

Supplement file

Methods

The European Respiratory Society (ERS) Centre for Research Collaboration (CRC) for paediatric bronchiectasis (Child-BEAR-Net; Children's Bronchiectasis Education, Advocacy and Research Network) steering and general committee members met to form a panel to develop a series of Quality Standards of Care statements for managing bronchiectasis in children and adolescents. The panel included a European Lung Foundation (ELF) representative, a parent advisory group (PAG) member, specialists in paediatric respiratory medicine expert in managing children and adolescents with bronchiectasis, as well as paediatric experts in infectious disease, environmental health, allergy, radiology, physiotherapy, the Cochrane Airways Group coordinating editor (also a family medical practitioner), a respiratory physiologist, statistician, and two global leaders in adult bronchiectasis. Conflicts of interest were declared at commencing the CRC and managed in accordance with ERS policies.

At the first meeting, in April 2021 the whole panel agreed upon adopting a Delphi approach (Figure S1). Between April 2021 and January 2022, nine virtual meetings (four involving only steering committee members) were held and the panel also communicated regularly by email. The last meeting occurred between the PAG, ELF member and the chairs.

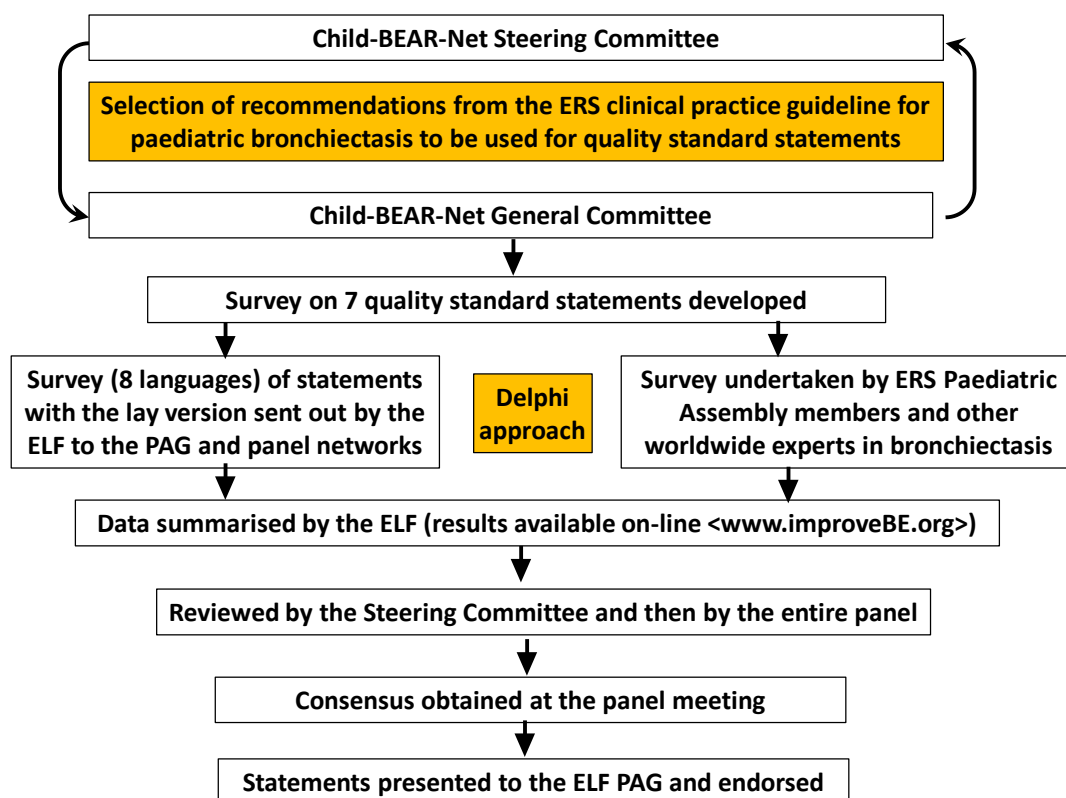


Figure S1: Schematic overview of methodology used to develop the consensus. Reproduced from related editorial.[1]

The first version of the Quality Standards of Care statements was based upon the 14 ERS clinical practice guidelines (CPG) recommendations for managing bronchiectasis in children and adolescents [2,3]. This was presented to the Child-BEAR-Net steering committee by the primary author. The steering committee members then selected nine recommendations from the CPG they deemed to be most important and measurable. These choices were next discussed by the whole panel and reduced to seven CPG recommendations. Draft Quality Standards of Care statements were formulated and modified further based upon discussions during the virtual meetings. After several iterations of the Quality Standards of Care statements by panel members and following their agreement with each of the seven statements, two international surveys were formulated for two groups of respondents; (i) parents/carers of children and adolescents with bronchiectasis, and adults who had bronchiectasis diagnosed when they were children or adolescents; and (ii) healthcare professionals who care for children and adolescents with bronchiectasis.

The Quality Standards of Care statements provided to survey participants were identical, although the parent/patient group had in addition an explanatory description in plain language accompanying each statement. Both surveys consisted of: (i) a demographics section, and (ii) responses to each of the seven Quality Standards of Care statements using a Likert scale (1=strongly agree and 5=strongly disagree). We used the SurveyMonkey platform (developed by ELF) with a direct link to the CPG [3].

The first survey, the parent/patient survey was available in eight languages. Links to the ELF-generated survey (open for more than 2-months (1st October 2021 to 9th December 2021) was sent to two PAGs (The CPG PAG [3] and another PAG in Brisbane, Australia [crelungs.org.au/cre-parent-and-community-advisory-group]). Panel members also promoted the survey in their clinics and through their networks. The second survey was an English-only version and involved healthcare professionals who cared for children and adolescents with bronchiectasis. This survey was available for 2-months (1st September 2021 to 31st Oct 2021) and was combined with another seeking feedback on defining bronchiectasis exacerbations for clinical trials in children and adolescents (ERS TF-2020-17). This web-based survey was sent to members of the ERS paediatrics assembly. Also, to capture data from non-ERS members, the panel members sent the link to their networks/collaborators and the ERS central CRC team contacted the European Paediatric Societies.

Data from both the parent/patient and healthcare professional surveys were summarised by the ELF panel member (JB). The survey results were reviewed by the steering group and the statements modified where necessary and later discussed with and then finalised by the full panel. Lastly, these statements were presented to the ELF-PAG for final review and endorsement at the last meeting.

Results

Overall, 209 people from 20 countries completed the parent/patient survey (32 did not state where they lived; Figure S2a). The physician survey had 348 respondents, of whom 49 were excluded as they either did not care for children and adolescents or did not fully complete the survey questions. The remaining 299 physicians were from 54 countries, of whom 266 (89%) were paediatric respiratory specialists. Most (77%) practiced in university-based

settings, and most (67%) cared for ≥ 10 children and adolescents with bronchiectasis (Figure S2b).

Figure S2a: Demographics: parent/patient survey

- 201 completed rating of QS statements and identified their location within 20 countries (see chart)
- 143 answered the status question:
 - 78% (n=135) a parent, relative or carer of a child or young adult with bronchiectasis
 - 22% (n=39) an adult with bronchiectasis (aged 18+) diagnosed as a child
- 157 answered the child's gender as:
 - 50% male
 - 50% female

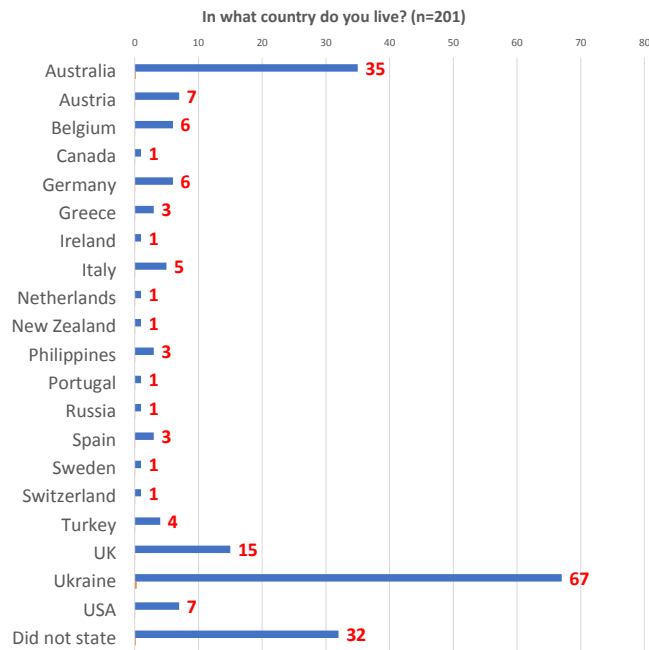
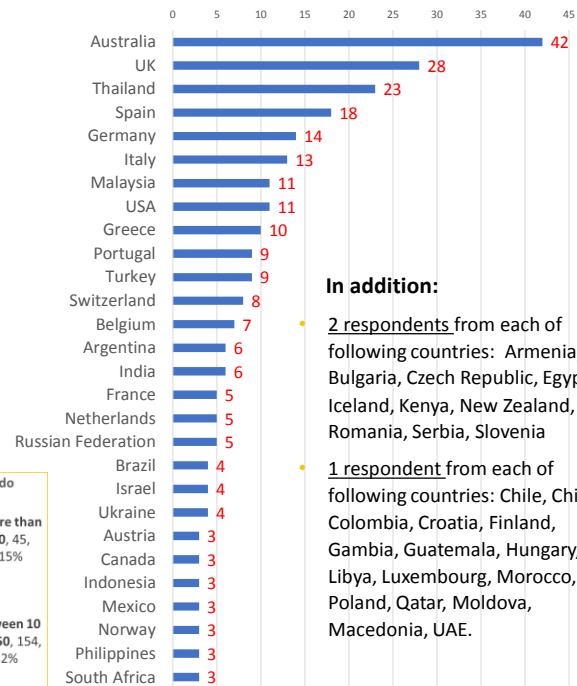


Figure S2b: Demographics: healthcare professionals

- 299 respondents completed survey
- All (100%) look after children/adolescents with bronchiectasis unrelated to cystic fibrosis
- Located in 54 countries:



In addition:

- 2 respondents from each of following countries: Armenia, Bulgaria, Czech Republic, Egypt, Iceland, Kenya, New Zealand, Romania, Serbia, Slovenia
- 1 respondent from each of following countries: Chile, China, Colombia, Croatia, Finland, Gambia, Guatemala, Hungary, Libya, Luxembourg, Morocco, Poland, Qatar, Moldova, Macedonia, UAE.

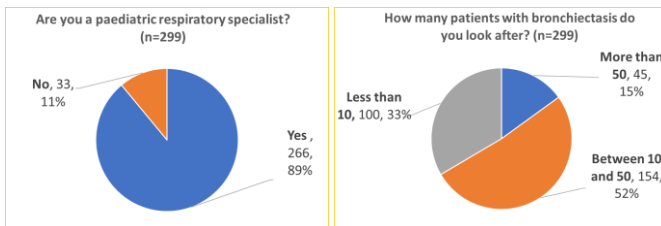


Figure S2: Demographics of the (a) patients/parents and (b) healthcare professionals who responded to the surveys [QS=Quality Standard]

For both surveys, our pre-defined consensus rate ($\geq 80\%$) at the first iteration was obtained for all statements except for Quality Standards statement-4 where agreement was 76% in the clinician survey and 67% in the parent/patient survey. After reviewing the free-text comments from the surveys for Quality Standards statement-4 and following discussion within the steering committee, this statement was amended to more accurately reflect the

intended use of long-term macrolides as recommended in the CPG [3]. Accordingly, Quality Standards statement-4 was altered from “Children and adolescents with bronchiectasis who have >1 hospitalised or ≥3 non-hospitalised exacerbations in the previous 12-months are offered long-term macrolide antibiotics” to “Children and adolescents with bronchiectasis who have >1 hospitalised or ≥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%. The weighted scores for the Quality Standards of Care statements ranged from 1.2 to 1.8 (Figure in the main manuscript). In general, agreement was marginally higher in the clinician than the parent/patient survey for all statements other than Quality Standards statement-5. The disagreement rate (strongly disagree or disagree) ranged from 0 to 7% and the ‘neither agree nor disagree’ rate was between 0 and 11%.

The CRC panel and ELF-PAG unanimously and independently endorsed these seven Quality Standards of Care statements (Table 1 in the main manuscript) and their supporting material (Table 2 in the main manuscript) at their respective final virtual meetings.

References

- 1 Chang AB, Boyd J, Bush A, et al. International consensus statement on quality standards for managing children/adolescents with bronchiectasis from the ERS CRC Child-BEAR-Net. *Eur Respir J* 2022; in press.
- 2 Chang AB, Bush A, Grimwood K. Bronchiectasis in children: Diagnosis and Treatment. *Lancet* 2018; 392: 866-879.
- 3 Chang AB, Fortescue R, Grimwood K, et al. Task Force report: European Respiratory Society guidelines for the management of children and adolescents with bronchiectasis. *Eur Respir J* 2021; 58: 2002990.