraction template was created to capture the following data: author, year, country, type of study, characteristics of the target population, and strategies for participation, engagement, and involvement of patients. Data were synthesized according to methods for recruiting, involving, or engaging patients and obtaining information from them. The entire process was performed by pairs of researchers.

**Results:** A total of 1,113 records were identified once duplicates were deleted. Of these, 55 were included. The review collected data on types of patients (patient representatives or patient experts) and their recruitment, which could be classified as open or nominated. The various involvement strategies included consultation, participation, and communication. Differences between involving and engaging patients in the CPGs development process were noted. Procedures for obtaining the opinion of patients included surveys, interviews, workshops, and focus groups, among others. The review also provided information on the importance of involving patients in the dissemination and implementation stages of CPG development and the methods for doing so.

**Conclusions:** When patients with RDs are actively involved in all phases of CPG development, they can contribute to the identification, prioritization, and inclusion of topics pertinent to RDs as questions to be addressed in the CPGs. These aspects might otherwise be overlooked by clinical experts and researchers. Therefore, involving patients with RDs is a promising approach to addressing gaps in the management of these diseases.

## PD58 The Repellent Effects Of *Cymbopogon Nardus* On *Aedes Aegypti* Mosquitoes: A Rapid Review

Ana Célia Rocha Medeiros, Allancelriston Alves Galdino, Edmar Candeia Gurjão and Erika Barbosa Camargo ([erika.barbosacamargo@gmail.com](mailto:erika.barbosacamargo@gmail.com))

**Introduction:** Arboviruses transmitted by the *A. aegypti* mosquito are a public health problem in Brazil. Citronella, known for its repellent properties, has been suggested as a possible sustainable and natural preventive measure against the arbovirus triad. This study aimed to carry out a rapid review of the efficacy and safety of the repellent properties of citronella for the *A. aegypti* mosquito.

**Methods:** The rapid review followed methods proposed by the Joanna Briggs Institute. Searches were conducted in the following literature databases: PubMed, LILACS, Embase, Scopus, Web of Science, and the Cochrane Library. Quality assessment was carried out using the AMSTAR-2 tool. The review aimed to determine the efficacy and safety of citronella (*C. nardus*) as a repellent for the *A. aegypti* mosquito, compared with usual methods.

**Results:** Citronella repels *A. aegypti* mosquitoes for between 12 and 480 minutes, depending on the concentration and formulation of the product. Considering its protection time, reapplying the product doubles the protective effect. Adding vanillin to the formula reduces the product's volatility. Citronella is not absorbed through the skin like DEET products, making it less toxic.

**Conclusions:** Citronella-based products can be used as a complementary measure of protection against arboviruses. Additional investigations are needed on the percentage of essential oil present in homemade formulations. Studies addressing the safety of citronella are imperative for its use in the public health system. Controlled studies evaluating its degree of repellency are also needed.

## PD59 Review Of The International Epidemiology Of Long COVID

Michelle Norris ([mnorris@hiqa.ie](mailto:mnorris@hiqa.ie)), Fearghal Comiskey, Carol Mc Loughlin, Niamh Merriman, Barrie Tyner, Aislinn O'Mahony, Marie Carrigan, Patricia Harrington, Máirín Ryan and Michelle O' Neill

**Introduction:** Approximately 65 million people worldwide have Long COVID. Long COVID is a complex condition with more