

What Do Young People with Rheumatic Disease Believe to be Important to Research About their Condition? A UK-Wide Study

Parsons et al. (2017)

<https://doi.org/10.1186/s12969-017-0181-1>

For which topic were research priorities identified?

rheumatic conditions

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

The Barbara Ansell National Network for Adolescent Rheumatology (BANNAR) is a network of research interested rheumatology professionals that focuses on ensuring that every young person in the UK has the best chance to benefit from developments in the field of adolescent and young adult rheumatology. A key objective for BANNAR is involving young people in developing the research priorities for the network and into future projects conducted by BANNAR members.

What was the objective?

to explore the research priorities of young people across the UK with respect to rheumatic conditions

What was the outcome?

a list of 5 research areas

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

focus group

How were the priorities for research identified exactly?

Step 1: 13 focus groups: 6 with 11-15 years olds and 7 with 16-24 years olds, researchers presented 5 areas which are currently researched, participants gave ideas and ranked them in terms of how much funding each area should get

Which stakeholders took part?

Young people aged 11-24 years old and under the care of a rheumatologist for a range of chronic conditions including: inflammatory arthritidis (juvenile idiopathic arthritis, inflammatory bowel disease associated arthritis, adult rheumatoid or psoriatic arthritis, ankylosing spondylitis) in addition to connective tissue diseases (such as SLE, scleroderma, vasculitides), chronic recurrent focal osteomyelitis, and chronic idiopathic pain syndromes. 63 participants.

How were stakeholders recruited?

Participants were recruited via senior rheumatology members and Arthritis Care (a UK based national charity).

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.