

Structure and functions of pediatric Aerodigestive programs: a consensus statement

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Dr Deboer, Prager, Friedlander, and Deterding are co-founders (Secretary, Treasurer, President, and Vice-President Respectively) and board members of Triple Endoscopy, Inc. They are also co-inventors with University of Colorado on PCT application "Pediatric Nasal Endoscope PCT/US16/39352. They have not received funding from these entities for this project or at the time of the writing of this manuscript.

Dr Rutter serves as consultant to consultant to Bryan Medical, which produces and markets an airway balloon of his patent. This is unrelated to the current study and he receives no revenue from this stent.

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Abbreviations: BAL-Bronchoalveolar lavage, EGD-esophagogastroduodenoscopy, FEES- Fiberoptic endoscopic evaluation of swallowing, PEG- Percutaneous esophagogastrostomy, TEF-Tracheoesophageal fistula, VFSS-Videofluoroscopic swallow study
Table of contents summary: Multi-disciplinary consensus definition of the aerodigestive care model with specific recommendations regarding associated personnel, infrastructure, research, and outcome measures.

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Contributors Statement

Dr. Boesch conceptualized the study, recruited the contributors, designed and distributed the questionnaires, provided data through questionnaires, analyzed and summarized results, and drafted the initial manuscript, and reviewed and revised the manuscript.

Dr. Balakrishnan assisted with study design, provided data through questionnaires, analyzed and summarized results, and reviewed and revised the manuscript.

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All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

SUMMARY

Aerodigestive programs provide coordinated interdisciplinary care to pediatric patients with complex congenital or acquired conditions affecting breathing, swallowing and growth. Although there has been a proliferation of programs as well as national meetings, interest groups and early research activity, there is as of yet no consensus definition of an aerodigestive patient, standardized structure and functions of an aerodigestive program, or a blueprint for research prioritization. The Delphi method was utilized by a multi-disciplinary and multi-institutional panel of aerodigestive providers to obtain consensus on four broad content areas related to aerodigestive care: 1. Definition of an aerodigestive patient, 2. Essential construct and functions of an aerodigestive program, 3. Identification of aerodigestive research priorities, and 4. Evaluation and recognition of aerodigestive programs and future directions. After three iterations of survey, consensus was obtained by either a supermajority of 75% or stability in median ranking on 33 of 36 items. This included a standard definition of an aerodigestive patient, level of participation of specific pediatric disciplines in a program, essential components of the care cycle and functions of the program, feeding and swallowing assessment and therapy, procedural scope and volume, research priorities and outcome measures, certification, coding, and funding. We propose the first consensus definition of the aerodigestive care model with specific recommendations regarding associated personnel, infrastructure, research, and outcome measures. We hope that this may provide an initial framework to further standardize care, develop clinical guidelines, and improve outcomes for aerodigestive patients.

INTRODUCTION

Advances in the care of critically ill children and neonates have created a growing population of children with complex chronic multi-organ system diseases¹. The care of these patients is costly and complex, characterized by multiple procedures, heavy reliance on technology and multi-specialist care, and frequent hospitalizations. Care for such challenging patients should be consistent, effective, cost-efficient, outcomes-driven, patient-centered, and family-focused. Thus, a high level of coordination and an integrated team approach is necessary in order to provide the highest level of care in an efficient manner.

The effectiveness of coordinated complex care clinics has been demonstrated in several pediatric populations. One study of the impact of a comprehensive primary care clinic for children with special health care needs demonstrated decreased non-ICU length of stay but no improvement in cost of care (cost shifted from inpatient to outpatient)². Another study reported a reduction in hospitalization rates and total costs billed to Medicaid for medically complex patients in the year following enrollment (in a complex care management program) compared to the year prior³. Others have demonstrated improved parent satisfaction and decreased caregiver strain with a coordinated multidisciplinary model of care^{4,5}.

An example of such a model is the “aerodigestive” clinic. Aerodigestive clinics provide coordinated interdisciplinary care to children with complex congenital or

acquired conditions affecting breathing, swallowing and growth to various degrees. These conditions include structural or physiologic airway disease, chronic parenchymal lung disease, lung injury from aspiration or infection, gastroesophageal reflux, eosinophilic esophagitis, esophageal dysmotility or stricture, dysphagia, and behavioral feeding problems. Examples of disorders commonly evaluated in aerodigestive programs are listed in **Table 1**.

Since the development of the first aerodigestive program at Cincinnati Children's Hospital Medical Center in 1999, a further 50 such centers have been established in 32 states. As these programs have developed, they serve as a valuable resource for pediatricians and other primary care providers; many of the conditions and presenting symptoms in **Table 1** lead to frequent visits to the primary care office or frequent hospital admissions and may be frustrating for pediatricians to manage alone. However, there is yet no accepted or standard definition of patients most appropriate for aerodigestive programs, or clearly-defined structure and functions of an aerodigestive program to guide referral and establish expectations. Nevertheless, there is greater recognition of aerodigestive care as a definable model of care with value to patients and medical centers as evidenced by the growing number of programs, the success of an annual aerodigestive conference, aerodigestive sessions at pediatric subspecialty conferences, and development of an aerodigestive list-serv. Along with these advances in clinical care, early publications have demonstrated clinical effectiveness, decreased cost, reduction in anesthetic episodes and resource utilization, and reduced care-giver burden by aerodigestive programs⁶

¹⁰. Furthermore, given the relatively low volumes and heterogeneity of these complex patients, research aims might best be identified and coordinated across multiple collaborating centers. We sought to utilize a broad base of aerodigestive expertise to develop a standard definition of a patient with an aerodigestive disorder, define the construct and essential functions of aerodigestive programs, identify research priorities, and investigate future directions for maturation of the field.

METHODS

We utilized the Delphi method to obtain consensus over a range of topics related to aerodigestive care. The Delphi method is an iterative, questionnaire-based method of obtaining consensus which has been adapted to use in healthcare¹¹⁻¹⁷. This process has particular strengths in situations where more quantitative evidence is either lacking or cannot be developed easily.

We sought common themes and recommendations that would attain a high level of consensus, with consensus defined as a supermajority of > 75% or a median response rate that did not change with repeated surveys. We identified *a priori* four broad content areas: 1. Definition of an aerodigestive patient, 2. Essential construct and functions of an aerodigestive program, 3. Identification of aerodigestive research priorities, and 4. Evaluation and recognition of aerodigestive programs and future directions. Descriptive statistics were performed using Excel 2014 (Microsoft Corp, Redmond, Washington). This study was reviewed and exempted by the Mayo Clinic Institutional Review Board.

Thirty-three specialists from eleven well-established aerodigestive centers in the United States were recruited to participate based on their national and international recognition in aerodigestive care (12 pediatric pulmonologists, 11 pediatric otolaryngologists, 8 pediatric gastroenterologists, and 2 speech-language pathologists). Participants were invited by the corresponding author based on active participation in long-standing or well-established programs, leadership in program creation, involvement at meetings and conferences, or in publication. A series of three questionnaires was administered electronically, with target participation of 100% for each questionnaire. The questionnaires started with more open solicitation of aerodigestive program processes, construct and research priorities. Results were grouped into themes and ranked based on frequency of response. Ranked results and summary statistics were returned to participants. Subsequent questionnaires requested ranking to achieve supermajority. By completion of the third questionnaire, each item had either achieved consensus by a supermajority of 75% or did not change by more than one rank, so no further questionnaires were administered.

RESULTS

Despite surveying a range of aerodigestive programs, differing by region, size, and duration of formal operation, consensus was achieved on almost all questions, with a supermajority of >75% agreement or stable median response. Response rates for questionnaires 1-3 were 100%, 97%, and 100% respectively.

1. Definition of patient with Aerodigestive disorder

A two-sentence structure for the definition of an aerodigestive patient was chosen. The definition developed and preferred by the majority (75.8%) of respondents is as follows:

“A pediatric aerodigestive patient is a child with a combination of multiple and interrelated congenital and/or acquired conditions affecting airway, breathing, feeding, swallowing or growth that require a coordinated interdisciplinary diagnostic and therapeutic approach to achieve optimal outcomes.

This includes (but is not limited to) structural and functional airway and upper gastrointestinal tract disease, lung disease due to congenital or developmental abnormality or injury, swallowing dysfunction, feeding problems, genetic diseases, and neurodevelopmental disability.”

2. Essential construct and functions of Aerodigestive program

For this aim respondents identified the core aerodigestive team members and the services that should be available within the center. These results are summarized in **Table 2**. Given that a multidisciplinary team meeting was identified as a key component of the aerodigestive care cycle, participants were asked which disciplines should be present for these meetings. These results are indicated in **Table 2**. Questioning the roles of care coordinator and nursing, 73% of respondents viewed these roles as the same while 44% also cited the benefits of specialty-specific nursing, especially in providing education and follow-up support for families. Nurse practitioners were identified as the preferred discipline

to serve as care coordinator (81%), though advanced practice nurses, registered nurses, and physician assistants were also identified as potential care coordinators. While general pediatricians may be helpful in these clinics, they have not been traditionally part of aerodigestive teams, with only two of the participating programs currently utilizing them in this way. Primary pediatrician roles identified by a supermajority of participants included: inpatient generalist consultation, outpatient generalist input, and as primary physician (88%, 81%, and 81%). Respiratory therapists are utilized in the programs of participants for education, procedural support, clinical assessments (especially ventilator settings), and performance of pulmonary function testing.

Participants also identified the essential defining functions and features of the care cycle of an aerodigestive program. These results are summarized in **Table 3**. During further clarification, 84% of respondents rated performance of combined endoscopy with all providers present together at the same time (ENT, GI, Pulmonology) as essential. This allows all providers to directly observe all portions of the evaluation and maintain a dialogue with each other. They were split on having all shared clinic visits performed together, in the same clinic space, with 55% citing this as “essential” and 45% as “beneficial but non-essential.” 70% of respondents supported a target timeframe for completion of initial diagnostic evaluation, defined as: time from first appointment for diagnostic evaluation until wrap-up from first diagnostic evaluation. The median time for this evaluation was 7 days with an interquartile range (IQR) of 5-17.5 days. It was acknowledged that this is modified by the urgency and specific needs of the

patient. 91% of participants cited wrap-up visits could occur either in person or over the phone. The experience of seeing the team working together was cited as making a strong impact on caregivers.

Feeding and swallowing disorders are recognized to be highly prevalent in patients with aerodigestive disorders, therefore clinical swallowing evaluations, fiberoptic endoscopic evaluations of swallowing (FEES), videofluoroscopic swallow studies (VFSS), and provision of direct feeding therapy were all identified as essential components of a program (97%, 97%, 100%, 100%). Clinical swallowing evaluations and VFSS were reported as essential for “majority of aerodigestive evaluations.” Speech-language pathologists were identified as the provider of choice for each of these assessments/therapies (100% for clinical swallowing evaluation, 81% for FEES, 81% for VFSS, 91% for feeding therapy) though the role for otolaryngologists in the performance of FEES was supported (78%). A role for occupational therapists for development, instruction, and modeling of feeding plans was well supported (78%) though responses were mixed for their role in clinical swallowing evaluations (70%), VFSS (39%), and FEES (34%). Forty-five percent of participating programs utilize occupational therapists for feeding and swallowing evaluations (clinical or instrumental).

Operative diagnosis and intervention are recognized as fundamental to aerodigestive care. Overall, respondents cited interventional procedures as performed by pediatric pulmonologists to be beneficial to aerodigestive program function but essential for pediatric gastroenterologists. Consensus for these

rankings was achieved based on unchanging median response over serial surveys, though some reached a supermajority of 75% at same rank. The importance of specific procedures cited is listed in **Table 4 and 5** and generally suggest the importance of a high level of procedural skill and expertise for pulmonologists and gastroenterologists, even if all proceduralists do not routinely perform all listed procedures. Respondents strongly endorsed the essential nature of proficiency in open and endoscopic airway reconstruction for otolaryngologists in aerodigestive programs (81%). This includes the following categories: 1. open or endoscopic procedures that directly increase the diameter of the cartilaginous skeleton of the airway, 2. endoscopic treatment of airway obstruction, 3. surgical procedures to treat aspiration, 4. surgical procedures to improve voice, 5. tracheostomy, and 6. foreign body removal. Respondents were then asked to identify a target minimum annual number for surgical categories 1 - 4 for a *program* to perform to maintain competency (**Table 6**). There was general agreement across disciplines and programs regarding these targets, with the exception of one center recommending higher volumes for open or endoscopic procedures that directly increase the diameter of the airway and endoscopic treatment of airway obstruction. Comparison of median responses from that program to other ENT respondents showed a significant difference in these categories (median 25 vs 6 [IQR 10-35 vs 5-25] and 25 vs 15 [IQR 13.5-27.5 vs 12-25]; Mann-Whitney $p=0.006$ and $p=0.044$, respectively).

3. Identify Aerodigestive research priorities

For this aim, participants were asked to list and then rank research areas that were of the greatest immediate importance and should be prioritized, as well as outcome measures of greatest importance to be utilized in aerodigestive research. The responses for top research priorities were stable with regards to ranking with the top ten being cited by 55-97% of respondents and the second ten by 9-36% and with rankings not changing from questionnaire two to three (**Table 8**). If taken as a group, issues related to aspiration (diagnosis, treatment, microbiome and sequela) ranked in top 10 for 91% of respondents. The responses for most important outcome measures were stable with regards to ranking with the top ten being cited by 67-100% of respondents and the second ten by 30-64% (**Table 8**). Sixty-one percent cited multicenter research as an “essential” function of Aerodigestive programs while 39% cited this as “beneficial but non-essential.”

4. Recognition of Aerodigestive programs

Ninety-seven percent of participants stated that current understanding of which patients are appropriate for aerodigestive program and what an aerodigestive program does only exists within large academic centers. Eighty-one percent strongly agree that aerodigestive care is a definable model of care, distinct and distinguishable from routine specialty care for complex pediatric patients. To this point, 91% of respondents agreed (64% strongly agreed) that this definable care model was worthy of program certification, similar to the Clinical Care Center models certified by the Cystic Fibrosis or Primary Ciliary Dyskinesia foundations. Respondents acknowledge that this is a future goal that must be founded on

validated, outcome-based care guidelines. 97% of respondents agreed (67% strongly agreed) that aerodigestive care, as a defined subspecialty, was worthy of dedicated funding streams for research and 88% strongly agreed that diagnostic coding should be modified to incorporate the time and complexity of delivering care in an integrated manner.

DISCUSSION

The results of this Delphi study indicate a broad consensus amongst providers from different subspecialties and across multiple geographic regions on the definitions, structure, functions, and priorities for aerodigestive care. In the context of limited published evidence, these results create a framework and an initial foundational definition for the model of pediatric aerodigestive care, based on expert consensus.

There is evidence of the value and benefit of a coordinated consistent approach to the care of children with complex chronic conditions. Substantially improved outcomes for children with cystic fibrosis have been achieved through standardization of definitions, multicenter research, development and dissemination of clinical care guidelines, and tracking and reporting of patient outcomes¹⁸⁻²⁰. Similarly, the Improve Care Now network has improved outcomes for inflammatory bowel disease via a similar approach²¹⁻²³. Aerodigestive programs provide diagnostic evaluation, treatment, and often longitudinal coordinated care to complex pediatric patients, similar to pediatric cardiovascular

centers, for which there are established, iteratively-revised guidelines for diagnosis, treatment, and program composition²⁴. Although accumulating evidence supports positive impacts of aerodigestive programs, development of a coordinated care model for this population is in its infancy. Further development of guidelines is aspirational and will need basis in evidence and proven outcomes.

This Delphi study leverages the knowledge and experience of a broad panel of subject matter experts; this is a specific strength of this process. Despite the range of disciplines, geography, and program history across the participant group, a supermajority consensus of 75% or stable median was achieved for all but three items, suggesting that our findings are robust. The panel remained split on the necessity for shared clinic visits to occur all together in the same physical space and on individual provider certification in aerodigestive care. Also, a recommendation for a target timeframe for completion of an aerodigestive evaluation did not quite reach a supermajority (70%). An additional strength was the high response rate, with only one respondent in 33 failing to return one of three questionnaires.

Major limitations arise from a lack of solid evidence on which to grade these recommendations, relying instead on expert opinion. Until such evidence exists, there is no better alternative. The utilization of iterative questionnaires without open group discussion, is both a strength and a limitation. In this format there

was some impairment in achieving deeper clarity in some responses that remain vague, such as “requirement for respiratory support” as an outcome measure. It is possible that this means something different to different respondents. The strength is that, because responses were pooled and anonymous, there was no single persuasive voice to dominate. We also recognize that the use of a 75% supermajority as the criterion for consensus differs from other Delphi studies. The original descriptions by the RAND Corporation did not specify criteria for consensus, and a wide range of criteria have been used in health care-related studies using this approach, suggesting that this method itself might benefit from standardization.

We believe that development of a robust and well-defined care model requires an initial step to define the population, structure and processes of the model. A trend towards formalizing and developing the aerodigestive care model is evident in the proliferation of programs, inclusion in the US News Best Pediatric Hospitals survey, the formation of aerodigestive interest groups at subspecialty meetings, development of an Aerodigestive Society, publication of aerodigestive-specific research, and the continued increase in attendance at aerodigestive conferences. These definitions are necessary for consistency in future research and development within aerodigestive care and, more pragmatically, to guide primary providers in determining which conditions and patients might benefit from care through such a model. We acknowledge that further refinements and development of care guidelines will require more rigorous evidence on many of the elements examined here and others outside of the scope of this study. Given

that aerodigestive disorders encompass heterogeneous rare disease states, fulfillment of this aim will require coordinated research between centers, perhaps based on the priorities identified here. One could envision a roadmap to maturation of the aerodigestive care model similar to the development of the chILD network for diffuse lung diseases or efforts led by the Cystic Fibrosis Foundation²⁵⁻²⁹. The results of this study provide an initial crucial step towards this larger goal by providing definition and framework to the care model and identifying research goals and direction for further maturation.

Based on our findings, we suggest that there exists a definable Aerodigestive Care Model, which merits further development and maturation, and which comprises specific personnel, infrastructure, research, and outcomes. A growing body of evidence suggests that this model delivers consistent, efficacious, cost-effective, outcomes-driven, patient-centered, and family-focused care. In the coming years, with continued effort, this may lead to documented improvement in outcomes, development and dissemination of care guidelines, standardization of approach, accreditation of aerodigestive care centers, an aerodigestive registry, and potentially aerodigestive-specific training opportunities.

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Table 1 – Common conditions evaluated and treated through aerodigestive programs

Table 2 – Relative importance of medical and surgical specialties in aerodigestive programs

Table 3 – Essential defining functions and features of aerodigestive care cycle

Table 4 – Recommended procedures, pediatric pulmonologist

Table 5 – Recommended procedures, pediatric gastroenterologist

Table 6 – Recommended minimum surgical airway procedures to be performed by aerodigestive programs annually

Table 7- Results of ranking of aerodigestive research priorities and outcome measures

Figure 1 - General algorithm for patient flow through aerodigestive program.

*Telephone or electronic acquisition of comprehensive patient history and parent/caregiver goals.

**Coordinated multispecialty clinic visits, radiographic and non-radiographic testing and procedures, combined airway and gastrointestinal endoscopy.

Table 1 – Common conditions evaluated and treated through aerodigestive programs

Aspiration and feeding disorders
Chronic cough
Craniofacial anomalies
Failure to thrive
Gastrostomy dependence
Laryngotracheal stenosis
Noisy breathing
Recurrent infection
Tracheoesophageal fistula/Esophageal Atresia
Tracheostomy dependence
Stridor/Recurrent croup
Vocal cord paralysis
Wheezing

Aerodigestive program referral more common when conditions occurring in complex patients with history of prematurity, central nervous system impairment, and/or genetic disease.

Table 2 – Relative importance of medical and surgical specialties in aerodigestive programs

Disciplines determined to be “Essential core members of team with input required for all patients”

- Care Coordinator*
- Gastroenterology*
- Nursing*
- Otolaryngology*
- Pulmonology*
- Speech-Language Pathology*

Disciplines determined to be “Essential core members of team with regular input but only needed for sub-set of patients”

- Sleep medicine
- Social work*
- Dietician#
- Respiratory therapy

Disciplines determined to be “Essential non-core members of team, available for sporadic consultation”

- Pediatric surgery
- Allergy and immunology
- Anesthesia
- Cardiology
- Child life
- Developmental pediatrics
- Genetics
- Interventional radiology
- Neurology
- Occupational therapy
- General pediatrics
- Pediatric critical care
- Cardiothoracic surgery
- Research assistant
- Radiology

* Core team members identified by >75% of respondents to be present at multi-disciplinary team meeting.

Dietitian attendance at team meeting was supported by 68% of respondents.

Table 3 – Essential defining functions and features of aerodigestive care cycle

Functions supported by > 75% of respondents:

- Care coordination
- Team meeting
- Pre-visit intake
- Pre-scheduling of appointments and procedures
- Shared clinic
- Combined endoscopy
- Wrap-up visit with family
- Summary document
- Provision of follow-up care (when applicable)
- Operational meetings

Table 4 – Recommended procedures, pediatric pulmonologist

Procedures performed by pulmonologist identified as “Essential; Absence of these skills significantly hampers function of program”			
Procedure	Average Rank	Median Rank	% rank 3
Bronchoalveolar lavage (BAL)	3.0	3	100
Bronchial brush	2.9	3	91
Tracheoesophageal fistula (TEF) identification	2.9	3	86
Fiberoptic intubation	2.8	3	86
Sleep state bronchoscopy	2.8	3	86
Endobronchial biopsy	2.8	3	84
Foreign body removal	2.6	3	69
Balloon dilation	2.5	3	63
Procedures performed by pulmonologist identified as “Beneficial; adds to range of diagnostic and therapeutic opportunity for aerodigestive patients”			
Procedure	Average Rank	Median rank	% rank 2
Cautery	2.1	2	55
Stenting	2.0	2	58
Transbronchial biopsy	2.0	2	71
Laser	1.8	2	71
TEF closure	1.8	2	65
Cryobiopsy ablation	1.7	2	61

Ranking:

3- Essential; Absence of these skills significantly hampers function of program

2- Beneficial; adds to range of diagnostic and therapeutic opportunity for aerodigestive patients

1- Not-beneficial; May be beneficial to others, but not necessary for aerodigestive patients

* Seen as ENT procedure

Table 5 – Recommended procedures, pediatric gastroenterologist

Procedures performed by gastroenterologist identified as “Essential; Absence of these skills significantly hampers function of program”			
Procedure	Average Rank	Median Rank	% rank 3
Biopsy	3.0	3	100
Dilation	3.0	3	97
Motility studies	2.9	3	91
Cautery	2.8	3	87
Percutaneous esophagogastrostomy (PEG) placement	2.8	3	75
GJ tube placement	2.7	3	68
Procedures performed by gastroenterologist identified as “Beneficial; adds to range of diagnostic and therapeutic opportunity for aerodigestive patients”			
Procedure	Average Rank	Median rank	% rank 2
Botox injection	2.3	2	58
Steroid injection	2.3	2	68
Stenting	2.2	2	52
Polypectomy	2.4	2	52
Banding	2.1	2	74
Transnasal esophagogastroduodenoscopy (EGD)	2.1	2	65
Clipping	2.0	2	84
Needle knife	1.8	2	84

Ranking:

3- Essential; Absence of these skills significantly hampers function of program

2- Beneficial; adds to range of diagnostic and therapeutic opportunity for aerodigestive patients

1- Not-beneficial; May be beneficial to others, but not necessary for aerodigestive patients

Table 6 – Recommended minimum surgical airway procedures to be performed by aerodigestive programs annually

Respondent	Median	Range	IQR	Mann-Whitney
Open or endoscopic procedures that directly increase the diameter of the cartilaginous skeleton of the airway				
All respondents	8	2-50	5-15.25	
ENT respondents	6	5-40	5-25	ns ^a
Non-ENT respondents	8	2-50	5-10	ns ^b
Outlier center	25	5-40	10-35	P=0.006 ^c
Endoscopic treatment of airway obstruction				
All respondents	15	5-50	10-25	
ENT respondents	15	5-50	12-25	ns ^a
Non-ENT respondents	11	6-40	10-20	ns ^b
Outlier center	25	10-30	13.5-27.5	P=0.04 ^c
Surgical procedures to treat aspiration				
All respondents	10	3-30	5-12.75	
ENT respondents	7	3-25	5-20	ns ^a
Non-ENT respondents	10	3-30	5-12	ns ^b
No differences between centers				
Surgical procedures to improve voice				
All respondents	5	3-15	5-10	
ENT respondents	5	3-15	4-10	ns ^a
Non-ENT respondents	6	3-15	5-10	ns ^b
No differences between centers				

a- not statistically significant compared to all respondents or non-ENT respondents

b- not statistically significant compared to all respondents or ENT respondents

c- As compared to remainder of centers

Table 7- Results of ranking of aerodigestive research priorities and outcome measures

Priorities for Aerodigestive research:

1. Outcomes, disease-specific
2. Validation of aerodigestive approach
3. Care pathways, development and validation
4. Aerodigestive patient registry
5. Diagnosis of aspiration
6. Standardization of diagnostic procedures
7. Treatment of aspiration
8. GERD, risks and evaluation of extra-esophageal disease
9. Factors for success of airway reconstruction
10. Value

Most cited outcome measures for Aerodigestive research:

1. Quality of life
2. Tracheostomy status/decannulation
3. Cost of care
4. Hospitalization/acute care utilization
5. Oral feeding status (multiple indices) and gastrostomy removal
6. Respiratory symptoms
7. Swallowing indices, by videofluoroscopic swallowing studies (VFSS) and fiberoptic endoscopic evaluation of swallowing (FEES)
8. Control of aspiration
9. Airway symptoms
10. Functional and developmental scores
11. Impact on caregivers
12. Family satisfaction
13. Growth indices
14. Requirement for respiratory support
15. Polysomnogram indices
16. Mortality
17. Respiratory infections
18. Aspiration biomarkers
19. Airway inflammatory biomarkers
20. Pulmonary function testing indices

Referral based on specific criteria



Intake*



Prescheduled itinerary



Multispecialty evaluation**



Team meeting and synthesis of findings



Wrap-up discussion with patient and family



Therapeutic interventions



Follow up care or transition out of program