Pediatric Rheumatology

COMMENTARY

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Uncovering the hidden socioeconomic impact of juvenile idiopathic arthritis and paving the way for other rare childhood diseases: an international, cross-disciplinary, patient-centered approach (PAVE Consortium)

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Abstract

Background Juvenile idiopathic arthritis (JIA) refers to a heterogeneous group of rheumatic conditions in children. Novel drugs have greatly improved disease outcomes; however, outcomes are impacted by limited awareness of the importance of early diagnosis and adequate treatment, and by differences in access across health systems. As a result, patients with JIA continue to be at risk for short- and long-term morbidity, as well as impacts on virtually all aspects of life of the child and family.

Main body Literature on the socioeconomic burden of JIA is largely focused on healthcare costs, and the impact of JIA on patients, families, and communities is not well understood. High quality evidence on the impact of JIA is needed to ensure that patients are receiving necessary support, timely diagnostics, and adequate treatment, and to inform decision making and resource allocation. This commentary introduces the European Joint Programme on Rare Diseases: *Producing an Arthritis Value Framework with Economic Evidence: Paving the Way for Rare Childhood Diseases (PAVE)* project, which will co-develop a patient-informed value framework to measure the impact of JIA on individuals and on society. With a patient-centered approach, fundamental to PAVE is the involvement of three patient advocacy organizations from Canada, Israel, and Europe, as active research partners co-designing all project phases and ensuring robust patient and family engagement. The framework will build on the findings of projects from six countries: Canada, Germany, Switzerland, Spain, Israel, and Belgium, exploring costs, outcomes (health, well-being), and unmet needs (uveitis, mental health, equity).

Conclusion This unique international collaboration will combine evidence on costs (from family to societal), outcomes (clinical, patient and family outcomes), and unmet needs, to co-design and build a framework with patients

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and families to capture the full impact of JIA. The framework will support the development of high-quality evidence, encompassing economic and clinical considerations, unmet needs, and patient perspectives, to inform equitable resource allocation, health system planning, and quality of care better aligned with the needs of children with JIA, their families, and communities. Knowledge gained from this novel approach may pave the way forward to be applied more broadly to other rare childhood diseases.

Keywords Juvenile Idiopathic Arthritis, Childhood Arthritis, Socioeconomic burden, Patient-centered research, Patient-partnered research, Rare disease, International collaboration, Participatory research

Background

Juvenile idiopathic arthritis (JIA) refers to a heterogeneous group of rheumatic conditions in children, jointly characterized by chronic immune-mediated arthritis of unknown etiology frequently resulting in low health-related quality of life, pain and impairment in children and adolescents. Individual JIA subtypes are considered rare diseases. Rare diseases are associated with significant costs, including a long and costly diagnostic odyssey [1–3], limited and expensive treatments [4–6], healthcare costs [7], and costs to patients, families, and society [8–10]. The literature highlights that JIA places a significant economic burden on society due to substantial healthcare costs, as well as informal caregiving and productivity loss [11–14]. However, these studies are largely limited to costs to the health care system, and do not include the burden of JIA on patients and their families. A recent scoping review of costing studies in JIA reported that while most included healthcare costs, very few included productivity losses, and family borne costs were rarely captured [15].

Studies on the socioeconomic burden of disease typically only include healthcare costs, and rarely incorporate costs to other government sectors, patients/families, and society [15–18]. This is perhaps driven by the fact that health technology assessment used to inform decision-making and resource allocation, has historically focused on health system costs. However, there has been increasing discussion regarding broader value assessment, moving beyond traditional measures to include a broader range of value elements, including burden, hidden costs, and patient perspectives [19–21]. The recent evaluation manual of the *National Institute for Health and Care Excellence* in the United Kingdom (UK) allows committees to weigh decisions based on disease severity, consider a broader evidence base, and allow flexibility in accepting uncertainty in specific situations, such as rare disease or pediatric populations [22].

To encourage more consistent and comprehensive measurement of socioeconomic burden, a framework of costs to consider in studies of rare diseases was recently developed, incorporating several costs to patients, families, and society [23]. However, outcomes beyond costs, including quality of life, caregiver burden, unmet needs, and equity urgently need to be considered and integrated. This framework is necessary to gather the evidence needed to inform equitable resource allocation, health system planning, and the provision of high-quality care, ensuring that JIA patients and their families receive necessary supports, including access to diagnostics and adequate treatments. JIA provides a unique opportunity to develop such a framework as i) we will continue to build on the work of an established network of researchers (including the *Understanding Childhood Arthritis Network—Canada-Netherlands Personalized Medicine Network in Childhood Arthritis and Rheumatic Disease* (UCAN CAN-DU) and *German Inception Cohort of Patients with Newly Diagnosed JIA* (ICON) cohorts), and ii) the resulting framework will be generalizable to other pediatric rheumatological diseases, creating a foundation that can be built upon or adapted as needed. Although the implementation of novel drugs and treatment strategies for JIA over the last two decades have greatly improved disease outcomes, patients remain at risk for both short- and long-term morbidity, impacting joint and general functioning, quality of life, and virtually all aspects of life for the child and family. While novel drugs can achieve disease control for many patients, delayed diagnosis results in delayed onset of treatment, resulting in increased morbidity, which impacts both the child (e.g., impacts to school and sports activities) and parents (e.g., increased informal caregiving), with the impacts of delayed diagnosis and treatment carrying into adulthood. Access to novel drugs is impacted both by lack of awareness among clinicians and society regarding the importance of early diagnosis (so called "window of opportunity"), as well as by differences in access to healthcare services, providers, diagnostics, and treatments across healthcare systems. Incorporating all aspects of impact into a value framework will significantly enhance our understanding of the burden on individuals, families, and society as a whole; providing the evidence needed to better inform clinical and health system decision-making and resource allocation.

Producing a childhood arthritis value-framework

To address this need, the goal of the European Joint Programme on Rare Diseases Producing an Arthritis Value-Framework with Economic Evidence: Paving the Way for Rare Childhood Diseases (PAVE) project is to co-build and design a value framework with patients and families. The framework will comprehensively measure the impact of JIA from different perspectives, centered on patients and families, providing high quality evidence to enable healthcare decision making to support resource allocation and policies better aligned with the needs of children with JIA, their families, and communities. The ultimate goal is to achieve better outcomes for patients across their lifetime, and better outcomes for families.

PAVE features a unique collaboration between international, cross-disciplinary partners, with foundational input from and reliance on patients. Fundamental to our work is the partnership with patient advocacy organizations, Cassie + Friends Society (Canada), Israeli Arthritis Foundation (INBAR, Israel), and the European Network

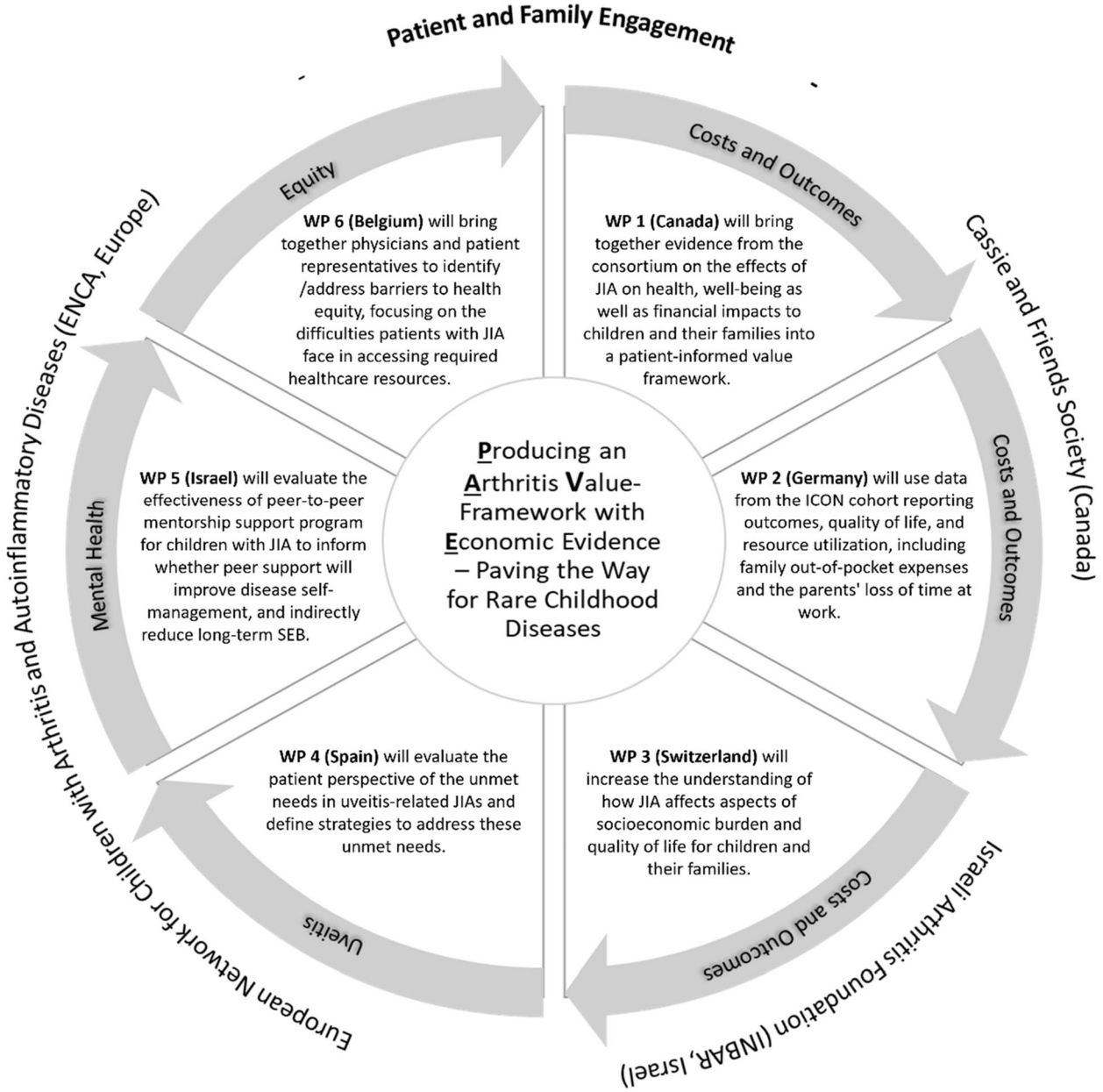

Fig. 1 Project overview: Producing an arthritis value framework with economic evidence – paving the way for rare childhood diseases. ICON: German Inception Cohort of Patients with Newly Diagnosed JIA; JIA: juvenile idiopathic arthritis; SEB: socioeconomic burden; WP: work package

for Children with Arthritis and Autoinflammatory Diseases (ENCA, Europe), who will work together to share the lived patient experience and act as active research partners. Cassie + Friends will play a crucial role in co-designing and building the patient-informed value-framework, drawing on their national information-sharing and patient engagement network. Integral to PAVE, these groups will work together to ensure the maximum use and integration of their patient networks and communication channels to educate, involve and empower a truly diverse cross-section of patients and caregivers. To ensure PAVE generates information that is relevant for patients and families, we will engage them through every stage of the project, including providing insights into inequities experienced, contributing to an overall holistic view of life with JIA, and to guide what, when and how information is best shared.

PAVE will draw on evidence from international projects, each contributing a critically important component to understanding the burden of JIA; Fig. 1. Canada and Germany will report costs and outcomes from the UCAN CAN-DU and ICON cohorts [24–27], respectively. Switzerland will measure costs and outcomes in German- and Italian-speaking populations. The remaining work packages will provide complementary data on the burden of complications associated with JIA, including uveitis, the most frequent and potentially most devastating extra-articular manifestation of JIA (Spain); mental health aspects of the socioeconomic burden and the effectiveness of peer-to-peer support (Israel); and factors and barriers to health equity for patients and their families (Belgium). The research undertaken in the projects includes multiple methods (non-interventional qualitative, quantitative, and mixed methods approaches, as well as a randomized interventional trial) and includes both prospective and retrospective data. The findings of all work packages will be synthesized and will feed into the development of the value framework. All projects have enrolled children, adolescents and young adults with JIA and/or their parents, and where possible, analyses will be aligned to allow comparability (e.g., by age group, JIA subtype). Our summary results will focus on resource use, rather than unit cost, to inform what areas of care drive costs while still allowing for variation and differences across health systems. All project work is ongoing since 2022, with initial results being disseminated in late 2025.

Conclusions

Featuring a unique collaboration among international, multi- disciplinary partners, PAVE is a patient-centered program that aims to co- design a value framework with children and young people living with arthritis and their families. The goal of this value framework is to guide the development of high-quality evidence necessary to inform clinical and health system decision-making and resource allocation that will improve the lives of those impacted by JIA. To this end, the framework encompasses economic (e.g., costs to the health system, patients and families, and society) and clinical considerations (e.g., health outcomes), as well as the patient perspective. This novel approach will pave the way forward with a framework and approach that can be adapted and applied to other rare childhood diseases.

Abbreviations

ENCA	European Network for Children with Arthritis and Autoinflammatory Diseases
ICON	German Inception Cohort of Patients with Newly Diagnosed JIA
INBAR	Israeli Arthritis Foundation
JIA	Juvenile Idiopathic Arthritis
PAVE	Producing an Arthritis Value-Framework with Economic Evidence: Paving the Way for Rare Childhood Diseases
UCAN CAN-DU	Understanding Childhood Arthritis Network Canada-Netherlands Personalized Medicine Network in Childhood Arthritis and Rheumatic Disease

Acknowledgements

D.M. is the Svare Chair for Value and Impact in Child Health Research at the Cumming School of Medicine, University of Calgary. She was previously supported by the Arthur J. E. Child Chair in Rheumatology (2012-2022).

The authors thank Faye Schreiber for editorial comments.

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Patient Advocacy Organizations: Jennifer Wilson, David Porte, Tsipi Egert, Yona Egert, Christophe Normand

Authors' contributions

All authors contributed to the conception of the work. The first draft of the manuscript was prepared by D.M., B.G. and G.C. All authors critically reviewed, provided comments and revisions on the first draft and read and approved the final manuscript.

Funding

This project has received funding from the European Union's Horizon 2020 research and innovation programme under the EJP RD COFUND-EJP N°

825575. This work was supported by the Canadian Institutes of Health Research (Grant #: 467966) [Work Package 1, Canada], Federal Ministry of Research and Education (FKZ 01GM2108) [Work Package 2, Germany], Swiss National Science Foundation (Grant #: 10ER1C_203749) [Work Package 3, Switzerland], Instituto de Salud Carlos III (Grant #: AC21_2/00034) [Work Package 4, Spain], Israeli Ministry of Health (Grant #: 3000018381) [Work Package 5, Israel], Research Foundation Flanders (FWO), Belgium (Grant G0G4221N) [Work Package 6, Belgium].

Availability of data and materials
Not applicable.

Declarations

Ethics approval and consent to participate
Not applicable.

Consent for publication
Not applicable.

Competing interests
No competing interests to declare.

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Received: 6 June 2024 Accepted: 29 July 2024
Published online: 09 August 2024

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