



## Introduction

- The US Latino population is projected to reach approximately 25% of the population by 2050, and it is estimated that more than three quarters of the US Latino population speaks a language other than English at home.<sup>1</sup>
- Limited English proficiency has a detrimental effect on Latino patients, lowering the quality of primary care they receive and affecting the continuity of their care.<sup>2</sup> By tackling language barriers, surgical subspecialties can also lower disparities in surgical care.<sup>3</sup>
- The Velopharyngeal Insufficiency Effects on Life Outcomes (VELO) survey is a quality of life (QOL) instrument used to assess the effects of velopharyngeal insufficiency (VPI) on the lives of young patients.<sup>4</sup>
- Because VPI can dramatically and negatively alter many aspects of life by severely limiting speech and swallowing, children with VPI are considered to have a lower quality of life.<sup>5</sup>
- However, there is no available translation of the VELO instrument for Spanish speaking families with limited English proficiency, which is a significant gap in access to healthcare.

## Background

- VPI occurs due to inadequate closure of the velopharyngeal sphincter, which requires proper functioning of the velum (soft palate) and lateral and posterior walls of the pharynx.<sup>6</sup>
- The most common clinical manifestations of VPI include hypernasality of speech, nasal air emission, and nasal reflux of swallowed food and liquids.<sup>7</sup> In addition, VPI can significantly hinder social communication.<sup>6</sup>
- VPI is most commonly associated with cleft palate. It is estimated that 20-40% of patients will exhibit residual VPI after palatal repair, requiring a second surgical procedure.<sup>6</sup>

## Anatomy

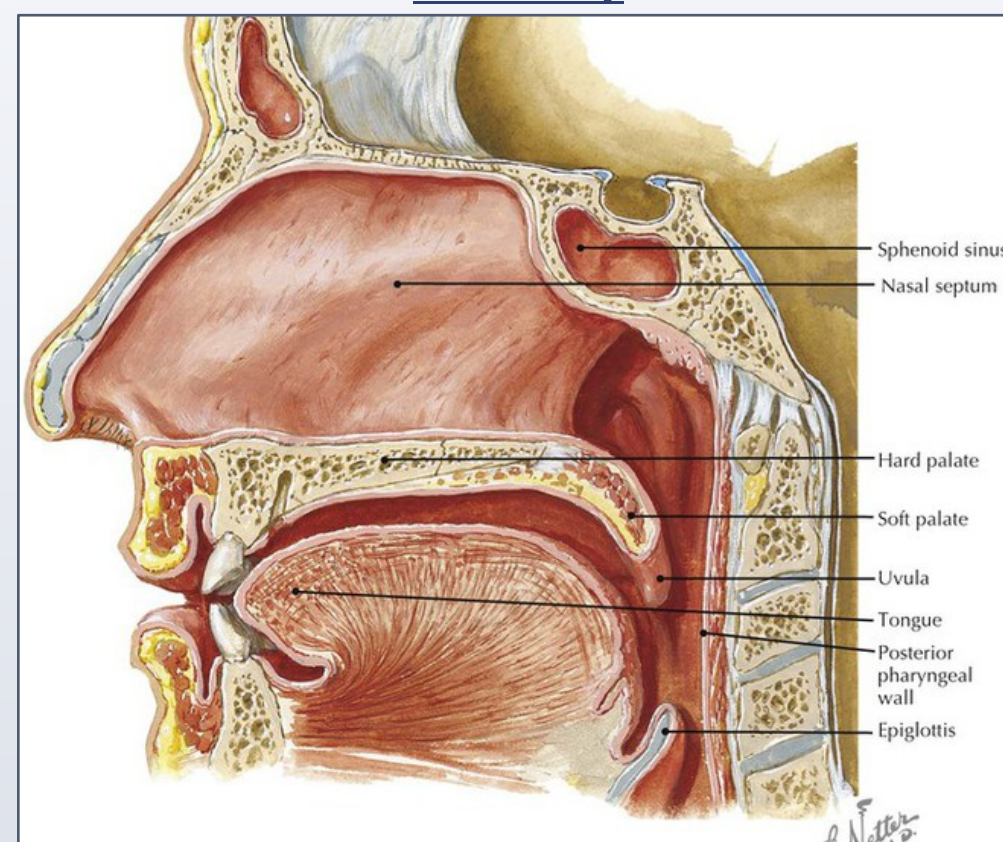


Figure 1: Pharynx<sup>8</sup>

## Methods

Our linguistic validation method followed a standard guideline that included forward translations, a backward translation, and cognitive interviewing.<sup>9,10</sup>

### Forward translations

- Two translators, both native Spanish speakers and fluent in English, independently produced a translation of the VELO assessment.
- The two translations were then reconciled into a single translation, the first version of the Spanish VELO.

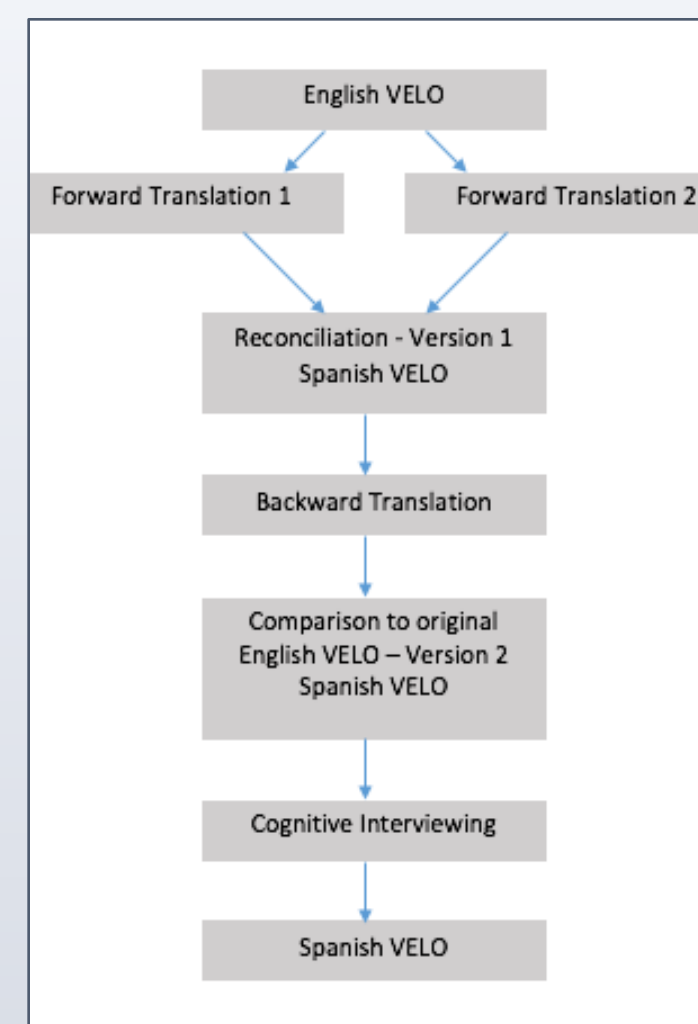
### Backward translation

- The reconciled translation was translated back into English by a third translator who did not have access to the original English VELO.
- This backward translation and the original English VELO were compared by the research team to find any translation discrepancies.

### Cognitive Interviewing

- The second version of the Spanish VELO was administered to Spanish-speaking parents seen at the Department of Otolaryngology.
- Parents were asked to interpret all items and provide possible alternatives for confusing translations.
- Revisions were made based on feedback from the interview.

## Linguistic Validation Process



## Materials

| Appendix A  |             | Appendix A   |       |
|---|-------------|--|-------|
| In the past four weeks, how much of a problem has your child had with (circle one for each question)? |             | In the past four weeks, how much of a problem has this been for you (circle one answer for each question)? |       |
|   | None at all | Very little  | Some  |
| <b>Speech Limitations (problems with...)</b>  |             |  |       |
| 1. Air comes out the or her nose when talking   | 0           | 1  | 2 3 4 |
| 2. Runs out of breath when talking  | 0           | 1  | 2 3 4 |
| 3. Difficulty speaking in long sentences  | 0           | 1  | 2 3 4 |
| 4. Speech is too weak   | 0           | 1  | 2 3 4 |
| 5. Difficulty being understood when in a hurry  | 0           | 1  | 2 3 4 |
| 6. Speech gets worse toward the end of the day  | 0           | 1  | 2 3 4 |
| 7. Speech sounds different than other kids  | 0           | 1  | 2 3 4 |
| <b>Swallowing Problems (problems with...)</b>   |             |  |       |
| 8. Liquids come from the nose while drinking  | 0           | 1  | 2 3 4 |
| 9. Solid food comes from the nose while eating  | 0           | 1  | 2 3 4 |
| 10. Others make fun of my child when food or liquids escape through the nose                          | 0           | 1  | 2 3 4 |
| <b>Situational Difficulty (problems with...)</b>  |             |  |       |
| 11. Speech is difficult for strangers to understand   | 0           | 1  | 2 3 4 |
| 12. Speech is difficult for friends to understand   | 0           | 1  | 2 3 4 |
| 13. Speech is difficult for family to understand  | 0           | 1  | 2 3 4 |
| 14. Difficulty being understood when not speaking face to face, eg. in a car                          | 0           | 1  | 2 3 4 |
| 15. Difficulty being understood on the phone  | 0           | 1  | 2 3 4 |
| <b>Emotional Impact (problems with...)</b>  |             |  |       |
| 16. Teased because of speech  | 0           | 1  | 2 3 4 |
| 17. Child gets sad because of speech  | 0           | 1  | 2 3 4 |
| 18. Gets frustrated or gives up when he or she is not understood                                      | 0           | 1  | 2 3 4 |
| 19. Is shy or withdrawn because of speech   | 0           | 1  | 2 3 4 |
| <b>Perception by Others (problems with...)</b>  |             |  |       |
| 20. Treated as if he or she is not very bright because of speech                                      | 0           | 1  | 2 3 4 |
| 21. Others ignore my child because of his or her speech   | 0           | 1  | 2 3 4 |
| 22. Others do not like to talk on the phone with my child because of his or her speech                | 0           | 1  | 2 3 4 |
| 23. Family or friends tend to speak for my child  | 0           | 1  | 2 3 4 |
| <b>Caregiver Impact (problems with...)</b>  |             |  |       |
| 24. I am worried or concerned about my child's speech   | 0           | 1  | 2 3 4 |
| 25. I find it difficult to understand my child  | 0           | 1  | 2 3 4 |
| 26. My child's speech problem slows me down or inconveniences me                                      | 0           | 1  | 2 3 4 |

Figure 2: English VELO<sup>4</sup>

## Results

The main purpose of this process was to ensure that there are no significant cultural gaps in the finalized Spanish VELO translation. Through these efforts, the Spanish VELO is both comprehensible and cognitively equivalent.

## Future Directions

Multisite study for reliability and validity testing of the Spanish VELO. This project would focus on the following measures as described in previous studies.<sup>11</sup>

### Criterion Validity

- Considered to be the extent to which a measure is related to an outcome. To measure: correlate VELO total score with a "gold standard", such as VPI severity.

### Construct Validity

- Determines whether the measure is associated with certain variables in theoretically predictable ways. To measure: correlate VELO score with 1) speech intelligibility deficit and 2) VP gap.

### Concurrent Validity

- Determines whether two assessments testing similar measures correlate strongly. To measure: correlate VELO total score with 1) Spanish pediatric voice handicap index and 2) Spanish PedsQL.

### Reliability and Internal Consistency

- Determines whether measurements are consistent between two time points, and how closely related a set of items in the VELO assessment are as a group.

## References

- Eamranond, Pracha P. et al. "Patient-Physician Language Concordance and Lifestyle Counseling Among Spanish-Speaking Patients." *Journal of Immigrant and Minority Health* 11.6 (2009): 494. Web.
- DuBard, C. Annette, and Ziya Gizlice. "Language Spoken and Differences in Health Status, Access to Care, and Receipt of Preventive Services Among US Hispanics." *American Journal of Public Health* 98.11 (2008): 2021-2028. Web.
- Jaramillo, Joshua et al. "The Hispanic Clinic for Pediatric Surgery: A Model to Improve Parent-provider Communication for Hispanic Pediatric Surgery Patients." *Journal of Pediatric Surgery* 51.4 (2016): 670-674. Web.
- Skirko JR et al. "Modification and Evaluation of a Velopharyngeal Insufficiency Quality-of-Life Instrument." *Archives of Otolaryngology-Head & Neck Surgery* 138.10 (2012): 929-935. Web.
- Barr L et al. "Quality of Life in Children with Velopharyngeal Insufficiency." *Archives of Otolaryngology-Head & Neck Surgery* 133.3 (2007): 224-229. Web.
- Conley, Stephen F. et al. "Identification and Assessment of Velopharyngeal Inadequacy." *American Journal of Otolaryngology* 18.1 (1997): 38-46. Web.
- Kummer, Ann. *Cleft Palate & Craniofacial Anomalies: Effects on Speech and Resonance*. Nelson Education, 2013. Print.
- Netter, Frank H. *Atlas of Human Anatomy*. Elsevier Health Sciences, 2012. Print.
- Canales, S, PA Ganz, and CA Coscarelli. "Translation and Validation of a Quality of Life Instrument for Hispanic American Cancer Patients: Methodological Considerations." *Quality of Life Research* 4.1 (1995): 3-11. Print.
- Varni, JW. "PedsQL Linguistic Validation Guidelines." (2010): n. pag. Print.
- Skirko, Jonathan R. et al. "Validity and Responsiveness of VELO." *Otolaryngology-Head and Neck Surgery* 149.2 (2013): 304-311. Web.