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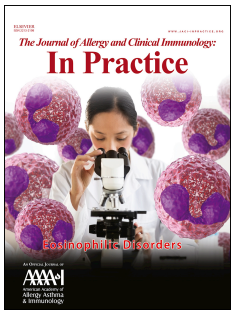

Standardization of reporting obstructive airway disease in children: A national Delphi process

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PII: S2213-2198(22)00936-9

DOI: https://doi.org/10.1016/j.jaip.2022.08.050

Reference: JAIP 4406

To appear in: *The Journal of Allergy and Clinical Immunology: In Practice*

Received Date: 26 February 2022

Revised Date: 17 July 2022

Accepted Date: 30 August 2022

Please cite this article as: de Jong CC, Ardura-Garcia C, Pedersen ES, Mallet MC, Mueller-Suter D, Jochmann A, Singer F, Casaulta CA, Regamey N, Moeller A, Goutaki M, Kuehni CE, Standardization of reporting obstructive airway disease in children: A national Delphi process, *The Journal of Allergy and Clinical Immunology: In Practice* (2022), doi: https://doi.org/10.1016/j.jaip.2022.08.050.

Standardization of reporting obstructive airway disease in children: A national Delphi process

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Disclosure statement

de Jong CCM, Ardura-Garcia C, Pedersen ESL, Mallet MC, Mueller-Suter D, Jochmann A, Casaulta CA, Regamey N, Moeller A, Goutaki M and Kuehni CE have nothing to disclose. F. Singer reports personal fees from Novartis, personal fees from Vertex, grants from Swiss Cystic Fibrosis Society, grants from Lungenliga Bern (Bern lung foundation), outside the submitted work.

Funding

This study was funded by the Swiss National Science Foundation (32003B_162820/1) and supported by the Research Fund of the Swiss Lung Association, Bern (2019-03_641670). Further funding to develop the Swiss Pediatric Airway Cohort (SPAC) came from the Lung League St. Gallen, Switzerland.

Word count:

Abstract: 248 words

Manuscript: 3160 words

Abstract

Background

Pediatric pulmonologists report asthma and obstructive bronchitis in medical records in a variety of ways and there is no consensus for standardized reporting.

Objective

We investigated which diagnostic labels and features pediatric pulmonologists use to describe obstructive airway disease in children and aimed to reach consensus for standardized reporting.

Methods

We obtained electronic health records from 562 children participating in the Swiss Pediatric Airway Cohort (SPAC) from 2017 to 2018. We reviewed the diagnosis section of the letters written by pediatric pulmonologists to referring physicians and extracted the terms used to describe the diagnosis. We grouped these terms into diagnostic labels (e.g., asthma) and features (e.g., triggers) using qualitative thematic framework analysis. We also assessed how frequently the different terms were used. Results were fed into a modified Delphi process to reach consensus on standardized reporting.

Results

Pediatric pulmonologists used 123 different terms to describe the diagnosis, which we grouped into 6 diagnostic labels and 17 features. Consensus from the Delphi process resulted in the following recommendations: (i) to use the diagnostic label ”asthma” for children older than 5 years and ”obstructive bronchitis” or ”suspected asthma” for children younger than 5 years; (ii) to accompany the diagnosis with relevant features: diagnostic certainty, triggers, symptom control, risk of exacerbation, atopy, treatment adherence, and symptom perception.

Conclusion

We found great heterogeneity in the reporting of obstructive airway disease among pediatric pulmonologists. The proposed standardized reporting will simplify communication among physicians and improve quality of research based on electronic health records.

Highlights box

1 What is already known about this topic?

Pediatric pulmonologists use a myriad terms to report asthma and obstructive bronchitis in medical records due to the lack of consensus on standardized reporting. (24/35 words)

2 What does this article add to our knowledge?

This is the first study that analyzed the terms used by pediatric pulmonologists to report diagnosis of obstructive airway disease in medical records and proposed standardized reporting based on consensus among specialists (32/35 words)

3 How does this study impact current management guidelines?

We recommend standardized reporting for children's obstructive airway disease that includes diagnostic labels and features that are relevant for treatment and follow-up. (22/35 words)

Key words: asthma, diagnosis, children, clinical practice, diagnostic labels, standardization, standardized reporting, reporting

List of abbreviations

API - Asthma predictive index

FeNO - Fractional exhaled nitric oxide

FEV1 - Forced expiratory volume in the first second

GINA – Global initiative for asthma

ICD – international classification of diseases

IQR – interquartile range

KEB - Cantonal Ethics Committee Bern (Kantonale Ethikkommission Bern)

PARC - Predicting asthma risk in children

REDCap – Research Electronic Data Capture

SPAC – Swiss Pediatric Airway Cohort

Introduction

Obstructive airway disease in children (e.g., obstructive bronchitis, asthma) is difficult to diagnose because symptoms are unspecific, vary over time, and are difficult for parents to describe [1-3]. Moreover, several tests are used to support the diagnosis, but there is no standalone diagnostic test [1, 2]. In infants and pre-school children diagnosis is especially difficult, as they cannot perform standard lung function tests, and symptoms of viral infections such as bronchiolitis can be similar [4]. Obstructive airway disease is also a heterogeneous entity including many subtypes (phenotypes), meaning that children with obstructive airway disease can have different clinical presentations and underlying etiology [5-8]. Therefore, the diagnosis is not uniform nor certain. Uncertainty is also reflected in physician's phrasing when they describe the diagnosis in medical records. Some physicians only report a single diagnosis of asthma, while many complement it by adding features such as severity, triggers or symptom control. These inconsistencies can lead to problems when patients are treated by different doctors, and when medical records are used in research. Although medical records may be less vulnerable to recall bias and more objective than patient reported information, the lack of standardized reporting complicates the use of diagnoses from medical records, which in turn affects research based on these information sources. For instance, these inconsistencies complicate ensuring accurate inclusion/exclusion criteria for observational or interventional studies. A more standardized reporting of obstructive airway disease would thus facilitate clinical research and communication between physicians, for instance when a patient switches doctor or hospital.

A measure to overcome heterogeneous reporting of diagnosis in medical records is the international classification of diseases (ICD). However, ICD-10 only differentiates asthma

into allergic, non-allergic, mixed, and not further specified [9]. This does not reflect the current scientific understanding. Previous studies aiming to standardize reporting for obstructive airway disease assessed which features were reported by guidelines and studies, but not the terms used in clinical practice [10-13]. The few exceptions were done in an adult primary care setting [14, 15]. We therefore lack real-world evidence on the diagnostic labels and features that pediatric pulmonologists use to describe obstructive airway disease in medical records.

In this study, we (1) investigated the diagnostic labels and descriptive features used by pediatric pulmonologists to describe obstructive airway disease in children and, based on this, (2) conducted a Delphi process with the goal to recommend a standard way of reporting children's obstructive airway disease in medical records.

Methods

Study population

We conducted this study using medical records from children participating in the Swiss Paediatric Airway Cohort (SPAC). SPAC is an observational study of children (0-17 years) referred to pediatric pulmonary outpatient clinics in Switzerland for respiratory symptoms such as wheeze, cough, dyspnea, or exercise-related respiratory symptoms. The SPAC study protocol has been published elsewhere [16]. Importantly, as SPAC is observational and embedded in routine care, it does not standardize reporting of information in medical records, nor diagnostic investigations or treatments. For SPAC, original data is extracted from medical records and patient-reported information is extracted from questionnaires. The questionnaire data was used only to describe the characteristics of the study population (i.e. reported symptoms and medication use in the past 12 months). For the main analysis, we only used data derived from medical records.

Study design

From medical records, we collected the hospital letters, which were sent by pediatric pulmonologists to the referring physicians (pediatricians or general practitioners) after a child's consultation in the outpatient clinics. We analyzed the descriptions of the diagnosis from the diagnosis section of these letters. We included one letter from each child (aged 0-17 years) who visited a participating SPAC outpatient clinic between July 2017 and November 2018 and who was diagnosed with an obstructive airway disease (Figure 1). If the child had multiple letters, we selected the letter from the first visit after which the parents gave informed consent. We read all diagnosis sections of these letters and included the child in the study if the diagnosis section of the hospital letter contained the terms "asthma,"

"wheeze," and/or "obstructive bronchitis". We then went through the remaining records again, to make sure that we had not missed children with obstructive airway disease labelled differently (e.g. as bronchial hyperreactivity or hyperresponsiveness). The inclusion of the child was independent of the pediatric pulmonologist who wrote the letter. The seven centers participating in SPAC represent all larger pediatric pulmonary outpatient clinics from German-speaking regions of Switzerland. All participating centers are either secondary or tertiary board qualified training centers in Pediatric Pulmonology. There were 1-5 board qualified pediatric pulmonologists working in each center.

Study procedures

The pediatric pulmonologists wrote the hospital letter or supervised the writing by junior physicians. The letter always starts with listing the diagnoses and then summarizes history, findings, interpretation, and suggested management. We entered all relevant information from the letters into an online REDCap database.

Qualitative analysis

We imported the text describing diagnoses into NVivo 12 to aid in the organization and classification of the text. We identified diagnostic labels and features used in the hospital letters to describe obstructive airway disease using thematic framework analysis (Figure 2). A physician (CdJ) coded the words used to describe obstructive airway disease in the diagnosis list using open-end coding. Next, we grouped the codes into themes, from now on called diagnostic labels, if the code was a term for the disease such as "asthma", or features if the code described the disease such as symptoms and triggers. Through this analysis, a list of diagnostic labels and features was produced (Table E1).

Quantitative analysis

We assessed how frequently each diagnostic label and feature was mentioned in the diagnosis section of the 562 hospital letters and stratified the results by age group and clinic. Because of children's inability to perform standard lung function tests under age 5 and increased self-management of symptoms during teenage years, we defined 3 age groups: 0-4, 5-9, and 10-17 years. We used descriptive analysis in STATA Version 15 and displayed proportions in histograms. Based on the frequency of use, we wrote a recommendation for each diagnostic label and feature. For example, "In standardized reports of obstructive airway disease in children, triggers should be stated". These recommendations were then used to start the Delphi process.

Delphi process

To propose a standardized way of reporting obstructive airway disease based on a consensus, we followed a modified Delphi process with several rounds of questionnaires [17]. For the Delphi process we invited one representative from each clinic who was either the head pulmonologist or was appointed by the head to be the center's representative for the study, so they all had a strong interest in the topic. The pediatric pulmonologists participating in the Delphi process are closely collaborating with colleagues from other European countries, in particular those organized with the ERS. They join international conferences, are members of ERS taskforces and scientific groups, and are trained according to the international guidelines including the HERMES exam of the European Respiratory Society, with the resources required for their training on site. The first Delphi questionnaire consisted of the list of recommendations for each diagnostic label and feature obtained from our qualitative analysis. We also included information on frequency of use of

these terms from our quantitative analysis. Pediatric pulmonologists could anonymously agree or disagree with each recommendation and they could write alternative recommendations if they chose. For each questionnaire, we analyzed the level of agreement and developed the next Delphi questionnaire with revised recommendations. After three rounds, we reached consensus with at least 70% agreement.

Ethics statement

The SPAC study has been approved by the Cantonal ethics committee of Bern (KEB 2016-02176) in Switzerland. All participating parents and adolescents 14 years or older gave informed written consent.

Results

Characteristics of the study population

We included hospital letters from 562 patients (65% male, median age 8 years, interquartile range [IQR] 5-11) (Figure 1 and Table I). Forty percent of the letters came from a first visit of a child in the hospital, 60% from a follow-up visit. Respiratory symptoms included wheeze, exercise-induced problems, dyspnea, night cough, and prolonged cough (>4 weeks in a row) (Table I). Overall, 509 (91%) children had used asthma inhalers including 390 (69%) with inhaled corticosteroids.

Spectrum and grouping of terms used to describe obstructive airway disease

We identified 123 codes used to describe obstructive airway disease in the diagnosis section of these 562 letters. We grouped these codes into 6 diagnostic labels and 17 features (Table E1).

The 6 diagnostic labels used were (1) bronchial asthma (used 446 times), (2) asthma (used 54 times), (3) small airways disease (used 2 times), (4) episodic viral wheeze (used 36 times), (5) multiple trigger wheeze (used 11 times), and (6) obstructive bronchitis (used 83 times). Often multiple labels were reported and the use of labels varied by age. Obstructive bronchitis, episodic viral wheeze or multiple trigger wheeze were reported in 88% of the diagnosis of children aged 0-4 years.

The 17 features used in the diagnosis section, in addition to the diagnosis itself, were: (1) certainty of diagnosis (e.g., ”suspected” and ”probably”); (2) age related phenotype (e.g., ”pediatric,” ”infant,” and ”toddler”); (3) symptoms (such as ”cough” and ”dyspnea”); (4) symptom perception; (5) pattern of symptoms over time (e.g., ”recurrent,” ”chronic,” and ”episodic”); (6) seasonal or perennial; (7) triggers (e.g., ”allergic,” ”infection,”

241 and ”exercise”); (8) related measures of disease severity, including terms describing the
242 severity directly, such as ”mild,” ”severe,” and ”difficult to treat,” along with terms
243 describing the frequency and severity of exacerbations, stability, and the effects on daily
244 life; (9) lung function, which included the terms ”obstructive,” ”partially reversible,” and
245 forced expiratory volume in 1 second (FEV1) values; (10) airway inflammation (e.g.,
246 fractional exhaled nitric oxide (FeNO) values); (11) airway hyperresponsiveness (e.g., ”mild,”
247 ”moderate,” or ”severe hyperresponsiveness” in ”methacholine,” ”mannitol,” or ”exercise
248 challenge test”); (12) atopy, including terms describing allergens children are sensitized to
249 and the clinical relevance of the sensitizations; (13) therapy (e.g., medications); (14)
250 symptom control (e.g., ”uncontrolled” and ”well controlled”); (15) therapy response (e.g.,
251 ”poor” or ”good response to treatment”); (16) compliance (e.g., ”malcompliance” and
252 ”medication frequently forgotten”); (17) risk of future asthma (e.g., asthma predictive index
253 [API] and predicting asthma risk in children [PARC] scores) [18, 19]. Several terms reported
254 in the diagnosis list did not fit into any of these features and were only used once (“type II”,
255 “atypical”, “known”, “residual”, and “since”).
256
257 **Frequency of used features to describe a diagnosis of obstructive airway disease**
258 The most frequently reported features were atopy (431, 77%) and triggers (468,
259 81%) (Figure 3, Table E1). Patterns of symptoms over time (mainly ”recurrence”), symptom
260 control, certainty of diagnosis (mainly ”suspected”), and related measures of disease
261 severity (mainly ”hospitalizations”) were mentioned in 97-139 (17-25%) of the letters. Test
262 results other than atopy, such as lung function and airway hyperresponsiveness, were
263 mentioned in 11-52 (2-9%) of the letters. Compliance, symptom perception, therapy
264 response and asthma prediction scores were rarely reported (3-10 times, 1-2%).

The frequency, in which the 17 features were mentioned in hospital letters, varied by patients age (Figure 3). Certainty of diagnosis, age related phenotypes, patterns of symptoms over time, measures of disease severity, and asthma prediction scores were mostly reported for preschool children, while triggers, allergy and other test results, symptom control, and symptom perception were mainly mentioned for children aged 5-17 years. Compliance was exclusively reported in children aged 10-17 years.

We found great heterogeneity between clinics in the reporting of diagnoses and related features. Most frequently mentioned across all clinics were certainty of diagnosis, patterns of symptoms over time, triggers, measures of disease severity, atopy, and symptom control (Figure 4).

Delphi process: Recommended standardized reporting for obstructive airway disease

We reached 71-100% agreement for each of the standardized reporting recommendations for obstructive airway disease after 3 rounds of the Delphi questionnaires (Table E2). Our final recommendations include the diagnosis and 7 features: certainty of diagnosis, triggers, symptom control, risk of exacerbation, atopy, treatment adherence, and symptom perception (Table II). Talbe III shows examples of standardized reporting of obstructive airway disease for two children.

In the first round, we reached agreement about reporting in the diagnosis list certainty of diagnosis (100%), triggers (100%), atopy and its clinical relevance (100%), symptom control (100%), and treatment adherence (71%). We also agreed to leave out information about reported symptoms (71%), the date of diagnosis (100%), frequency of episodes (71%), stability (100%), limitations during sports and daily activities (71%), therapy (86%), and prediction scores (100%) in the diagnosis section of the letter.

In the second round, we reached agreement to report the diagnostic label asthma (e.g., leaving out the label “bronchial”) in children aged 5 years or older (81%). We agreed to include the severity as ”severe” or ”difficult to treat asthma” if the Global Initiative for Asthma (GINA) guideline definitions are met (86%), but to drop “mild” or “moderate” severity as there are no guideline definitions for these severities (100%). We agreed to add risk of exacerbation in the diagnosis list as an additional marker of severity by including the number of severe exacerbations in the last 12 months, and month and year of the last severe exacerbation (100%). We agreed as well to include differential diagnoses if the diagnosis was only suspected (86%), poor symptom perception (100%), and airway hyperresponsiveness as a measure of the certainty of diagnosis (86%). We decided to drop symptom persistence and seasonality since this information is also captured by triggers (100%), and to drop treatment step according to GINA guidelines (86%).

In the third round, we agreed to distinguish two diagnostic labels for children under age 5 years (A) recurrent obstructive bronchitis and (B) suspected asthma (which cannot be confirmed because the child is too young to measure spirometry and FeNO (100%). We agreed to use the label obstructive bronchitis if attacks are only triggered by infections and to use the label suspected asthma if any other trigger is present (exercise outside of an infection period or an allergic trigger). We also agreed to list results of relevant diagnostic tests in the diagnosis list to display the level of certainty of the diagnosis (100%). For example, “asthma confirmed by a methacholine challenge test in 09/2020.”

Discussion

This study is the first to propose standardized reporting recommendations for diagnostic labels of obstructive airway disease in children. The recommendations are based on an analysis of the diagnosis section from 562 hospital letters sent in 2017 and 2018 from pediatric pulmonology outpatient clinics of 7 Swiss hospitals to the referring physician. This evidence, which reflects current practice, was used to guide a Delphi consensus process among pediatric pulmonologists in the German-speaking part of Switzerland.

Comparison with other studies

We found four other studies that proposed standardized ways physicians should use to describe a diagnosis of asthma. All are from primary care and relate to adult patients and all based their recommendations either on features mentioned in national registries, in guidelines, or in the literature. A Swiss study systematically reviewed scientific articles and clinical guidelines to identify evidence-based indicators (i.e., features) that could be used to monitor adult chronic conditions for primary care [10]. They found 21 features for asthma: diagnostic tests and results (e.g., spirometry, bronchial provocation test), symptoms, activity limitations, symptom control, smoking (e.g., habit and cessation advice), therapy, triggers, exacerbations, and adherence. The list is comparable to ours, except for smoking, which is less relevant for childhood asthma.

Minard et al. performed a literature review to identify studies that propose a standardized asthma data set for clinical research. [20] As they did not identify any study, they asked a team of 50 different health care administrators, health care workers, and information management/technology experts to select relevant features of asthma in adults. They selected: certainty of diagnosis, diagnostic test results (spirometry, bronchial

provocation, and allergy test), smoking, occupation, triggers, asthma control, symptoms, activity limitations, exacerbations, measures to prevent exacerbations (environmental, smoking cessation, immunization), adherence, and therapy. We have a similar list but we kept fewer features in our final recommendation because the participating pediatric pulmonologists wanted to keep the diagnosis list as concise as possible to improve feasibility of its use in everyday clinical care.

Two studies on asthma in adults did also use a Delphi process to reach consensus for standardized reporting, as it allows stakeholders to shape and support the recommendations, especially when those recommendations are based on current practice. A study from the UK obtained consensus among an international team of 27 experts on features to include in an international severe asthma registry. They selected features based on existing national severe asthma registries and reached consensus after 3 Delphi rounds and 2 meetings [13]. They selected: patient details like height and weight, occupation, medical history including smoking, comorbidity, blood/sputum, allergy, lung function and other test results, symptom control, medication, GINA treatment step, adherence, and management plan. In our study, the pediatric pulmonologists agreed after 3 Delphi rounds so an extra meeting was not necessary. A Dutch study aimed to achieve consensus for standardized reporting of asthma in medical records for general practice. They started with a list of 65 features used in the Dutch College of General Practitioners guidelines to describe a diagnosis of asthma. After 3 Delphi rounds and one meeting to resolve the final disagreements, they concluded that a modified Delphi procedure is an appropriate method to reach agreement on standardized reporting for medical records. They stated that a starting point, such as a set of existing guidelines, is essential for the success of the process [12]. Unfortunately, they did not publish a list of the selected features. We also believe that

we reached consensus relatively easily (after only 3 rounds) because we started the discussion by presenting results from the analysis of the terms pediatric pulmonologists had used over the previous 2 years.

Choosing diagnostic labels for obstructive airway disease in children has been a matter of debate. Although many studies attempted to distinguish between subgroups of patients and to define phenotypes [21-23] others do not support the distinction of asthma phenotypes for clinical care because phenotypes may change over time within a child, and there is no general agreement on how to define phenotypes prospectively [23-25]. Instead, studies suggest to report a simple diagnostic label (e.g., asthma), plus relevant features or traits, which ideally are treatable [5-8]. The distinction in diagnostic label for children under and over age 5 years is a consequence of the uncertainty of diagnosis in young children because they cannot perform most diagnostic tests yet [21-25]. For children younger than age 5, we distinguished between “obstructive bronchitis” if the trigger is only infectious and “asthma” if children also report triggers other than infections. Many preschool children have only few episodes of wheeze triggered by respiratory infections. Preschoolers reporting wheeze triggered apart from infections have a higher likelihood to remain symptomatic later in life. As these children cannot perform standard objective tests, information about triggers of episodes of bronchial obstruction is important for the prognosis and follow-up care [21-25]. Adding explanatory features is important because a simple diagnostic label (e.g., asthma) does not cover the heterogeneity of the disease [5-8, 24, 25]. Also, our participants agreed that, in addition to a simple diagnostic label, it is important to report features relevant for treatment and follow-up.

Strengths and limitations

Our study is the first to propose standardized reporting of diagnosis in children with obstructive airway disease. We expect that our recommendations have a good chance to be implemented in clinics because they are based on empirical evidence from current clinical practice and have been agreed upon In a Delphi process by a large number of leading pediatric pulmonologists. Our study was limited to the German-speaking part of Switzerland, as it would have exceeded our resources to code the diagnostic labels and features used in three languages. Terminologies to report obstructive airway disease in medical practice will differ among languages and countries. In our proposal we focused on the aspects of obstructive airway disease that are transportable across countries. For example, triggers for asthma symptoms differ between countries, but the proposal to always report triggers as an aspect of obstructive airway disease is internationally applicable. Furthermore, we only included letters from children enrolled in the SPAC study. However, since study participation depended on participant or parental consent—not on pediatric pulmonologist consent—we do not believe that this has introduced bias.

Implication for clinical practice and research

Standardized reporting according to our proposal will overcome prior inconsistencies between physicians with a more nuanced description than the ICD-10 codes. Standardized reporting will improve communication between physicians when children change health care provider. It will also help with future observational and interventional studies because inclusion and exclusion criteria will be more accurate. With respect to research, adding descriptors to the diagnostic terms might not help to separate asthma from non-asthma patients. It also adds complexity to the description of the diagnosis. On the positive side, it will contribute to a better description of the individual asthma phenotypes and traits which

406 are relevant for the child and thus be valuable to study specific subgroups of children with
407 asthma and to support personalized health care [7]. If diagnoses written in medical records
408 are standardized, research can be done at a faster rate and at lower cost because physicians
409 and researchers do not need to search as long for information in medical records [26, 27].
410

411 **Conclusion**

412 This study recommends standardizing reporting of obstructive airway disease in
413 children, which includes the features that are relevant for treatment and follow-up.
414 Implementation of these recommendations can lead to better clinical care for these
415 children, as well as more accurate data for clinical research.

Ethics approval and consent to participate

The Bernese ethics committee (KEB 2016-02176) approved the Swiss Pediatric Airway Cohort and all participating parents and adolescents aged above 14 years gave informed consent.

Authors' contributions

CdJ, EP, CAG, MG, and CK developed the concept and designed the study. CdJ, EP, MCM, DMS, AJ, FS, CC, NR, JB, and AM collected the data. CdJ analyzed the data, with aid of EP, CAG, and MG. CdJ, EP, CAG, MG, and CK drafted the manuscript. All authors contributed to iterations and approved the final version.

Acknowledgements

We are grateful to all the children and their parents for participating in this study. Data collection was funded by the Swiss National Science Foundation (32003B_162820/1) and supported by the Research Fund of the Swiss Lung Association, Bern (2019-03_641670). Further funding to develop the Swiss Pediatric Airway Cohort (SPAC) came from the Lung League St. Gallen, Switzerland.

Availability of data and material

The SPAC dataset is available upon reasonable request by contacting Claudia Kuehni.

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Figure and tables

Figure 1 Flow chart for inclusion of one hospital letter per child diagnosed with obstructive airway disease participating in the Swiss Paediatric Airway Cohort (SPAC)

Figure 2 Flow chart of qualitative and quantitative analysis steps, as well as the Delphi process

Figure 3 The proportion of letters in which pediatric pulmonologists reported features of children with obstructive airway disease, stratified by the patients age (N=562)

Figure 4 The proportion of letters in which pediatric pulmonologists report features of children with obstructive airway disease, stratified by center (N=562)

528 **Table I** Characteristics of study participants (N=562)

	Total n (%)	
Age		
0-4 years	112	(20)
5-9 years	211	(38)
10-17 years	239	(43)
Sex, male	365	(65)
Clinic		
A	187	(33)
B	149	(27)
C	80	(14)
D	66	(12)
E	35	(6)
F	25	(4)
G	20	(4)
First visit	226	(40)
Follow-up visit	336	(60)
Reported respiratory symptoms*		
Wheeze	388	(69)
Dyspnoea	278	(49)
Exercise related breathing problems	343	(61)
Night cough	232	(41)
Prolonged cough (> 4 weeks)	169	(30)
Medication*		
Any asthma inhaler	509	(91)
SABA alone	119	(21)
ICS +/- SABA	203	(36)
ICS + LABA	187	(33)

529 * in the last 12 months

530

531

532 **Table II**. Standardized reporting recommendations for children's obstructive airway disease
533 based on consensus among pediatric pulmonologists through the Delphi process.
534

Proposed standardized reporting recommendations for obstructive airway disease in children.

1 **Diagnosis**: asthma or recurrent obstructive bronchitis[1]

2 **Certainty**: confirmed (name tests, month/year) or suspected[2] (state differential diagnosis)

3 **Triggers**

4 **Symptom control**: well, partly, or uncontrolled[3]

5 **Risk of exacerbation**: number of severe exacerbations[4] in the last 12 months and month/year of last severe exacerbation

6 **Atopy**: sensitizations and clinical relevance

7 **Treatment adherence**: poor, moderate or good[5]

8 **Symptom perception:** state symptom perception if poor perceived[6]

535

536 [1] **Diagnosis**: use obstructive bronchitis if attacks are **only** triggered by infections. Use asthma if any other
537 trigger (such as exercise outside of an infection period or an allergic trigger) is present. Use severe asthma if
538 the child has severe asthma or difficult to treat asthma if the child has difficult to treat asthma according to the
539 definition from the GINA guidelines.
540 [2] **Certainty**: if the diagnostic tests were inconclusive or if the child could not perform diagnostic tests, state
541 "suspected asthma."
542 [3] **Symptom control**: use "well," "partly," or "uncontrolled," according to the definition from the GINA
543 guidelines.
544 [4] **Risk of exacerbation**: if an attack needed an emergency consultation, state "severe exacerbation".
545 [5] **Treatment adherence**: good = almost always; moderate = only for symptoms; poor = very rarely.
546 [6] **Symptom perception**: if the patient/parents report different subjective symptom control compared to
547 symptom control from the physical examination and/or test results, use "poor symptom perception"
548

549

550 **Table III** Examples of standardized reporting of children's obstructive airway disease

Example 1: Patient aged 8 years

Diagnosis

1. **Asthma**
   - confirmed by reversible bronchial obstruction in lung function testing (01/2018)
   - triggers: sport and pollen
   - symptoms: partially controlled
   - no hospitalizations, last severe exacerbation in 06/2020
   - atopic sensitization: grasses with clinical relevance and cats without clinical relevance
   - good adherence
   - poor symptom perception
2. **Atopic eczema**

Example 2: Patient aged 4 years

Diagnosis

1. **Suspected asthma**
   - DD recurrent obstructive bronchitis
   - triggers: respiratory infections and physical activity
   - symptoms: well controlled
   - 3 hospitalizations, last severe episode in 01/2021
   - atopic sensitization: birch without clinical relevance
   - poor adherence
2. **Atopic eczema**

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Supplementary material

Table E1: Diagnostic labels and features used by paediatric pulmonologists to describe the diagnosis of obstructive airway disease: grouping of wording from the qualitative analysis, order of use, frequency, and recommendation from the Delphi process (N=562). We used the original wording from letters, which was mostly in German, but letters included a few English terms (such as "episodic viral wheeze", or "brittle asthma"

Diagnostic labels and features	Terms used in original letter	n (%)	Recommendation from Delphi process
Diagnostic label	Asthma, asthma bronchiale, small airway disease, episodic viral wheeze, multiple trigger wheeze, obstructive bronchitis	562 (100%)	Use obstructive bronchitis if attacks are only triggered by infections. Use asthma if any other trigger (such as exercise outside of an infection period or an allergic trigger) is present.
Certainty of diagnosis	Verdacht auf, hochgradiger Verdacht auf, Dringender Verdacht auf, Möglicherweise, Wahrscheinlich, Sehr wahrscheinlich	117 (21%)	State suspected asthma if the diagnostic tests were inconclusive or if the child could not perform diagnostic tests.
Exclusion of differential diagnosis	Schweisstest, Bronchoskopie, Röntgenthorax, CT-Thorax		
Age-related phenotype	Frühkindliches, Kleinkindes, Infantiles	49 (9%)	Age-related phenotypes should not be stated in the diagnosis list
Symptoms	Husten, Wheeze, Atemnot / ohne Atemnot, Asymptomatisch	38 (7%)	Symptoms should not be stated in the diagnosis list
Symptom perception	Subjektiv, Slechte perzeption	11 (2%)	State symptom perception if the patient has poor perception. Poor symptom perception: if the patient/parents report different subjective symptom control compared to symptom control from the physical examination and/or test results.
Pattern of symptoms over time	Rezidivierende, Wiederholte, Mehrfache, Frequenz, Chronisch, Episodisch, Monatlich	135 (24%)	Patterns of symptoms over time should not be stated as separate feature in the diagnosis list. Recurrent should be stated as part of obstructive bronchitis.
Seasonal/ Perennial	Saisonal, Perennial	20 (4%)	Seasonal/perennial should not be stated in the diagnosis list
Triggers	Allergisch, Exogen, Pollinosum, Nicht allergisch, Infekt, Anstrengung, Multifaktoriell, Wetter, Psychisch, Triggers/Auslöser unklar	468 (81%)	State triggers
Related measures of disease severity	Leichtes, Mildes, Nicht aktiv, Difficult to treat	99 (18%)	State the number of severe exacerbations in the last 12 months and month/year of last severe exacerbation. Severe exacerbation: if an attack needed an emergency consultation
Exacerbations	Exazerbation, Hospitalisation, Atemunterstützung, Intensivmedizin, Respiratorische, Partiallinsuffizienz, Respiratorische, globalinsuffizienz		
Stability	Instabil, Stabil, Sehr stabil, Brittle		
Effect on daily life	Leistungsintoleranz, Keine Einschränkungen		
Lung function	Lungenfunktion, Obstruktiv, Leichte, Mittelschwere, Nicht obstruktiv, Gemischt	36 (6%)	Diagnostic test results other than allergy tests results should be stated in

	obstruktiv und restriktiv, FEV1		the diagnosis list to state the level of certainty of the diagnosis
Broncho-dilator Reversibility	Teilreversibilität, Vollständig, Fixiert		
Airway inflammation	FeNO	11 (2%)	Diagnostic test results other than allergy tests results should be stated in the diagnosis list to state the level of certainty of the diagnosis
Airway hyper-respon-siveness	Belastungs-Lungenfunktion, Methacholine, Mannitol, Bronchiale Hyperreagibilität (Leichte, Mittelschwere, Schwere, Keine)	52 (9%)	Diagnostic test results other than allergy tests results should be stated in the diagnosis list to state the level of certainty of the diagnosis
Atopy	Sensibilisierung	431 (77%)	State sensitizations and clinical relevance
Klinischer Relevanz	Fraglicher, Gesicherter, Wenig, Eindeutig, Hochrelevant, Wahrscheinlich, Wahrscheinlich nicht, Ohne eindeutige, Keine		
Therapy	SABA (Ventolin), LABA, ICS, (Axotide Flutiform, Seretide, Symbicort) LTRA (Montelukast), Bronchovaxom, Omalizumab, Ohne Therapie	46 (8%)	Therapy should not be stated in the diagnosis list
Symptom control	Kontrolliert, Kontrolliert nach GINA, Gut kontrolliert, Vernünftig kontrolliert, Partiell bis gut kontrolliert, Partiell kontrolliert, Teilweise, kontrolliert, Mässig kontrolliert, Ungenügend kontrolliert, Unkontrolliert, Nicht kontrolliert, Ungenügend eingestellt, Slecht eingestellt, Mässiger Kontrolle, Nicht genügend Kontrolle, Unzureichender, Symptomkontrolle	139 (25%)	State symptom control as well, partly, or uncontrolled, according to the definition from the GINA guideline.
Therapy response	Gut auf Therapieansprechend, Slecht auf Therapie ansprechend, Hochsignificant verbessert nach Therapie	3 (1%)	State treatment adherence as good = almost always, moderate = only for symptoms or poor = very rarely
Compliance	Malcompliance, Mässige compliance, Oft vergessen	3 (1%)	Compliance should not be stated in the diagnosis list
Risk of future asthma	Asthma predictive index (API), Predicting asthma risk in children (PARC) score	10 (2%)	Risk of future asthma should not be stated in the diagnosis list
Terms not grouped into features	Typ II, Atypisch, Bekanntes, Residuelles, Seit	-	-

Table E2. Delphi questionnaires to reach consensus on standardized reporting of obstructive airway disease in children

First Delphi questionnaire Recommendation	Results from the analysis	Agree	Dis-agree	Agree-ment	**Second Delphi questionnaire** Recommendation	Agree	Dis-agree	Agree-ment	**Third Delphi questionnaire** Recommendation	Agree	Dis-agree	Agree-ment
Diagnostic labels												
Obstructive bronchitis and wheeze are used interchangebly and should be grouped together as wheeze.	Both terms are mainly used in children aged 0-4 years (>88%).	1	6	14%	Below the age of 5, we should use one label "obstructive airway disease" instead of "obstructive bronchitis", "wheeze", "frühkindliches asthma" oder "infantiles asthma"	1	6	14%	Below the age of 5 years, we should distinguish two conditions A) recurrent obstructive bronchitis and B) suspected asthma (which cannot be confirmed yet, because the child cannot perform lung function testing).	7	0	100%
Asthma bronchiale and asthma are used interchangebly and should be grouped together as asthma	Both terms are used at all ages	4	3	57%	Asthma bronchiale is an old fashion term, which has been replaced with asthma in modern literature and guidelines. Therefore, the term asthma bronchiale should be stated as asthma above the age of 5 years.	6	1	86%				
Features												
Triggers should be stated	83% stated triggers in the diagnosis field of hospital letter	6	1	86%								
Severity should not be stated in diagnosis field, because it is subjective and mild/moderate are not used in guidelines anymore. Severity is partially covered by symptoms control	3% stated severity	3	4	43%	In children with severe asthma severity should be stated. Hereby it should be differentiated between: "Severe Asthma" and "difficult to treat Asthma"	6	1	86%				
Number and timepoint of last exacerbation should be stated as number of exacerbations and hospitalisations ever in life and month + year of the last exacerbation	13% stated exacerbations/hospitalisations	4	3	57%	Number and timepoint (month/year) of exacerbations should only be stated in the diagnosis list if severe (leading to hospitalisation), it was recent (within the last 12 months), and relevant for follow-up	7	0	100%				
Frequency of episodes/recurrence should not be stated in diagnosis field. It is very variable and partially covered by number of exacerbations.	<1% stated frequency of episodes/recurrence	5	2	71%					Recurrence should be stated as part of the diagnostic label “obstructive bronchitis”, because it needs to be recurrent to receive the diagnosis	7	0	100%
Episodic/Recurrence should be stated	20% stated episodic or recurrent. Chronic was only stated in 2 children (<1%)	4	3	57%	The recurrence or persistence of symptoms is captured by the triggers and should not be stated in the diagnosis list.	7	0	100%				
Stability should not be stated in diagnosis field. It is subjective and partially covered by the number of exacerbations)	1% stated stability	7	0	100%								

First Delphi questionnaire Recommendation	Results from the analysis	Agree	Dis-agree	Agree-ment	**Second Delphi questionnaire** Recommendation	Agree	Dis-agree	Agree-ment	**Third Delphi questionnaire** Recommendation	Agree	Dis-agree	Agree-ment
Symptom control should be stated as well controlled, controlled, partially controlled or uncontrolled	25% stated symptom control, of which 50% stated good symptoms control and 50% stated partial or poor symptoms control	6	1	86%								
Limitations of sports and daily activities should not be stated in diagnosis field. It can be stated under anamnesis.	1% stated limitations	5	2	71%								
Therapy should not be stated in diagnosis field. Prescriptions can be found under treatment.	8% stated therapy	6	1	86%								
Treatment step according to GINA should be added to diagnosis field		1	6	14%	Treatment step according to GINA should not be added to diagnosis field.	6	1	86%				
Compliance should be stated in children >10 years **if the compliance is poor**	1% stated the compliance. Only poor compliance was stated.	5	2	71%								
Therapy response should not be stated in diagnosis field. It can be stated with the therapy	1% stated therapy response	7	0	100%								
Certainty of diagnosis should be stated as suspected if there is uncertainty about the diagnosis	21% stated that the diagnosis was suspected with different levels of certainty	7	0	100%	If the diagnosis is only suspected, then a differential diagnosis should be stated	6	1	86%				
Symptom perception should be stated in children >10 years **if the symptom perception is poor**	2% stated the symptom perception. Only poor symptom perception was stated.	3	4	43%	Poor perceiver should be stated as this is important information for follow-up	7	0	100%				
Symptoms should not be stated in diagnosis field. They can be found under anamnesis.	7% stated symptoms	5	2	71%								
Asthma predictive index (API) / predicting asthma risk in children (PARC) should not be stated in diagnosis field. It can be stated with the diagnostic tests.	2% stated asthma predictive index or	7	0	100%								
Since when the child was diagnosed should not be stated in diagnosis field. It can be stated under anamnesis, but is not very relevant for daily clinical practise.	<1% stated since when the child was diagnosed	7	0	100%								

First Delphi questionnaire Recommendation	Results from the analysis	Agree	Dis-agree	Agree-ment	**Second Delphi questionnaire** Recommendation	Agree	Dis-agree	Agree-ment	**Third Delphi questionnaire** Recommendation	Agree	Dis-agree	Agree-ment
Diagnostic test results other than allergy test results should be stated as for example reversible obstructive lungfunction or severe bronchial hyperreactivity in methacholine test	23% stated diagnostic test results other than allergy test results of which 95% abnormal test results and only 5% normal test results	4	3	57%	Obstructive lung function (fixed or reversible) should be in the diagnosis list.	3	4	43%	Diagnostic test results other than allergy tests results should be stated in the diagnosis list to state the level of certainty of the diagnosis	7	0	100%
					Airway inflammation measured by FeNO should be stated in the diagnosis list.	2	5	29%				
					Airway hyperresponsiveness measured by bronchial challenge tests should be stated in the diagnosis list as it reminds of a correct diagnosis.	6	1	86%				
Allergy test results should be stated as sensitizations for or no sensitizations for common inhalation allergens	77% stated allergy test result in the diagnosis field of the hospital letter	7	0	100%								
The clinical relevance of the allergy test results should be stated as with, without or unclear clinical relevance	27% stated the clinical relevance of the positive allergy test results	7	0	100%								

1497 patients invited for SPAC

73 refused
578 never replied

846 participated in SPAC

48 without a hospital letter and 45 without a questionnaire
191 hospital letters without obstructive airway disease (without the words “asthma”, “wheeze”, and “obstructive bronchitis”) in the diagnosis list

562 hospital letters with obstructive airway disease in the diagnosis list from children from whom we received a questionnaire