

## Evaluation of ACCQUIREnet Data Model for a Cleft-Centric Learning Health System

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The authors declare that they have no conflicts of interest or financial disclosures. No funding was received for this study.

**Background:** Outcomes research in cleft palate care is limited by small sample size, longitudinal care, numerous phenotypic variations, and the lack of a well-established learning health system. The objective of this study is to conduct a critical appraisal of data quality and data collection for a cleft-centric multi-institutional learning health network and assess its ability to evaluate data process metrics and clinical outcome measures.

**Methods:** This study represents a cross-sectional analysis of prospectively collected data from 2021-2023. Five cleft treatment centers collected real-time data during routine clinic appointments according to a standardized protocol and were evaluated within PRECEDE-PROCEED and RE-AIM frameworks. 1,676 English-speaking children and adolescents with cleft lip and/or palate met inclusion criteria for this study. Our outcomes of interest included data quality outcomes of data completeness and data accuracy. Data quality outcomes included completeness of primary data forms and variables (patient demographics, cleft phenotype) and completeness of secondary data forms and variables (patient race, clinic visit information, operational data). Data accuracy was assessed for key definition errors, proper CDM specification, and inaccurate values.

**Results:** Four out of five teams met criteria for data completeness. All teams met criteria for data accuracy. For teams that met data quality criteria, process metrics and clinical outcome measures demonstrated the ability to compare team performance.

**Conclusions:** In conclusion, our cleft-centric data model achieves overall accuracy and demonstrates the ability to answer clinical questions for selective teams that meet criteria for completeness. Continuous evaluation of data quality and implementing guidelines for team participation is necessary to ensure accurate data interpretation. Our cleft-centric network demonstrates useful applications of PRECEDE-PROCEED and RE-AIM data models and serves as a schema for other early-stage multi-institutional endeavors.