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JUVENILE IDIOPATHIC ARTHRITIS: IT’S NOT JUST AN OLD PERSON’S DISEASE
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My abstract has been or will be presented at a scientific meeting during a 12 months period prior to EULAR 2016: No
Is the first author applying for a travel bursary and/or an award for undergraduate medical students?: No

Background: Juvenile Idiopathic Arthritis (JIA) is a common form of chronic arthritis in children and young people (CYP), diagnosed under the age of 16 [1,2]. It is a long-term condition (LTC) that is poorly understood by the general public, and can severely impact patient quality of life [3,4]. Therefore, it is important to support CYP in self-managing their condition, particularly as they transition into adult health services. The need for interactive health communication applications (IHCAs) to improve knowledge and health behaviours of CYP with LTCs, supplementary to clinical advice, is well reported in the literature [5]; however, many existing resources are static and do not actively engage CYP in learning about their condition.

Objectives: Our research aims to improve the understanding of JIA amongst the general public, musculoskeletal researchers, and CYP living with JIA, using a variety of resources.

Methods: Four resources were developed to raise the understanding of JIA: two magazine articles, a presentation to musculoskeletal researchers, and the IHCA, translated from existing static resources produced by charities in the United Kingdom (UK). An expert advisory group (EAG) helped to design, distribute and evaluate the research. Distribution of the resource to CYP with JIA, aged 11 to 18, was achieved via JIA charities across the UK.

Results: The Biological Sciences Review article, aimed at young Biologists, focuses on the role of the immune system in JIA, highlighting the impact of the disease on quality of life. The New Scientist article discusses the pathophysiology of the disease, and novel therapies currently used. A presentation at The University of Manchester’s Centre for Musculoskeletal Research’s seminar addressed a diverse team of researchers, exposing them to JIA and the importance of patient involvement. The IHCA resource takes CYP on an interactive journey about JIA, the medicines that they take, and how they can be proactive in leading a healthy lifestyle.

Conclusions: The project helps to raise awareness of JIA. In addition, it is hoped that it will strengthen national and international relationships with regards to user involvement in research. Finally, this research will add to the wealth of literature on eHealth interventions, representing a ‘smart way of thinking’, to improve efficiency in a modern healthcare delivery system, by optimising input from costly professional organisations, in a way that CYP find more accessible.


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