

Research Questions that Matter to Us: Priorities of Young People with Chronic Illnesses and their Caregivers

von Scheven et al. (2020)

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For which topic were research priorities identified?

chronic illnesses

In which location was the research priority setting conducted?

North America - USA

Why was it conducted at all?

The rising number of children carrying chronic disease with them into adulthood presents the research community with an obligation to address their unique needs. Authentic involvement of individuals and communities directly affected by the condition being studied ensures that research answers the questions of those most affected.

What was the objective?

to identify the highest priority research questions of young people living with chronic illness and their caregivers

What was the outcome?

a list of 15 research questions

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: focus groups: during first focus group session participants shared their experiences of living (or caring for someone) with a chronic condition and generated an extensive list of questions, 300 questions developed. Step 2: data processing: categorizing these questions by topic, resulting in 21 topics. Step 3: focus groups: during second focus group participants prioritized the topics they wanted researchers to focus on and ranked the specific questions they were most eager to have answered.

Which stakeholders took part?

Caregivers, adolescent patients. Participants: 12 caregivers, 5 young adult patients, 6 adolescents.

How were stakeholders recruited?

Participants were recruited by flyers and website advertisements from two local children's hospitals. Three cohorts of participants were recruited: adolescent patients age 15-18 years, young adult patients age 19-25 years, and caregivers (parents or guardians).

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.