



# International consensus statement on quality standards for managing children/adolescents with bronchiectasis from the ERS CRC Child-BEAR-Net

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Shareable abstract (@ERSpublications)

**Child-BEAR-Net has developed internationally derived, parent- and patient-informed, consensus-based quality standard statements for managing children and adolescents with bronchiectasis that can be used to improve the quality of care they receive** <https://bit.ly/3xTRjPt>

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## Introduction

Bronchiectasis represents a clinical syndrome of recurrent or persistent wet/productive cough with abnormal bronchial dilatation in chest computed tomography (CT) images [1, 2]. Previously considered rare [1, 3], it is globally more common than cystic fibrosis (CF) [4, 5], and has high patient burden, needs and treatment costs [4, 6, 7].

Unlike in adults, recent research has shown that paediatric bronchiectasis may be reversible if detected early in its course and treated effectively [1, 2]. Early diagnosis and optimal care (*i.e.* quality care) are necessary requirements for obtaining reversibility and/or improved clinical outcomes [1, 2]. Consistent and high-quality care for children/adolescents with bronchiectasis will help prevent progressive lung disease

and lung function deterioration, and improve quality of life and outlook, from improved lung function [8, 9] and reduced frequency and severity of exacerbations.

Currently, the quality of care for people with bronchiectasis is inequitable. In Australia, Indigenous adults with bronchiectasis die approximately 22 years earlier than other Australians with this diagnosis [10]. There is also reported inequity within a single centre, between children with CF and those with bronchiectasis [11]. Compared to age-matched children with CF, children with bronchiectasis have substantial and significantly poorer lung function, fewer medical reviews, and poorer access to chest physiotherapists [11]. Furthermore, in New Zealand, despite their significantly worse lung function, adolescents with bronchiectasis are also significantly less likely to receive appropriate transition care than those with CF [12]. Indeed, in many countries, children/adolescents with bronchiectasis are still managed as an “add-on” patient group in CF centres. During discussions with the European Lung Foundation (ELF)-established parent advisory group (PAG), some parents raised issues about poor accessibility to health services, including those provided by chest physiotherapists and respiratory physicians with expertise in bronchiectasis, especially when compared to services available to other chronic respiratory disorders within the same health facility. These elements are invariably important in the care of people with bronchiectasis.

Unsurprisingly, the ELF-PAG for the European Respiratory Society (ERS) clinical practice guideline for managing bronchiectasis in children and adolescents [2] expressed the urgent need for standardised quality care. Many steps are required for achieving quality improvement. The first is the availability of a series of quality standards based upon current recommendations, which is considered important by parents of children/adolescents with bronchiectasis, and to practising clinicians in the field. Availability of internationally derived quality standard statements that are clear, measurable and achievable for managing paediatric bronchiectasis is an important and necessary step for the care of children and adolescents, and their families, as well as informing future policy and practice directions.

Quality standard statements based upon the British Thoracic Society (BTS) guidelines for managing adults with bronchiectasis are available [13]. The BTS document consists of 11 quality statements and is used in audits in the UK and other European countries to drive healthcare improvements for adults with bronchiectasis [13, 14]. However, no such document exists currently for paediatric bronchiectasis.

In response to this gap, one of the initial objectives of Child-BEAR-Net (Children’s Bronchiectasis Education, Advocacy and Research Network) was to develop such a document [15]. Child-BEAR-Net is an ERS-funded Clinical Research Collaboration (CRC) [15]. The statements presented here represent an international consensus from both parents/patients and clinician perspectives.

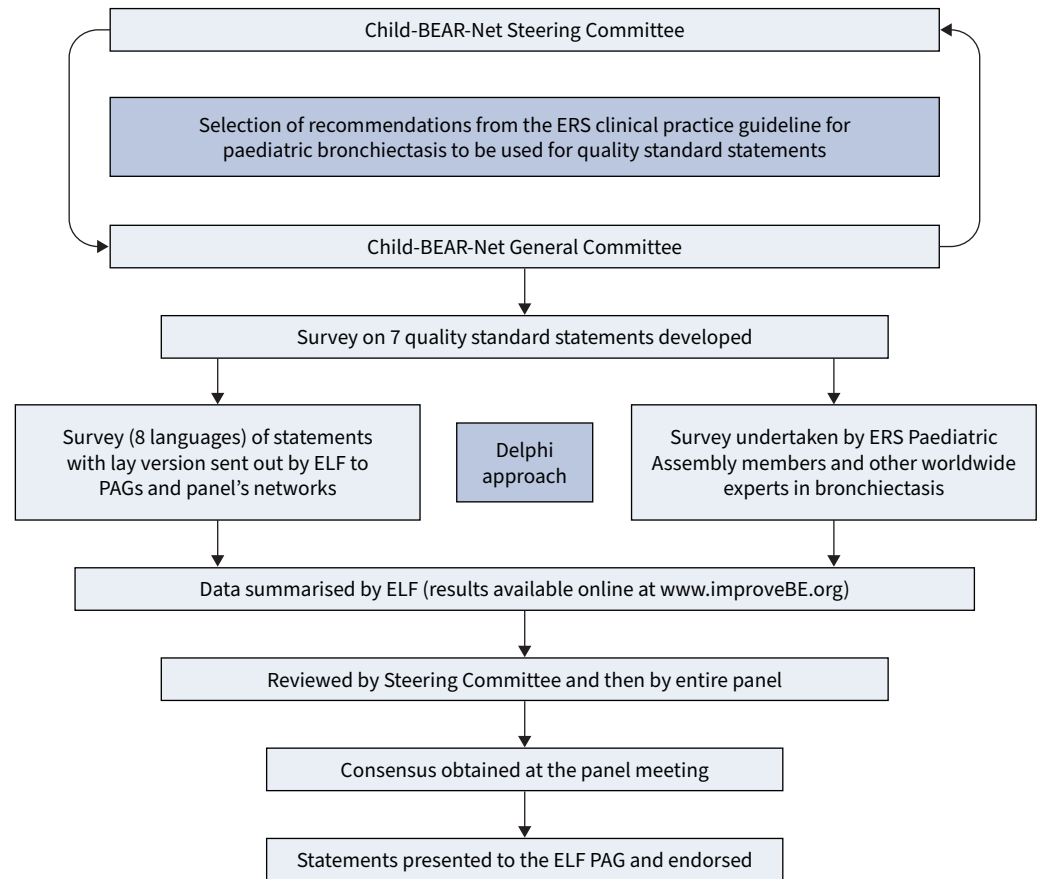
### Obtaining consensus

The methodology used is summarised in figure 1. Briefly, at the first meeting, the whole panel agreed upon adopting a Delphi approach. We held nine virtual meetings and also communicated by email.

Seven draft quality standard statements were formulated during these meetings. After panel members agreed with these statements, two international surveys were formulated for: 1) parents/carers of children/adolescents with bronchiectasis, and adults who had bronchiectasis diagnosed when they were either children or adolescents; and 2) clinicians who care for children/adolescents with bronchiectasis. Both surveys consisted of: 1) a demographics section; and 2) responses to each of the seven quality standard statements using a Likert scale (1 corresponding to “strongly agree”, and 5 to “strongly disagree”). We used the SurveyMonkey platform with a direct link to the clinical practice guideline [2].

201 people from 20 countries completed the parent/patient survey (32 did not state where they lived). The physician survey had 348 respondents, but 49 were excluded as they either did not care for children or adolescents or did not complete the survey. The remaining 299 physicians were from 54 countries, 89% (n=266) were paediatric respiratory specialists, of whom 77% practiced in university-based settings, and most (67%) cared for  $\geq 10$  children/adolescents with bronchiectasis.

For both surveys, our pre-defined consensus rate ( $\geq 80\%$ ) at the first iteration was obtained for all statements, except for statement 4 (agreement in clinician survey 76%, parent/patient 67%). After reviewing the free-text comments, we amended statement 4 to more accurately reflect the recommendation in the clinical practice guideline [2]: from “Children and adolescents with bronchiectasis who have  $>1$  hospitalised or  $\geq 3$  non-hospitalised exacerbations in the previous 12 months are offered long-term



**FIGURE 1** Schematic overview of methodology used to develop the consensus. The Child-BEAR-Net (Children’s Bronchiectasis Education, Advocacy and Research Network) steering and general committee members formed a quality standards panel that consisted of a European Lung Foundation (ELF) representative, parent advisory group (PAG) member, and experts in paediatric respiratory medicine, including managing bronchiectasis, as well as paediatric experts in infectious diseases, radiology, physiotherapy, and lung physiology, two global leaders in adult bronchiectasis, and the Cochrane Airways Group coordinating editor (who is also a primary care physician). ERS: European Respiratory Society.

macrolide antibiotics” to “Children and adolescents with bronchiectasis who have >1 hospitalised or  $\geq 3$  non-hospitalised exacerbations in the previous 12 months are offered at least a 6-month trial of macrolide antibiotics and the response assessed”.

For the six remaining statements, the agreement rate (strongly agree (score=1) or agree (score=2)) was high to very high, and ranged from 81% to 98% (weighted scores 1.2–1.7). In general, agreement was marginally higher in the clinician than the parent/patient survey for all statements other than quality standard statement 5. The disagreement rate (strongly disagree/disagree) ranged from 0–7% and the “neither agree or disagree” rate was 0–11%. The details and the full results from both surveys are available on the Child-BEAR-Net website at [www.improveBE.org](http://www.improveBE.org).

The CRC panel and ELF-PAG unanimously and independently endorsed these seven quality standard statements (table 1) at their respective final virtual meetings.

## Discussion

We achieved an international consensus amongst clinicians, parents and patients with bronchiectasis and produced seven quality standard statements for managing children and adolescents with bronchiectasis. This document from the ERS CRC Child-BEAR-Net presents the first quality standard statements for paediatric bronchiectasis.

**TABLE 1** Summary of quality standard statements for clinically significant bronchiectasis in children and adolescents

1)	Children and adolescents suspected of bronchiectasis have this confirmed by a chest computed tomography scan
2)	Children and adolescents with bronchiectasis are taught appropriate airway clearance techniques by a respiratory physiotherapist
3)	Children and adolescents with bronchiectasis with an acute exacerbation are prescribed at least 14 days of antibiotics
4)	Children and adolescents with bronchiectasis who have >1 hospitalised or $\geq 3$ non-hospitalised exacerbations in the previous 12 months are offered at least a 6-month trial of macrolide antibiotics and their response assessed
5)	Children and adolescents with bronchiectasis have the minimum panel of diagnostic tests undertaken
6)	Children and adolescents with bronchiectasis receive specialist paediatric respiratory physician care
7)	Children and adolescents with bronchiectasis are reviewed at least 6-monthly by a multidisciplinary team

Our quality standard statements are based upon recommendations from the ERS clinical practice guideline [2]. A paediatric-specific document is necessary, as although paediatric and adult bronchiectasis have shared features, there are also substantial differences. Children and adolescents require age-appropriate parental care, support and input. Biologically, children and adolescents have significantly different pathogen profiles (bacterial [16] and microbiota [17]), age-related immunological responses [18] and likely outcomes of treatment [1]. Diagnostic [1] and treatment methods can also differ in some areas, *e.g.* the substantial differences in applying airway clearance techniques, which are age- and cognition-dependent [19]. The comorbidities and relative frequency of underlying aetiologies are also different between adults and children [20]. Thus, our quality standard statements are different to the BTS quality standards document [13, 21], although we used it as a guide.

The quality of care that patients receive is inherently important in clinical practice when attempting to achieve the best outcomes for patients and their families. Ultimately, the health system and society also benefit from reduced mortality and hospitalisations, and patients having an overall improved quality of life [22]. Indeed, there is little doubt that standards matter [23], although defining standards is complex and sometimes it can be difficult to achieve consensus [24]. Recognising the importance and maintenance of standards of care, many countries (*e.g.* Australia and the UK [25, 26]) now have a governmental body/commission to help the health system deliver quality care and to provide regular reports [27]. For similar reasons, specialised societies, such as the BTS, have a “Standards of Care” Committee. Quality in healthcare is defined as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes, and are consistent with current professional knowledge” [27]. Quality standards are “a set of statements which describe the level of care consumers can expect from a health service. They aim to protect the public from harm and improve the quality of care provided” [27].

Arguably, standards of care are even more important in relatively neglected diseases, where inequity can be frequent and substantial. Bronchiectasis is one such disease, as currently it remains one of the most neglected pulmonary disorders [28], especially in children [29], and a marked inequity exists with other chronic respiratory diseases [10–12]. The requirement for better health services and clinical research for improving the lives and outcomes of children and adolescents with bronchiectasis, and the lives of their families, was highlighted recently by an international parent/patient survey of their clinical needs [6].

Improving healthcare is complex and requires many steps with coordinated action between health professionals, health systems, other government and non-government agencies, and communities [22]. These international consensus quality standard statements for managing children/adolescents with bronchiectasis are an initial step in improving the overall quality of care received by these patients. They are novel, being the first for paediatric bronchiectasis, and are significant as they complement the clinical practice guideline and will assist its implementation [2]. The quality standard statements will require updating when new evidence becomes available. To help address the current inequity, these statements can be used by: 1) parents/patients to access and advocate for quality care for their children/themselves; 2) health professionals to advocate for their patients; and 3) health systems as a monitoring tool and for reimbursement for patients. Implementing and auditing these standards are the next challenges to face.

Conflict of interest: E. Alexopoulou, A. Bush, A.J. Collaro, C. Constant, K. Douros, R. Fortescue, M. Griese, K. Grimwood, A. Hector, A.T. Hill, A. Kantar, B. Karadag, O. Mazulov, F. Midulla, A. Moeller, Z. Powell, M. Proesmans,

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