

HNQOL survey

	timepoint	N	MEAN	MIN	MAX	STD	significance level	p-value from mixed model
Eating	Screening	53	80.8805	29.16667	100	18.87842		ref
	6 months	35	74.80952	29.16667	100	18.24744	*	0.0285156
	12 months	32	75.13021	8.333333	100	22.95596		0.0688483
	24 months	25	80.75	54.16667	100	13.99198		0.4304148
Emotion	Screening	52	62.17949	12.5	95.83333	19.98853		
	6 months	35	72.14286	16.66667	100	27.112	***	0.000034
	12 months	33	75.12626	4.166667	100	21.98595	***	0.0000008
	24 months	25	75.73333	16.66667	100	22.7167	***	0.0000034
Pain	Screening	53	62.85377	12.5	100	21.7688		
	6 months	35	64.82143	6.25	100	29.12186		0.5005594
	12 months	33	64.83586	0	100	28.621		0.34542
	24 months	25	66.58333	12.5	100	29.63098		0.2508016
Speech	Screening	54	47.91667	18.75	100	21.82018		
	6 months	35	53.5119	0	100	31.70732		0.1527897
	12 months	34	51.47059	0	100	33.1455		0.2701334
	24 months	24	59.375	0	100	23.45787	*	0.0244326

VRQOL instrument

	timepoint	N	MEAN	MIN	MAX	STD	significance level	p-value from mixed model
	Screening	52	24.9615	10	49	9.2968		
	6 months	33	23.6061	11	41	10.1271		0.3887803
	12 months	29	24.5172	12	43	9.7417		0.3401234
	24 months	22	23.6818	12	50	10.8469		0.5548782

significance key

- *p<0.05
- ** p<0.01
- ***p<0.001