

Going Beyond Pain: Expanding the JIA Option Map

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About the Study

Young people with juvenile idiopathic arthritis (YPJIA) experience physical and psychological symptoms that negatively impact a wide range of functional activities. YPJIA and their families need more information and decision support to help manage these symptoms. Our team previously developed the JIA Option Map, a web-based patient decision aid for JIA pain management. Our current work aims to expand the JIA Option Map to include interventions for other relevant symptoms and tips to participate fully in activities. With funding from the Canadian Initiative for Outcomes in Rheumatology cAre (CIORA), we sought to identify which symptoms and aspects of daily function should be added to the JIA Option Map.

Our team comprises 35 members, and includes patient partners, health care providers (HCPs), researchers and policy makers. HCPs include pediatric rheumatologists, nurses, occupational therapists, physical therapists, psychologists, social workers and dietitians. We held seven virtual research team meetings to identify and discuss the symptoms and functional activities that were relevant to YPJIA. Subsequently, we distributed an online survey to the research group and conducted two online consensus meetings to agree on the most important symptoms and functional activities to add to the JIA Option Map. Patient engagement is central to this project and is described at the following link: https://www.ktpathways.ca/system/files/resources/2022-12/2022-Vol-6_IKTRN-casebook.pdf

Which Symptoms Are the Most Important to Add to the JIA Option Map?

Seventeen individuals completed the survey, including four patient partners, 11 HCPs from four different professions, and seven researchers. Fatigue, stress, anxiety, joint stiffness, poor sleep, feeling down and joint swelling were rated as the most relevant. School and leisure were the highest rated functional activities, followed by activities of daily living and work. Eighteen people participated in the consensus meetings, including three patient partners and clinicians from four different professions. Both meetings determined that fatigue, stress/anxiety, and joint stiffness were the most important symptoms to add. All functional activities were considered important to add, with school and daily living activities rated as the most important.

Implications

Future work will help ensure that the expanded JIA Option Map integrates evidence-based information to address these symptoms and their impact on functional activities. Patient

partners and clinicians are essential to help us ensure that this app will be easy to use and implement in clinical practice, to help young people and their families discuss treatment options and make the best decisions to manage their own health.

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