

Clinical and Research Priorities for Children and Young People with Bronchiectasis: An International Roadmap

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For which topic were research priorities identified?

bronchiectasis

In which location was the research priority setting conducted?

international

Why was it conducted at all?

The global burden of children and young people (CYP) with bronchiectasis is being recognised increasingly. They experience a poor quality of life and recurrent respiratory exacerbations requiring additional treatment, including hospitalisation. However, there are no published data on patient-driven clinical needs and/or research priorities for paediatric bronchiectasis. Parent/patient-driven views are required to understand the clinical needs and research priorities to inform changes that benefit CYP with bronchiectasis and reduce their disease burden.

What was the objective?

to develop a roadmap to guide health services and research priorities pertinent to the needs of CYP (children and young people) and their parents/carers with bronchiectasis, in order to reduce their disease burden and improve their short- and long-term outcomes

What was the outcome?

a list of 10 research topics

How long did the research prioritization take?

July 2019 - September 2020

Which methods were used to identify research priorities?

survey

How were the priorities for research identified exactly?

Step 1: survey 1: for parents and patients, survey on quality of life, clinical needs and research priorities framed around concerns about your child's/your health, participants asked to rate effect on health. Step 2: survey 2: for health practitioners, survey was limited to research priorities, the 49 survey items were generated by working group based on research questions raised from our CPG and items adapted from adult data, practitioners asked to rate importance. Step 3: selection of the top 10 research priorities and formulating consensus statements: research priorities from both surveys were collated, condensed and summarized to identify the top 10 priorities, top 10 priorities were also reviewed by the Australian-based PAG, consensus statements were then formulated by the working group based on these research priorities

Which stakeholders took part?

Parent/patient survey: 225 participants: 70 (31%) adults with bronchiectasis diagnosed during childhood, 155 (69%) parents/carers of a CYP with bronchiectasis from 21 countries. Health practitioner survey: 258 health practitioners from 54 countries.

How were stakeholders recruited?

No information provided.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of two parent advisory groups: CPG and an Australian-based PAG.