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

Anabel Granja Dominguez (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, Allancleriston Alves Galdino, Edmar Candeia Gurjão and Erika Barbosa Camargo (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), Fearghal Comaskey, 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

than 200 symptoms, which can substantially affect the lives of individuals. The evidence base for Long COVID is evolving rapidly and, therefore, an up-to-date understanding of the prevalence and risk factors of Long COVID is necessary to inform service delivery and allocation of healthcare resources.

Methods: A systematic literature review was conducted. Long COVID epidemiological literature published after October 2021 was identified in the MEDLINE, Embase, and Cochrane Library databases. Data extraction and quality appraisal were completed by one reviewer and checked for accuracy and omissions by a second reviewer. The following subgroups of interest were identified: general population; children and older adults; individuals who are medically vulnerable; and individuals with a history of severe COVID-19. Narrative synthesis of the prevalence and symptoms of Long COVID and of risk factors associated with the development of Long COVID was conducted.

Results: Over 3,000 documents were identified, of which 51 primary research studies met the inclusion criteria and were deemed of fair or good quality. Long COVID prevalence estimates ranged from 1.8 to 53.1 percent in the general population; 0.1 to 65.7 percent in children; 5.6 to 80.8 percent in older adults; 12.4 to 29.7 percent in medically vulnerable individuals; and 9.8 to 94.6 percent in individuals with a history of severe COVID-19. A wide range of symptoms were identified, with fatigue and neurological and respiratory symptoms being commonly reported. Female sex and increased age were identified as risk factors for developing Long COVID.

Conclusions: Long COVID is a complex condition involving a wide range of symptoms, which may result in significant reductions in quality of life and functioning in some individuals, a substantial burden on healthcare systems, and broader economic impacts. In planning healthcare delivery for this population, a focus on multidisciplinary holistic care will be necessary.

PD60 The Importance Of Systematic Reviews Addressing Questions Of Prevalence In Health Technology Assessment

Celina Borges Migliavaca (celinabm7@gmail.com),

Timothy Hugh Barker, Cinara Stein, Verônica Colpani, Zachary Munn and Maicon Falavigna

Introduction: The use of systematic reviews (SRs) of interventions is commonplace in health technology assessment (HTA). However, SRs synthesizing other data types, such as prevalence, are rarely used. These SRs may complement the HTA process by gathering complementary evidence essential for developing trustworthy recommendations. We aimed to discuss the importance and application of SRs of prevalence in the context of HTA.

Methods: A methodological working group, the Prevalence Estimates Reviews – Systematic Review Methodology Group (PERSyst), was created to provide guidance on how to improve the development of SRs and meta-analyses of prevalence. As part of the

group's work, a guide for HTA developers regarding the value of SRs of prevalence was developed.

Results: There are many benefits to including SRs of prevalence in the process of HTA. These include providing data for estimating burden of disease; helping to set priorities regarding technology assessment; informing the absolute impact on health outcomes from association measures (e.g., relative risk) reported in clinical studies; and providing data for estimating resource requirements for and feasibility of implementing health technologies under consideration. Within the GRADE framework, prevalence estimates are necessary to assess the quality of diagnostic test accuracy evidence and to support decision-making using the Evidence to Decision framework.

Conclusions: Although not commonly used, SRs of prevalence are an important tool in the process of HTA. There is a need for standardization of methodologies and guidance on how to use these reviews in the HTA process.

PD61 Thromboprophylaxis After Major Orthopedic Surgeries: Health Technology Assessment To Promote Access To Oral Anticoagulants

Mayra Carvalho Ribeiro (mayracr@unicamp.br),

Giovana Fernanda Santos Fidelis,

Carlos Roberto Silveira Correa,

Lucieni de Oliveira Conterno and

Flávia de Oliveira Motta Maia

Introduction: While implementing an evidence-based guideline for venous thromboembolism (VTE) prophylaxis in a Brazilian tertiary hospital, we identified an unmet need for patients undergoing major orthopedic surgery. The Brazilian Unified Health System (SUS) does not provide access to direct oral anticoagulants (DOACs) or enoxaparin. Therefore, an assessment of the efficacy, safety, and budgetary impact of these medications from a hospital perspective is warranted.

Methods: Our Health Technology Assessment Center performed an overview of systematic reviews (SR) to compare the efficacy and safety of DOACs with enoxaparin. The Cochrane Library, Embase, and MEDLINE databases were searched in May 2023. The relative risks of symptomatic VTE, clinically relevant bleeding, and mortality were collected. The AMSTAR-2 tool was used to assess the methodological quality of included SRs. Treatment costs and estimates of the number of patients undergoing knee or hip arthroplasty were derived from historical institutional data.

Results: Of the 32 SRs included in the analysis, seven performed a network meta-analysis. All SRs had at least one flaw in a critical methodological domain, mainly in not providing the list of excluded studies. Regarding mortality rates, most SRs did not detect any differences between the treatments. The risk of experiencing VTE