Funded by:	Arthritis Australia
Recipient:	Dr Sarah Wallwork
Intended Department	Allied Health and Human Performance, University of South Australia
Project:	Co-designing the VITAL Project for juvenile idiopathic arthritis

SCIENTIFIC SUMMARY

What were the main scientific objectives of the grant?
There were two main scientific objectives of this grant:

1. To co-design an education and activity intervention, specific to children and young people with juvenile idiopathic arthritis, that uses validation to support engagement, and that works with the relevant interest holders, rather than making the decision for them.
2. To explore the relationship between pain and markers of disease activity in children and young people with juvenile idiopathic arthritis.

What were the main scientific achievements of the grant?
This grant included two separate studies:

Study 1: VITAL co-design workshops
We hosted 4 online workshops between March and October 2025, to Understand, Brainstorm, Prototype, and Refine a new approach to pain management for children and young people with juvenile idiopathic arthritis (JIA). Workshops were hosted online to facilitate participation from those who were from interstate/regional/remote regions and for those who had difficulty travelling. Workshops were facilitated by our co-design expert, CI Davis. Due to the large number of participants attending workshops, we divided participants into 3 groups (by age) when undertaking workshop activities. These groups were facilitated by CIA Wallwork, CI Pates (consumer), and a research assistant. Workshop activities included card-sorting activities and graphic storyboarding using Miro, a web-based visual collaboration platform.

Twenty-eight participants took part in one or more co-design workshops. This included children/young people with JIA (n=13; 46%; 8 girls, 4 boys, 1 non-binary; range 6-25 years; 30% identifying as neurodiverse), caregivers (n=14; 50%), and a physiotherapist (n=1; 4%). Sixteen participants attended all 4 workshops. Participants were predominantly female (82%) and came from a mix of locations including metropolitan (71%), regional (11%), and rural (18%).

Workshop 1: ‘Understanding’ focused on exploring participants lived experience of living with JIA. Participants identified 216 experiences that were considered either ‘best experiences’ or ‘worst experiences’. ‘Best experiences’ related to others (friends/family/peers) understanding JIA and having age-appropriate explanations of JIA.

‘Worst experiences’ related to feelings of not being believed, not knowing how to manage flare-ups, and missing out on things because of their JIA.

Workshop 2: ‘Brainstorm’ focused on identifying opportunities for interventions, including for who, structure of interventions, types of resources that may be developed, and the commitment/dosage of that intervention. Participants identified the need for greater public awareness of JIA, information about transitioning into adult care, and information about medication options. Suggestions were made about improving awareness of invisible conditions more broadly. Another key opportunity was for accessible information, with suggestions for bite-size chunks of information to suit different learning styles, developmental level, and abilities.

Workshop 3: ‘Prototype’ involved reviewing a range of possible intervention/resource prototypes. Participants reviewed 6 prototypes that were developed by the research team, based on the findings of Workshops 1 and 2. Participants highlighted areas for more specific or additional information, but found the information factual and helpful.

VITAL prototypes: The six prototypes that were developed and presented at Workshop 3 include: (1) a deck of cards that address questions about JIA (e.g., ‘understanding JIA’, ‘treatment and healthcare professionals’, ‘feelings and friends’, and ‘pain’; (2) a deck of cards related to ‘invisible conditions’, highlighting many conditions that young people live with, without wanting to shine a spotlight on JIA; (3) a ‘validation-informed practice course’ for healthcare practitioners; (4) an online ‘on-demand’ course for practitioners to upskill in managing JIA-related pain; (5) a handbook with detailed information that relates to cards of option 1, above, target age 12+ years; and (6) an activity book that pairs with the handbook, target age 5-12 years. One prototype was chosen for further development in the workshops, which included a deck of cards addressing questions about JIA (Prototype #1, above). Prototypes #3 and #4 will continue to be developed by the research team to supplement the prototype developed in Workshop 4, to be included in the final VITAL intervention.

Workshop 4: ‘Refining’ used a collaborative process to finalise intervention/resource elements. Participants emphasised the need for consistent language to ensure accessibility. They wanted clear messages on the cards, with simple graphics, accurate terminology, and practical strategies.

The final VITAL intervention involves delivery of evidence-based pain science information, graded, valued activity prescription, and clinician validating communication. The intervention first requires healthcare professionals delivering the intervention to upskill in validating communication (i.e., undertake the ‘validation informed practice course’) and in JIA-related pain management (i.e., undertake the ‘JIA pain management online on-demand course’). The intervention is delivered alongside a deck of 80 cards, each of which provides small chunks of information to supplement the main intervention components. The cards are divided into 6 themes, addressing topics that were identified by participants across the four workshops. The cards are double-sided, include large text and simple graphics. Each card addresses a question, with the question posed on one side and the answer given on the other (see Figures 1 and 2, below). An information pamphlet is also included in the set of

cards to provide instructions for use as well as a QR code linking to additional resources. The cards can be used as prompts for conversation at home, school, or in a clinical setting, can be given to friends and family so they can be more informed, or for any other chosen activities.

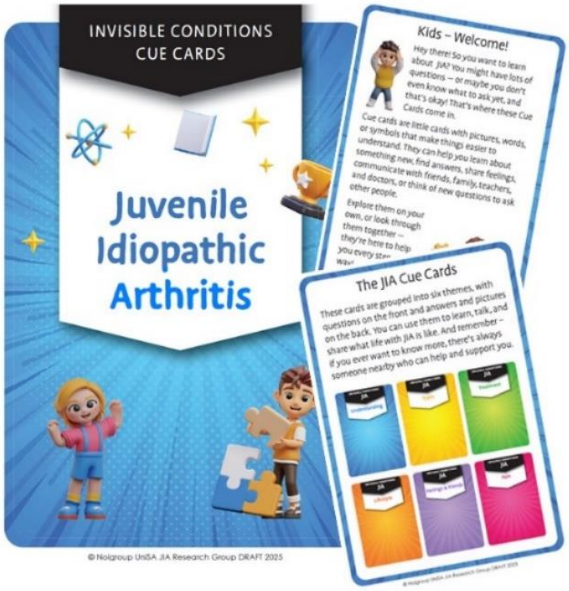

Figure 1. JIA card instructions

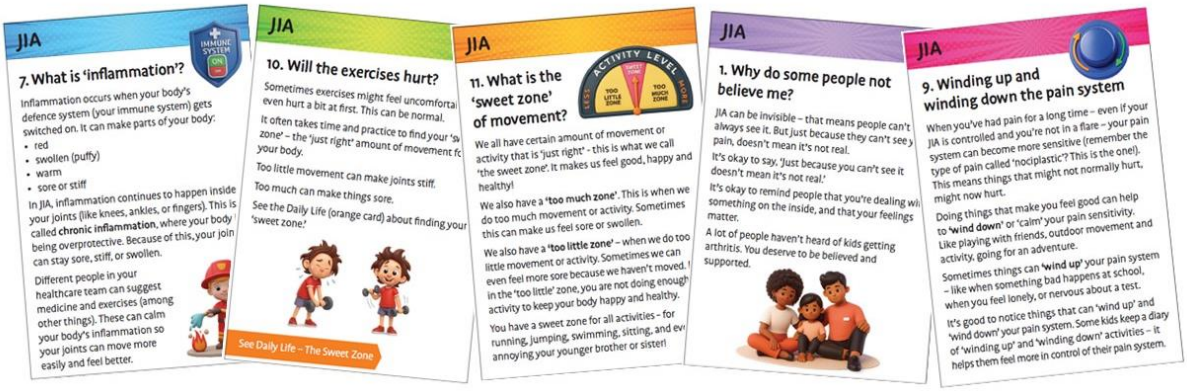

Figure 2. Examples of JIA cards.

Study 2: Scoping review

During the first co-design workshop of Study 1, it was identified that children and young people with JIA often experience dismissal/disbelief of their pain by a healthcare professional when their symptoms are not consistent with clinical findings. For example, when seeking care for a flare-up of their joint pain, if the healthcare professional was unable to find any 'evidence' of disease activity, they would feel that the healthcare professional would disbelieve their pain. In response to this, we conducted a scoping review to explore the relationship between pain and markers of disease activity in JIA.

We searched MEDLINE, EMBASE, Scopus, and google scholar for studies that explored the relationship between subjectively reported pain and objective and clinical makers of disease

activity, including blood biomarkers, imaging, and physician assessments. 18,211 studies were generated by the search, with 122 included in the review.

The findings of the review demonstrated that concordance between pain and markers of disease activity was uncommon. Most studies exploring associations between pain and blood biomarkers found either no relationship, or a very weak or inconsistent relationship. For imaging studies, several MRI studies showed discordance. More concordance was identified between pain and physician outcomes; however, this was confounded by these outcomes including subjective/pain-related components. Overall, the relationship between pain and makers of disease activity in JIA was inconsistent and highlights the need for healthcare professionals to evaluate pain and disease activity as distinct aspects to inform JIA management.

What problems, if any, did you encounter in achieving the project's objectives, and how did you address them?

The project ran smoothly across the 12 months, and we encountered only minor problems. Minor problems and strategies engaged with address them included:

1. We had difficulty recruiting physiotherapist participants into the co-design workshops. We instead decided to focus workshops on young people with JIA and their families which also helped to maintain a safe space for families to share their stories.
2. For our final workshop in October, our lead co-design workshop facilitator (CI Davis) was in Europe completing a fellowship. As the workshops were online, he was still able facilitate the workshop remotely.
3. Participant attendance for the final workshop was slightly below the attendance rate of the previous workshops (n=16 in Workshop 4, compared to n=26, 22, and 25 for Workshops 1, 2, and 3, respectively). This was mostly due to participant sickness and flares in JIA. To overcome this, we mailed out the final prototype designs to all participants and provided the option for them to give feedback/suggestions via email.

What is the plan for dissemination of findings?

We have one manuscript 'under review' at an international rheumatology journal (scoping review) and we are in the final stages of writing up a manuscript for the co-design workshops. We anticipate this will be submitted to a journal during March 2026. We have submitted two abstracts to present this work at the Australian Rheumatology Australia Conference in May. I will be presenting on the findings of the co-design workshops in a topical session at the Australian Pain Society Annual Scientific Meeting (Adelaide) in April and at the International Association for the Study of Pain World Congress on Pain in Bangkok in October.

The deck of JIA cards is currently being finalised with our industry partner, Neuro Orthopaedic Institute (NOIgroup). Once completed, we will promote the cards through NOIgroup's clinical education networks, the Juvenile Arthritis Foundation Australia (JAFA), and other clinical and professional networks.

Future plans: We are now seeking funding to test the feasibility, acceptability, and preliminary efficacy of the VITAL intervention to reduce pain, increase physical activity, and

improve mental health for children and young people with JIA. I have recently submitted a fellowship application to the Channel 7 Children's Research Foundation to undertake this work.

Funding: We would like to acknowledge the support of Arthritis Australia and the ARA Research Trust in funding this work.