

## Childhood Arthritis Prospective Study

# The role of illness beliefs in children with Juvenile Idiopathic Arthritis

### How do we understand illness?

We build a mental representation from what people tell us and from our experiences of being ill. We try to "make sense" of our illness.



These illness representations are built on illness beliefs (our thoughts) and feelings.



#### Did you know...

people build a representation of the world in their mind to understand it?

How we deal with our illness is based on these beliefs and feelings. Research shows this is important because it influences depression, anxiety, pain and disability.

We need to improve our knowledge and understanding of illness beliefs in children with JIA.



There is nothing I can do to control my arthritis. If it hurts it hurts, I can't stop it from hurting. Bianca, age 11



I don't think after having it for so long it would just disappear. lan, age 15



Good days are when I can't feel the pain and I can get on with my sports and my life and that. And then some days I can feel pain and I have to sit down and be steady with myself and lie down.

Carrie, age 11

It does make me angry if it's painful and I can't play out. Neil, age 11



If I managed to do something now that affected it or made it worse or if it were really hurting me and I just left it, it may cause more damage. I don't know. Harrison, age 16



#### Things we know about illness beliefs:

- Interviews with children showed that young people build mental representations in a similar way to adults.
- Everyone has a unique way of understanding illness.
- Because we try to "make sense" all the time, new information can change our mental representations.

#### **Implications**

- We are developing an age appropriate tool to capture a child's mental representation of JIA.
- This will help us know the role of illness beliefs in children with JIA.
- A tool can help us provide support to children and their families.