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BACKGROUND

Outcomes research in cleft care is limited by small sample size, longitudinal care, numerous phenotypic variations, and the lack of a well-established learning health system.

Project aim: 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

- Cross-sectional analysis of prospectively collected data from 2021-2023 at 5 cleft treatment centers evaluated with 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.
- Data quality outcomes: completeness of primary data (patient demographics, cleft phenotype) and completeness of secondary data (patient race, clinic visit information, operational data).
- Data accuracy outcomes: key definition errors, CDM specifications, and inaccurate values.

RESULTS

4 out of 5 teams met criteria for data completeness.
All teams met criteria for data accuracy.

Variable	Team A		Team B		Team C		Team D		Team E		Team F	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
# New patients seen (infants)	40.00	4.52	3.33	3.21	0.00	0.00	17.33	2.89	0.00	0.00	0.00	0.00
# New patients seen after infancy	46.00	3.44	23.67	21.78	0.33	0.58	27.00	12.77	0.33	0.58	1.67	1.15
# Clinic days	47.33	156.35	38.67	1.53	4.00	3.00	48.00	4.36	0.67	1.15	23.67	24.54
# Scheduled encounters	332.00	21.57	307.00	52.00	15.67	13.66	300.33	19.14	0.67	1.15	61.67	41.48
# Scheduled patients	306.33	15.44	275.67	55.43	15.67	13.66	287.67	11.02	0.67	1.15	60.00	38.69
# Completed encounters (checked-in and evaluated)	309.67	158.97	238.00	55.56	13.00	13.75	270.00	8.19	0.67	1.15	60.00	41.58
# No-shows	20.00	10.06	29.33	2.08	1.33	2.31	24.00	24.00	0.00	0.00	0.33	0.58
# Cancellations	2.00	9.14	36.00	7.21	0.00	0.00	6.33	7.09	0.00	0.00	0.33	0.58
# Prenatal consultations	17.00	43.90	0.33	0.58	NA	NA	1.33	1.53	NA	NA	NA	NA
# Declined participation	0.33	0.52	3.00	1.73	0.00	0.00	0.00	0.00	NA	NA	119.33	118.04
# Withdrawn from participation	0.33	21.24	0.00	0.00	NA	NA	0.67	1.15	NA	NA	31.67	49.66
# Discharged from team	38.67	19.62	4.33	0.58	NA	NA	NA	NA	NA	NA	2.33	2.52
# Transferred to another team	3.33	52.69	0.00	0.00	NA	NA	NA	NA	NA	NA	NA	NA

Team	# Oronasal fistulas	# Oronasal fistula procedures	# Repeat oronasal fistula procedures	# VPI procedures	# Repeat VPI procedures	Average length of stay	30-day readmission rate	30-day mortality rate	CL revision rate	CP revision rate	PSO indication rate	PSO performance rate	PSO completion rate
A	Mean	12.33	3.67	0.33	6.67	1.33	NA	0	0.12	0.38	0.28	0.89	0.62
	SD	4.9	2	4.04	3.58	0.58	NA	0	0.22	11.08	10.05	6.06	17.91
B	Mean	8.67	2	0.33	6.33	0.67	NA	0	1.2	0.13	0.03	0.83	0.07
	SD	4.62	1	0.58	1.53	0.58	NA	0.01	0.01	0.35	0.06	0.01	0.29
C	Mean	0.33	0	0	3	0.33	NA	NA	NA	NA	0	NA	NA
	SD	0.58	0	0	2.65	0.58	NA	NA	NA	NA	0	NA	NA
D	Mean	13.33	4.33	1	0	0	NA	0.03	0	0.41	0.65	0	NA
	SD	3.06	3.06	1	0	0	NA	0.03	0	0.1	0.34	0	NA
E	Mean	0	0	0	0	0	NA	NA	NA	NA	0	NA	NA
	SD	0	0	0	0	0	NA	NA	NA	NA	0	NA	NA
F	Mean	NA	NA	NA	NA	NA	NA	NA	NA	NA	0	NA	NA
	SD	NA	NA	NA	NA	NA	NA	NA	NA	NA	0	NA	NA

Team	CLEFT-Q Eating and Drinking score	CLEFT-Q Nasal score	CLEFT-Q Speaking-related Distress score	CLEFT-Q Speech Function score	CLEFT-Q Dental score	CLEFT-Q Facial score	CLEFT-Q Felt score	CLEFT-Q Jaw score	CLEFT-Q Lip score	CLEFT-Q Nostril score	CLEFT-Q Scar score	CLEFT-Q School Life score	CLEFT-Q Social Life score	FACE-Q Appearance-related Distress score	FACE-Q Breathing score	FACE-Q Smile score	N COS score	
A	Mean	83.87	65.7	77.48	73.41	56.71	66.54	83.87	83.87	69.15	65.45	66.53	75.97	81.08	21	NA	NA	19.41
	SD	26.58	21.89	26.05	28.57	15.94	18.49	28.03	30.92	28.15	24.42	18.51	22.34	38.25	5.02	NA	NA	6.39
B	Mean	79.42	54.7	77.71	75.22	53.21	60.69	79.42	79.42	59.92	53.86	53.64	73.5	74.84	22.95	NA	NA	18.33
	SD	18.24	6.79	3.83	5.46	2.45	4.3	18.24	18.24	9.23	7.06	7.05	7.66	71.51	4.73	NA	NA	1.72
C	Mean	75.5	63.37	80.21	85.1	54.27	62.26	75.5	75.5	65.05	59.42	86.63	71.89	71.52	13.95	91.6	47.61	11.25
	SD	10.61	18.87	2.78	12.92	25.86	17.78	10.61	10.61	26.97	21.18	12.14	15.14	19.67	0.25	8.38	41.46	9.75
D	Mean	73.12	60.18	75.02	70.35	52.13	61.82	73.12	73.12	62.38	59.2	51.8	71.43	72.51	22.72	77.46	49.04	23.21
	SD	6.59	3.14	1.35	2.39	3.37	2.55	6.59	6.59	2.04	1.31	1.66	2.55	2.87	1.62	1.66	2.7	2.28
E	Mean	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
	SD	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
F	Mean	76.3	62.6	71.6	68.65	55.61	59.54	76.3	76.3	65.31	59.21	63.9	77.72	77.95	23.7	85.77	56.6	18.04
	SD	8.91	2.38	2.72	1.78	2.45	10.88	8.91	8.91	0.14	6.01	2.63	2.59	4.37	1.83	5.98	NA	0.76

CONCLUSIONS

Our cleft-centric data model achieves overall accuracy and demonstrates the ability to answer clinical questions for selective teams that meet criteria for completeness. Our network demonstrates useful applications of PRECEDE-PROCEED and RE-AIM models and serves as a schema for other early-stage multi-institutional endeavors.