

Have your say

Join the young people's advisory group for a study about young people and chronic pain

Who am I looking for? Young people aged 13–19 who live with chronic musculoskeletal (MSK) pain - ongoing pain in your bones, joints or muscles lasting three months or more. That includes conditions like JIA, hypermobility-related pain, chronic back pain and other long-term MSK conditions. Parents and carers of young people with chronic MSK pain are welcome too.

What's this about? I'm Catherine, a PhD researcher at the University of Stirling. I'm running a study about how young people manage chronic pain in everyday life - not just the medical side, but the real stuff: routines, relationships, identity. Earlier this year, young people from Your Rheum and the JIA Champions helped me check that my interview questions and information sheets made sense. Now the study is about to start, and I want a small group who stay with it.

What would the group do? The advisory group helps decide how the study talks to young people. Things like:

- Which platforms and places the study should use to reach young people, and which it shouldn't.
- The words and pictures it uses - what sounds real and what sounds like a leaflet.
- What gets made (a short video? something written? both?) and what a young person's involvement should and shouldn't look like in public.
- How the findings get shared, so they reach people like you and not just journals.

These are real decisions; where the group says "not like that", the study changes. The things the group can't change are the ones ethics committees have fixed - how consent works, how people's information is protected, and how I keep people safe.

What's the time ask? A small group of three to six people, meeting online. The first session is planned for October 2026, with a handful of sessions over the following months - each about an hour, at times that work around school, college and work. You can step away at any point.

This is not the research study itself. Nobody in the group is being interviewed or studied. If you'd also like to take part in the study as a participant when it opens, that's a separate decision with its own information sheet - you can do one, the other, or both.

A few honest boundaries. I'm a researcher, not a clinician, so I can't give advice about anyone's pain or care. I read messages on weekdays. If you need someone to talk to now, Childline is 0800 1111 (under-19s), or your GP.

Interested? Get in touch:

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If you're under 16, I'd ask that a parent or guardian knows you're taking part; I'll send a short information note for you and for them before the first session.