

LAY SUMMARY

Overview:

In this project, we worked alongside children and young people with juvenile arthritis, and their caregivers, to co-design a new intervention for juvenile arthritis. The intervention targets pain science education and graded physical activity and uses validating communication to support engagement.

What problems did you try to solve, or gaps in knowledge did you try to fill?

Juvenile idiopathic arthritis (JIA) affects ~30,000 Australian children and young people causing significant pain, reduced engagement in valued life activities, and poor mental health. While there is no cure, staying active can help. Yet, many children with JIA are inactive; they report feeling unsure whether activity is safe, that they are isolated from their peers, and that their pain is disbelieved, particularly as their symptoms are often 'invisible'. In this project, we aimed to co-design a new intervention for children and young people with juvenile arthritis to address this.

What did you discover during the course of the grant?

In this project, we discovered the key priorities and areas of unmet need for children and young people with juvenile arthritis and developed a brand-new intervention to address them. Young people reported feeling that their experiences are dismissed and disbelieved by others, expressed a need for greater awareness of juvenile arthritis, and want to better understand how they can manage their arthritis flare-ups while still being able to participate in fun activities with their friends.

Have the findings of the research already benefited people with musculoskeletal disease?

The findings of this research have already benefitted the 28 children and young people with JIA and their caregivers, who were involved in the co-design workshops. Participants reported feeling that their experiences were heard by others, that they enjoyed connecting with others who shared similar experiences, and that they got a lot out of the co-design workshops.

How might the findings inform further research to help sufferers in the future?

The findings from this research has informed the development of an entirely new non-drug intervention to improve pain and function in children and young people with juvenile arthritis. Subsequent research will involve testing the intervention in a clinical trial.

Are you planning to continue the research?

To progress this research, we are applying for funding to enable us to test the feasibility, acceptability, and preliminary efficacy of the new co-designed intervention, as the critical 'next step' towards clinical implementation.

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