



Speech Outcomes For Cleft Lip/Palate: Results From A Multi-Center Learning Health Network

Kristina Dunworth, BA¹, Amanda Del Risco, BA¹, Denisse Porras Fimbres, BS¹, Alexander Allori, MD, MPH²

¹Duke University School of Medicine, Durham, NC, USA

²Division of Plastic, Maxillofacial, and Oral Surgery; Department of Surgery; Duke University Health System; Durham, NC, USA

Purpose

Multi-center networks have gained attention for facilitating research of chronic conditions, such as cleft lip/palate. Inspired by this movement, several hospitals banded together to form the Allied Cleft & Craniofacial Quality-Improvement and Research Network (ACCQUIREnet). This network prospectively collects standardized outcomes measures and stores the data in a condition-specific registry. Here, we assess the ability of this registry to compare outcomes by (1) age, (2) cleft phenotype, and (3) treatment center - focusing on speech, as an example.

Background

ACCQUIREnet is a Learning Health Network (LHN) designed to improve care and facilitate research of cleft lip/palate. The network collaborates to contribute to and house a cleft-specific registry of short- and long-term outcomes data intended to support robust multicenter outcomes research. Data are systematically collected according to a standardized protocol outlined by the International Consortium of Health Outcomes Measures in their “Standard Set” of cleft-patient-centered outcomes measures. The registry collects data on many outcome domains including appearance, oral health, major surgical complications, and many others.

In this pilot project, we explored the speech domain as an example to evaluate the registry’s ability to answer meaningful questions about cleft care. Specifically, we predicted that the registry would be able to compare outcomes by (1) age, (2) cleft phenotype, and (3) treatment center.

Methods

Data were collected prospectively during routine patient appointments at 4 cleft treatment centers between 2019-2021. The sample included non-syndromic, English-speaking children with the following cleft phenotypes: cleft lip with/without cleft alveolus (CL±A); unilateral and bilateral cleft lip, alveolus, and palate (uCLAP and bCLAP); and cleft palate (CP). Primary outcomes are described in Table 1. Median outcome scores were compared among cross-sections based on age, phenotype, and treatment center.

Outcome	Measure	Possible Scores
Articulation	Percent Consonants Correct (PCC)	0-100
Velopharyngeal valve competency	Velopharyngeal Competency Rating Scale (VPC-R)	0 = Competent 1 = Marginally Incompetent 2 = Incompetent
Functional intelligibility	Intelligibility in Context Scale (ICS)	1-5
Patient-reported speech quality	CLEFT-Q Speech Function	0-100

Table 1. Primary outcomes included clinician-reported PCC and VPC-R, parent/guardian-reported ICS, and patient-reported CLEFT-Q Speech Function.

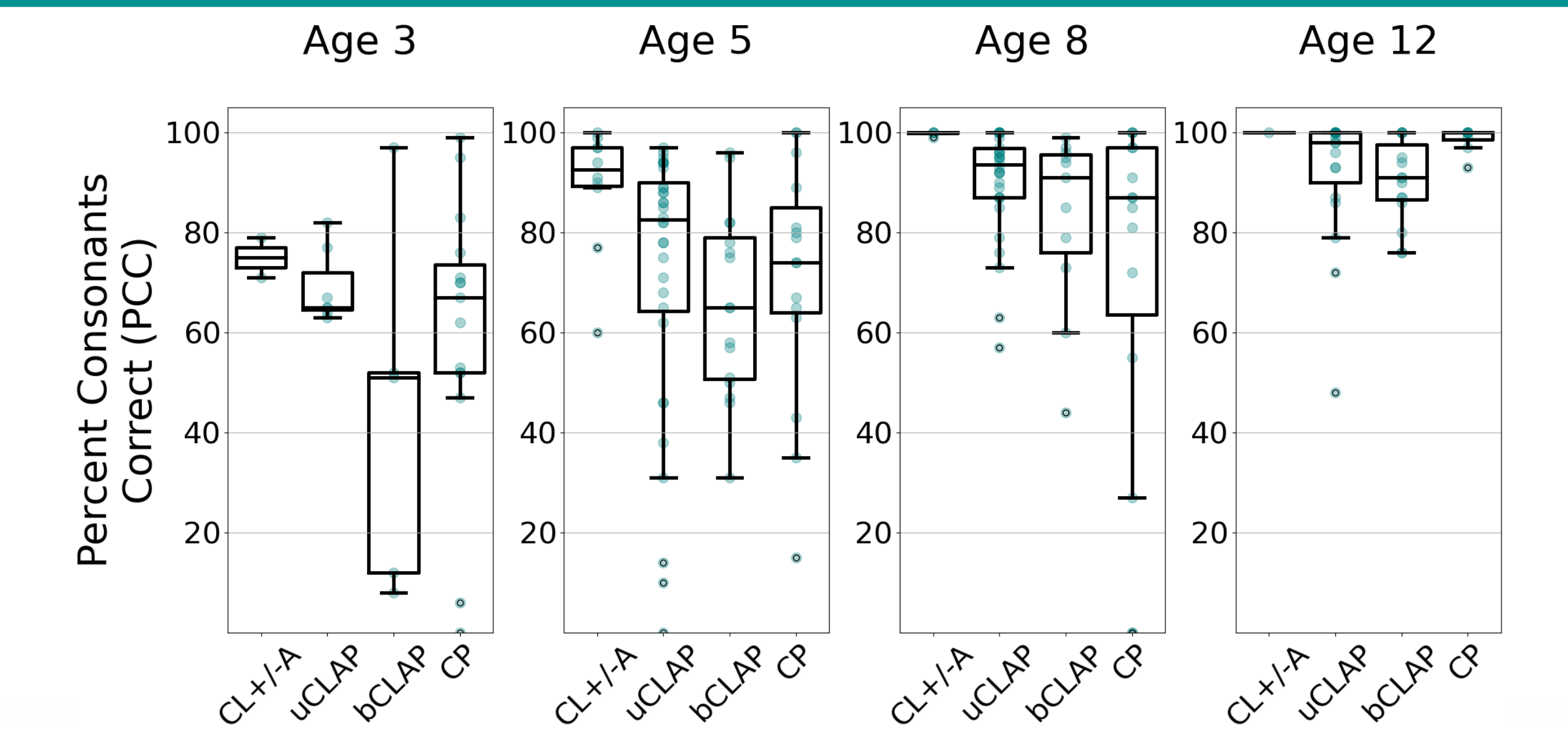


Figure 1. Distribution of PCC scores by cross-sections of age and phenotype. Each subplots represents a different age group. Phenotypes are separated along the horizontal axis for each age.

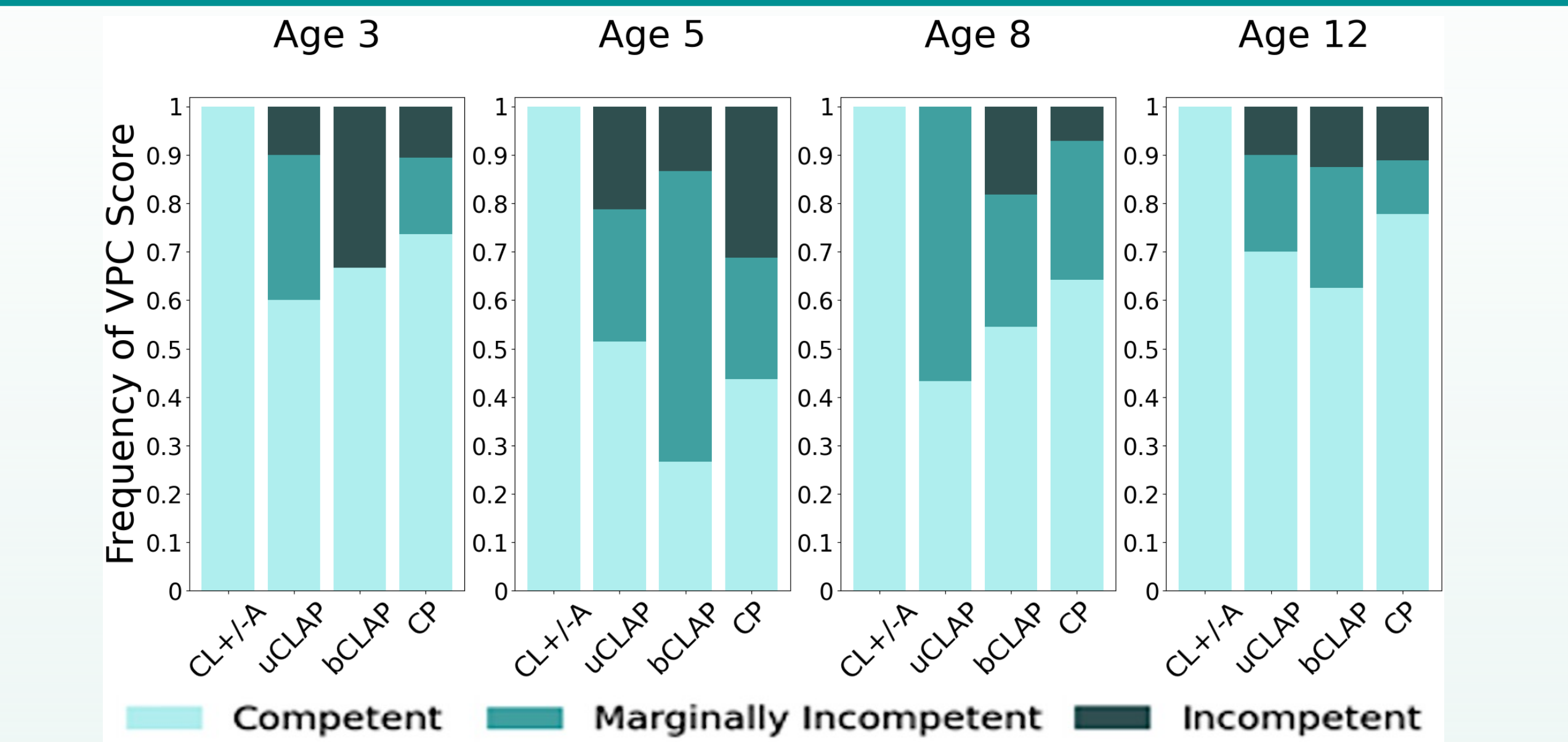


Figure 2. Distribution of VPC-R scores by cross-sections of age and phenotype. Each subplots represents a different age group. Phenotypes are separated along the horizontal axis for each age.

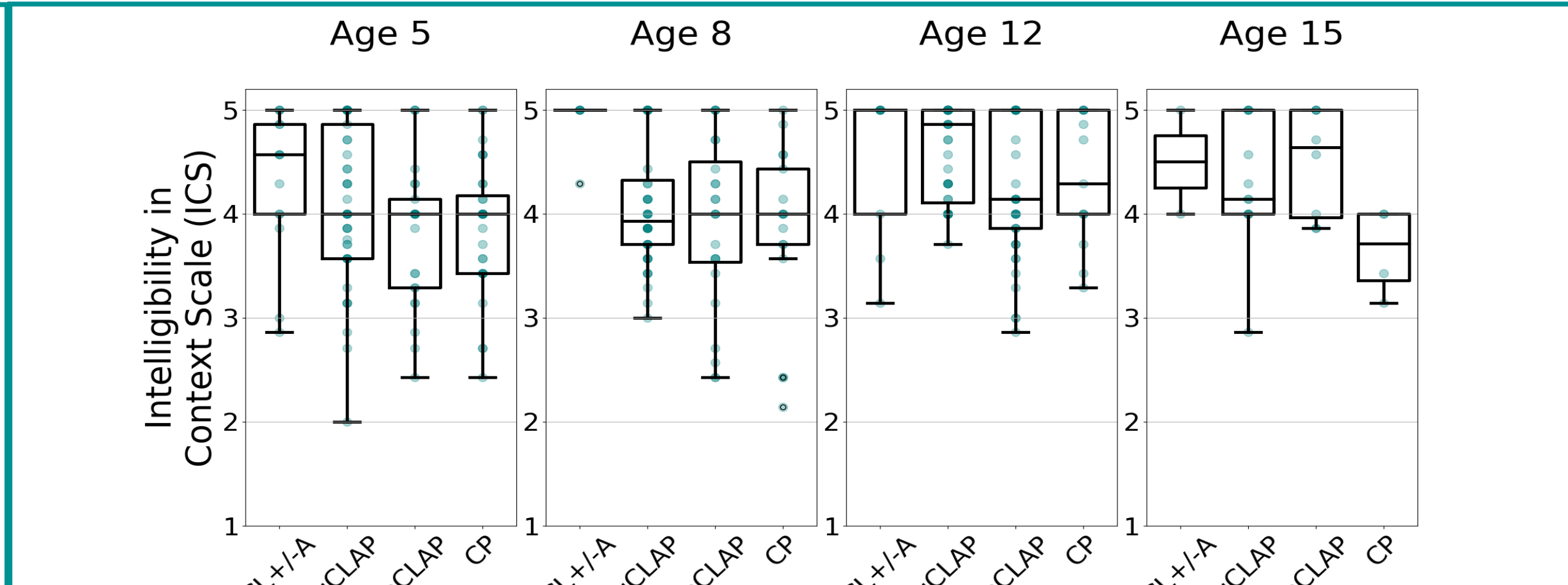


Figure 3. Distribution of ICS scores by cross-sections of age and phenotype. Each subplots represents a different age group. Phenotypes are separated along the horizontal axis for each age.

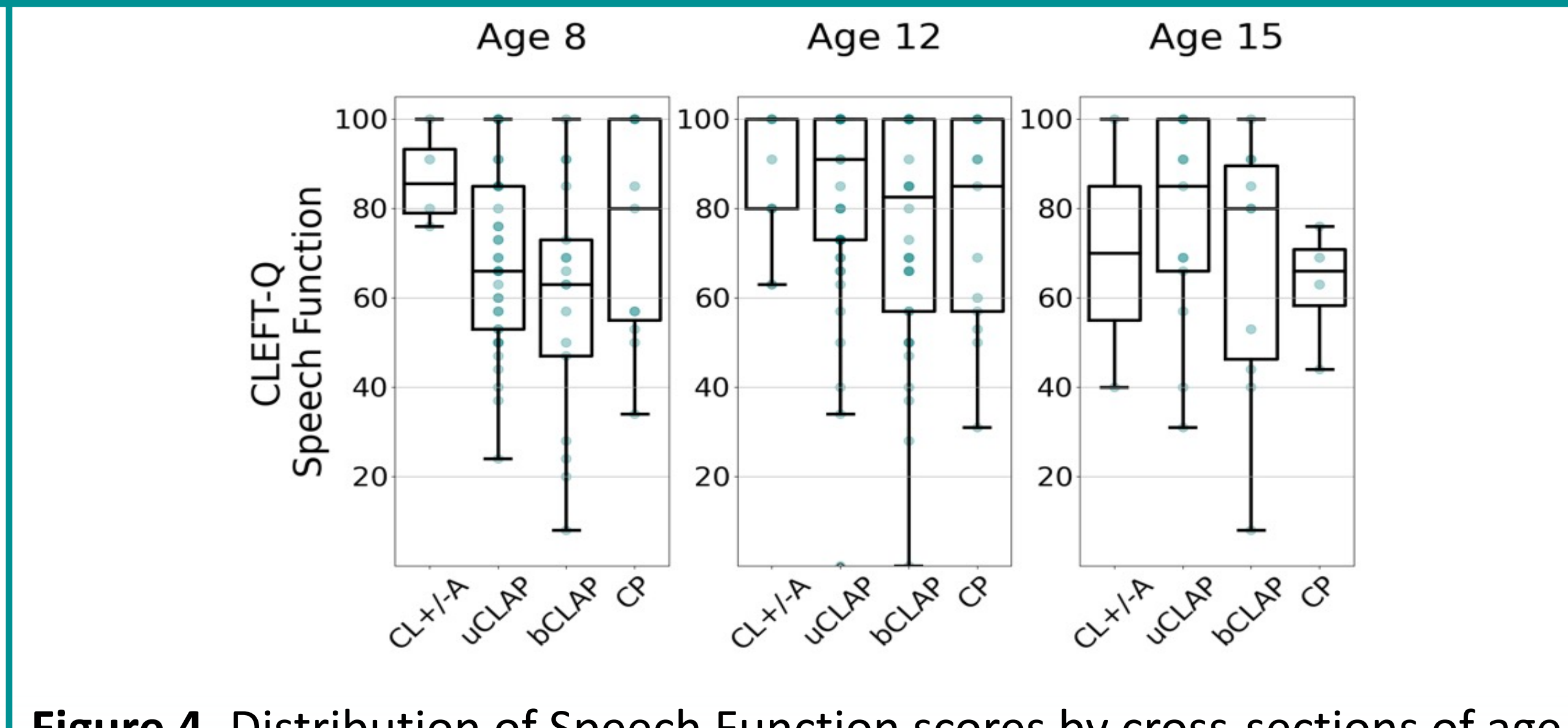


Figure 4. Distribution of Speech Function scores by cross-sections of age and phenotype. Each subplots represents a different age group. Phenotypes are separated along the horizontal axis for each age.

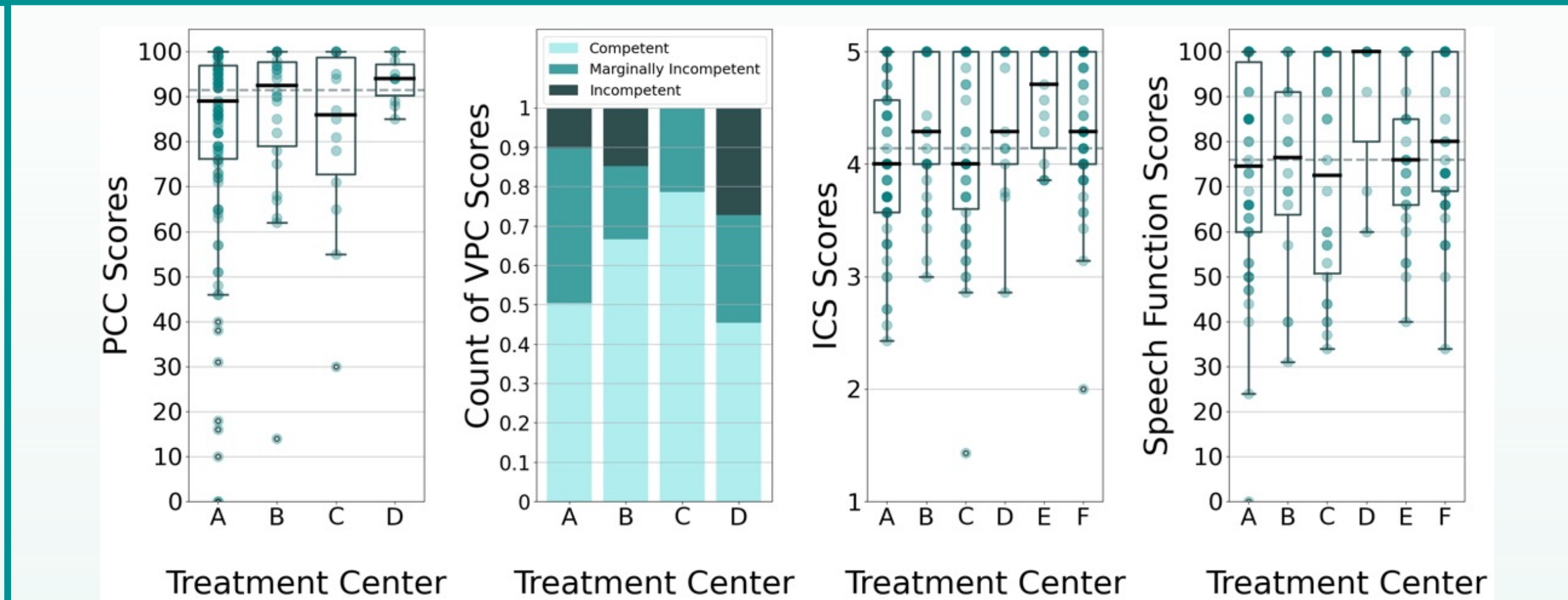


Figure 5. Distribution of all outcome scores for cross-sections of patients with the uCLAP phenotype from each treatment center. Each subplots represents a different outcome measure (L to R: PCC, VPC-R, ICS, Speech Function). Centers are separated along the horizontal axis.

Results

Older age groups exhibited better median PCC scores than younger groups. Patients with CL±A exhibited better PCC scores than patients with CP (Figure 1). Treatment centers exhibited similar PCC scores (Figure 5).

VPC pathology was worse in 5- and 8-year-olds but improved thereafter. Patients with CL±A exhibited better VPC scores than patients with CP (Figure 2). Treatment centers exhibited some variation in VPC scores (Figure 5).

Variation in ICS scores across age groups was phenotype-dependent. Patients with CL±A exhibited better ICS scores than patients with CP (Figure 3). Treatment center E reported the best median ICS score (Figure 5).

Variation in CLEFT-Q Speech Function scores across age groups was phenotype-dependent. Patients with CL±A exhibited better Speech Function scores than patients with CP (Figure 4). Treatment center D reported the highest median Speech Function score (Figure 5).

Conclusions

The ACCQUIREnet registry enabled comparison of cleft speech outcomes by age, cleft phenotype, and treatment center. The observed improvement in speech with age suggests that teams are rendering appropriate speech care. This descriptive project demonstrates proof of concept that the registry supported by this LHN can be used to answer meaningful questions about cleft care.

Acknowledgements

Banafsheh Sharif-Askary, MD
Lynn Grames, MA, CCC-SLP
Carlee Jones, MS, CCC-SLP
Jennifer Kern, MS, CCC-SLP
Jillian Nyswonger-Sugg, MS CCC-SLP
Arthur Suárez, MS, CCC-SLP
Karen Thompson, MA, CCC-SLP
Jessica Ching, MD

Brent Golden, MD, DDS
Corinne Merrill, BSN, RN
Phuong Nguyen, MD
Kamlesh Patel, MD, MSC
Carolyn R. Rogers-Vizena, MD
S. Alex Rottgers, MD
Gary B. Skolnick, MBA