

Healthcare and Research Priorities of Adolescents and Young Adults with Systemic Lupus Erythematosus: A Mixed-Methods Study

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For which topic were research priorities identified?

systemic lupus erythematosus

In which location was the research priority setting conducted?

Australia - Australia

Why was it conducted at all?

Managing juvenile-onset systemic lupus erythematosus (SLE) is particularly challenging. The disease may be severe, adolescent patients have complex medical and psychosocial needs, and patients must navigate the transition to adult services.

What was the objective?

to identify the healthcare and research priorities of young patients with systemic lupus erythematosus and describe the reasons underpinning their priorities to inform patient-centered care

What was the outcome?

a list of 7 research topics

How long did the research prioritization take?

October 2013 - February 2014

Which methods were used to identify research priorities?

focus group; interview

How were the priorities for research identified exactly?

Step 1: interviews and focus groups: focus groups were convened by age groups (14-18 years, 19-30 years), specific research questions were developed before from a literature review, participants took part in priority allocation exercises for 5 areas relevant to SLE: general research topics in medical management, prevention and diagnosis, and lifestyle and psychosocial (3 topics), research questions addressing medical management (11 questions), research questions addressing prevention and diagnosis (5 questions), research questions addressing lifestyle and psychosocial care (4 questions), and healthcare specialties (11 specialties), for each exercise 10 tokens (each representing 1 vote) were given to each participant, participants instructed for each exercise to distribute all their tokens to the different research topics, research questions, and healthcare specialties, resulting in 7 priority topics

Which stakeholders took part?

Young patients with SLE. 26 participants.

How were stakeholders recruited?

Purposively sampled patients aged 14 to 30 years who were diagnosed with SLE before age 18 from 5 hospitals in New South Wales, Australia, were invited to participate.

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.