Supplemental information

Evaluating parental personal utility

of pediatric genetic and genomic testing

in a diverse, multilingual population

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Supplemental Materials

Figure S1. Distrust in the competence of the healthcare system by education
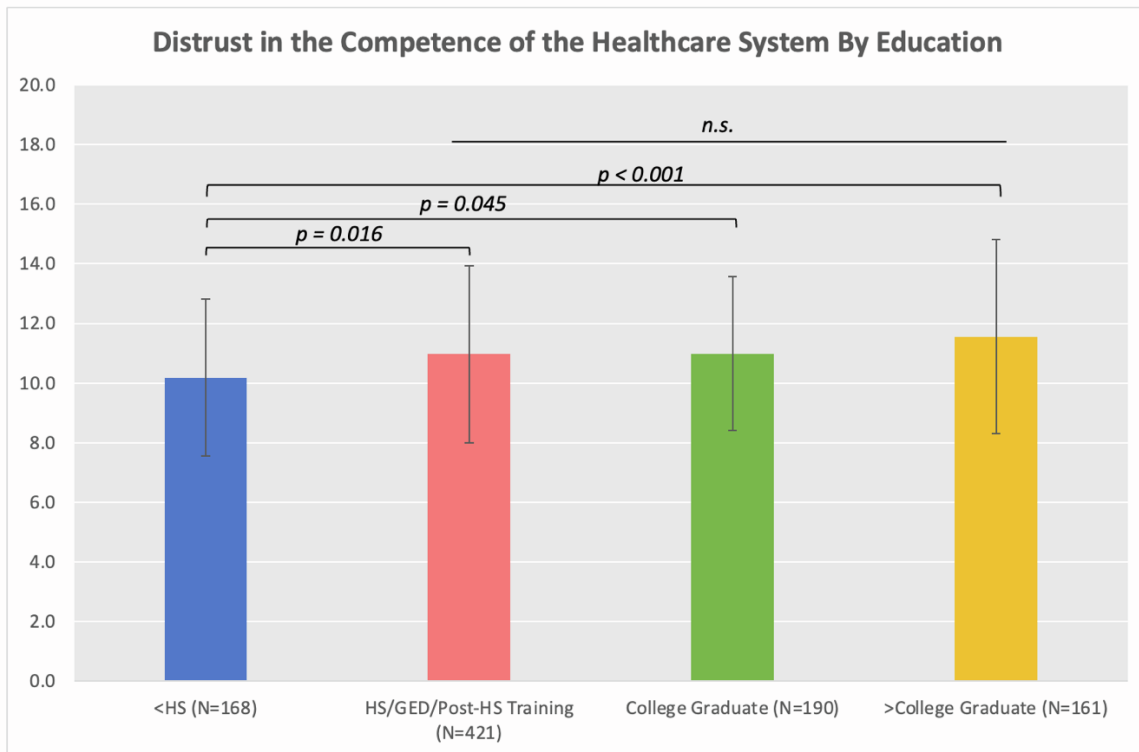

Figure S1. ANOVA and post hoc Tukey tests between highest level of education completed by parents/guardians and distrust in the competence of the healthcare system displayed above (($F_{(3,936)}$ = 6.3, p = 0.001). Displayed p-values reflect post-hoc Tukey results (n.s. = not significant). Those with less than a high school education scored significantly lower on the distrust scale compared to the other three education levels. No differences found between HS/GED/Post-HS Training, College Graduate and >College Graduate.

Abbreviations: HS: High school; GED: General Education Development Test

Figure S2. Personal utility summary score across three largest population groups
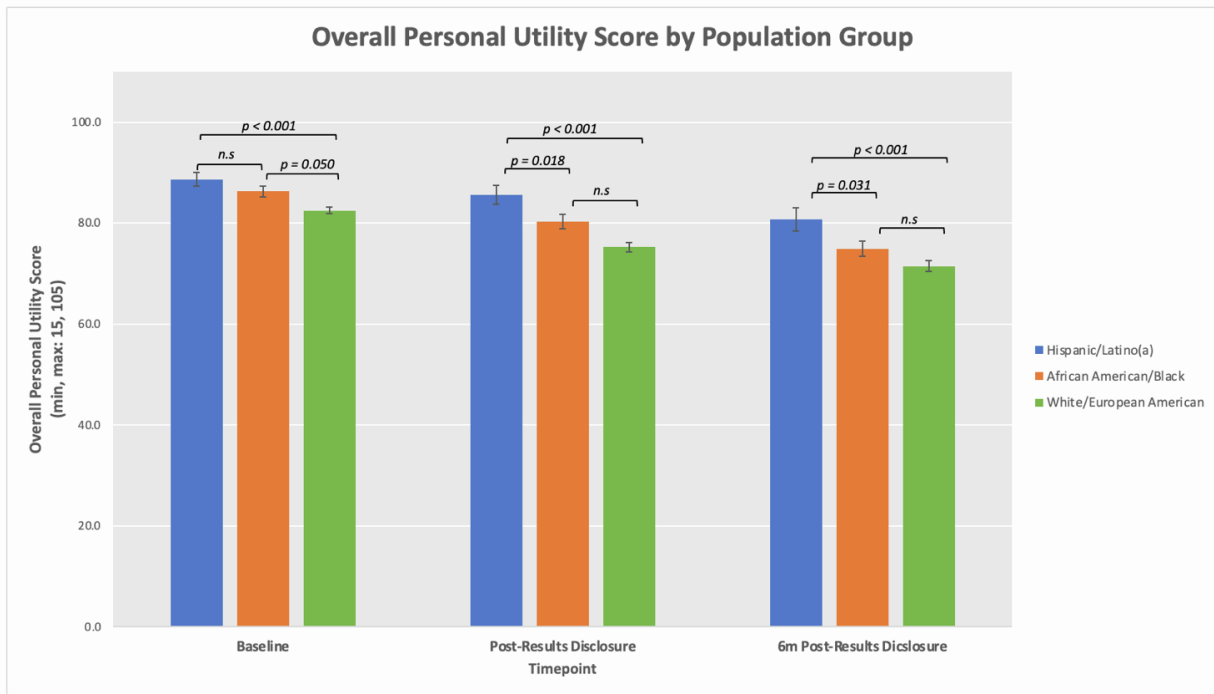

Figure S2. ANOVA and post-hoc Tukey tests between overall personal utility score and the three largest population groups (Hispanic/Latino(a) (H/L), African American/Black (AA) and European American (EA)) across three time points (baseline: $F_{(2,786)} = 12.5$, $p < 0.001$; post-results disclosure: $F_{(2,785)} = 19.5$, $p < 0.001$; 6m post-results disclosure: $F_{(2,713)} = 12.0$, $p < 0.001$). Displayed p-values reflect post-hoc Tukey results (n.s. = not significant). Post-results disclosure, H/L participants had greater personal utility scores than EA and AA participants. At baseline, H/L participants had greater personal utility than EA participants, but H/L and AA participants did not significantly differ. At post-results disclosure and 6m post-results disclosure, no differences found between AA and EA.

Table S1. Factor analysis of the adapted pediatric Personal Utility Scale (PrU) measure (N=944)

Survey item[a]	Factor 1[b] (*Practical Utility*)	Factor 2[c] (*Informational Utility*)	Factor 3[d] (*Parental Psychological Utility*)
1. Help with my child's life planning	0.78	0.29	0.20
2. Inform plans for my child's school or career	0.82	0.18	0.17
5. Help me or our family mentally prepare for the future	0.19	0.10	0.96
6. Help to better understand my child's health	0.17	0.12	0.96
7. Contribute to my child's self-knowledge	0.67	0.38	0.23
8. Help me cope with my child's health risks	0.74	0.39	0.25
9. Help me feel more in control of my child's health	0.78	0.33	0.20
10. Help me feel more in control of my child's life	0.77	0.30	0.19
11. Simply to provide information	0.31	0.75	0.08
12. Satisfy my curiosity about my child	0.43	0.65	0.15
13. Help my child use social programs, like resources and services	0.79	0.28	0.17
14. Improve communication with my family members	0.78	0.28	0.19
15. Feel good about helping the medical community	0.23	0.79	0.13
16. Feel good about having information for family members	0.45	0.64	0.17
17. Feel good about taking responsibility for my child's health	0.35	0.76	0.16

[a] Original scale consisted of 17 items; however, only 15 items were used in this analysis, two items (items 3 and 4) were removed a priori since they were not applicable to the entire study cohort

[b] Scale reliability for Practical Utility: Cronbach's α = 0.94

[c] Scale reliability for Informational Utility: Cronbach's α = 0.87

[d] Scale reliability for Parental Psychological Utility: Cronbach's α = 0.97

Table S2. Outcomes assessed to evaluate personal utility

Measures	Survey question	Response options	Source	Baseline	Post-results disclosure	6m post-results disclosure
					Time point	
Outcome Measure						
Parent's Expectations of Personal Utility of Genomic Results	In this next section, we will ask you how useful you believe your child's test results will be in making future decisions. We know you have not yet received the results, but we want to know what you expect may happen when you do get them. Please indicate how useful you think your child's results will be for the following purposes: 1. Help with my child's life planning 2. Inform plans for my child's school or career 5. Help me or our family mentally prepare for the future 6. Help to better understand my child's health 7. Contribute to my child's self-knowledge 8. Help me cope with my child's health risks 9. Help me feel more in control of my child's health 10. Help me feel more in control of my child's life 11. Simply to provide information 12. Satisfy my curiosity about my child 13. Help my child use social programs, like resources and services 14. Improve communication with my family members	1, Not at all useful | 2, A little useful | 3, Somewhat useful | 4, Neutral | 5, Useful | 6, Very useful | 7, Extremely useful | 98, Don't Know	CSER measure adapted for pediatric populations from the Personal Utility Scale (PrU)(1)	X	-	-

	15. Feel good about helping the medical community 16. Feel good about having information for family members 17. Feel good about taking responsibility for my child's health					
Personal Utility of Genomic Results after Results Disclosure	In the next section, we will ask you questions about how useful your child's test results will be in making future decisions. Please indicate how useful you find the following outcomes of your child's test result: 1. Help with my child's life planning 2. Inform plans for my child's school or career 5. Help me or our family mentally prepare for the future 6. Help to better understand my child's health 7. Contribute to my child's self-knowledge 8. Help me cope with my child's health risks 9. Help me feel more in control of my child's health 10.Help me feel more in control of my child's life 11. Simply to provide information 12. Satisfy my curiosity about my child 13. Help my child use social programs, like resources and services 14. Improve communication with my family members 15. Feel good about helping the medical community 16. Feel good about having information for family members 17. Feel good about taking responsibility for my child's health	1, Not at all useful | 2, A little useful | 3, Somewhat useful | 4, Neutral | 5, Useful | 6, Very useful | 7, Extremely useful | 98, Refused	CSER measure adapted for pediatric populations from the Personal Utility Scale (PrU)(1)	-	X	X

Table S3. Covariates and population characteristics included in the analysis

Provided as an excel due to size of table.

Table S4. Bivariate analyses of selected variables with Personal Utility Scale (PrU) summary score

Bivariate Analysis of Variables	N[a]	PrU Summary Score, M(SD)	P-Value[b]
Relationship to child			
Mother	1562/1782	79.4 (21.7)	0.27
Father	143/1782	76.4 (22.5)	
Legal Guardian	77/1782	78.3 (23.0)	
Health system			0.65
Montefiore Medical Center	605/1782	79.4 (23.6)	
Mount Sinai Health System	117/1782	79.0 (20.9)	
Previous genetics testing			**0.008**
No	1056/1782	80.3 (21.5)	
Yes	705/1782	77.5 (22.0)	
Self-reported race and ethnicity[c]			**<0.001**
African American/Black	266/1782	77.8 (24.3)	
Hispanic/Latino(a)	830/1782	83.2 (20.4)	
White/European American	408/1782	73.5 (21.0)	
How was the survey administered?			0.98
Phone/Videoconference	1487/1782	79.1 (22.0)	
In-person	295/1782	79.1 (20.9)	
Education level			**<0.001**
< HS	321/1782	81.9 (22.2)	
HS Grad/GED/Post-HS Training	797/1782	82.5 (20.5)	
College graduate	355/1782	75.4 (21.9)	
> College graduate	303/1782	72.0 (22.5)	
Insurance Type			**<0.001**
Public	1150/1782	81.3 (21.3)	
Private	632/1782	75.2 (22.3)	
Case-level interpretation of genetic test result			**<0.001**
Positive/Likely Positive	315/1782	89.1 (18.2)	
Uncertain	906/1782	76.4 (21.6)	
Negative	561/1782	78.0 (22.6)	
Language of Survey during Immediate Timepoint			**<0.001**
Spanish	402/1782	85.0 (19.9)	
English	1380/1782	77.4 (22.1)	
Language of Survey during 6m Timepoint			**<0.001**
Spanish	1327/1782	84.6 (20.6)	
English	379/1782	77.7 (22.0)	
Brief Health Literacy Score	1782/1782	79.1 (21.8)	**<0.001**
Healthcare Distrust Values Subscale Score	1780/1782	79.1 (21.8)	**<0.001**
Healthcare Distrust Competence Subscale Score	1780/1782	79.1 (21.8)	**<0.001**

[a] N reflects number of responses from both timepoints: post-results disclosure and 6 months post-results disclosure. Variations in total N (N=1782) reflect missing values in the original variables.

Table S5. Multivariate linear regression of the personal utility summary score assessed at post-results disclosure using measures of understanding and mode of result delivery

	Full Sample (N=912)[a]		EA Only (N=212)		AA Only (N=137)		H/L Only (N=417)	
	β (95% CI)	p-value	β (95% CI)	p-value	β (95% CI)	p-value	β (95% CI)	p-value
Measures of Understanding								
Perceived Understanding								
Level 2 vs Level 1	6.84 (2.22, 11.46)	**0.004**	19.47 (5.81, 33.62)	**0.005**	10.39 (-2.34, 23.11)	0.109	7.52 (1.33, 13.70)	**0.017**
Level 3 vs Level 1	10.17 (5.81, 14.56)	**<0.001**	22.18 (9.27, 35.10)	**0.001**	18.18 (5.19, 31.16)	**0.007**	9.26 (3.58, 14.94)	**0.001**
Objective Understanding Summary Score	-2.27 (-3.46, -1.08)	**<0.001**	-2.83 (-5.92, 0.27)	0.073	-5.01 (-8.67, -1.34)	**0.008**	-1.72 (-3.35, -0.09)	**0.038**
Mode of Result Disclosure								
In Person vs Telehealth	-0.97 (-4.45, 2.50)	0.583	1.81 (-5.94, 9.56)	0.646	4.40 (-6.04, 14.83)	0.405	0.59 (-4.30, 5.47)	0.814
Socioeconomic Factors								
Education Level								
HS/GED/Post-HS training vs <HS	1.59 (-2.13, 5.31)	0.402	-1.73 (-22.11, 18.65)	0.867	4.78 (-5.89, 15.46)	0.376	3.21 (-1.21, 7.63)	0.154
College Graduate vs <HS	-4.52 (-9.01, -0.02)	**0.049**	-7.04 (-27.77, 13.69)	0.504	5.73 (-7.95, 19.42)	0.408	-1.46 (-7.39, 4.46)	0.628
College+ vs <HS	-5.14 (-10.07, -0.22)	**0.041**	-1.49 (-22.22, 19.23)	0.887	-5.61 (-20.87, 9.65)	0.468	-5.4 (-14.09, 3.29)	0.223
Survey Language								
Spanish vs English	1.65 (-1.95, 5.26)	0.368	_[b]	-	9.33 (-20.99, 39.65)	0.543	-0.38 (-4.72, 3.97)	0.864
Insurance Type								
Private vs Public	-2.09 (-5.09, 0.90)	0.171	5.10 (-1.29, 11.49)	0.117	-1.62 (-9.88, 6.63)	0.698	-4.99 (-9.84, -0.14)	**0.044**
Health Literacy Score	-0.48 (-0.90, -0.05)	**0.027**	-0.91 (-2.13, 0.30)	0.141	-1.19 (-2.57, 0.18)	0.088	-0.28 (-0.81, 0.25)	0.295
Healthcare Distrust								
Values Subscale	0.23 (-0.22, 0.68)	0.319	0.89 (-0.130- 1.92)	0.087	-0.68 (-1.96, 0.59)	0.290	0.36 (-0.28, 0.99)	0.273
Competence Subscale	-0.76 (-1.33, -0.18)	**0.010**	-1.51 (-2.73, -0.29)	**0.016**	-0.52 (-2.14, 1.10)	0.528	-0.67 (-1.52, 0.19)	0.126
Clinical Factors								
Case-Level Clinical Interpretation								
Positive/Likely Positive vs Negative	14.62 (10.85, 18.39)	**<0.001**	15.12 (6.89, 23.35)	**<0.001**	21.29 (8.67, 33.91)	**0.001**	13.89 (8.70, 19.07)	**<0.001**
Uncertain vs Negative	-0.66 (-3.63, 2.31)	0.663	0.08 (-6.69, 6.85)	0.981	-4.99 (-13.95, 3.97)	0.272	1.70 (-2.48, 5.88)	0.425
Previous Genetic Testing								
Yes vs No	-2.12 (-4.74, 0.50)	0.112	-3.5 (-9.15, 2.16)	0.225	6.56 (-1.79, 14.91)	0.122	-4.29 (-8.06, -0.53)	**0.026**

[a] While not shown, all models controlled for the genetic counselor who returned the results.
[b] Language omitted from model due to collinearity.

Abbreviations: EA: White or European American; AA: Black or African American; H/L= Hispanic/Latino(a)

Table S6. Multivariate linear regression of the personal utility summary score assessed at 6m post-results disclosure using measures of understanding and mode of result delivery

	Full Sample (N=800)[a]		EA Only (N=183)		AA Only (N=116)		H/L Only (N=380)	
	β (95% CI)	p-value	β (95% CI)	p-value	β (95% CI)	p-value	β (95% CI)	p-value
Measures of Understanding								
Perceived Understanding								
Level 2 vs Level 1	6.91 (2.71, 11.11)	**0.001**	1.19 (-9.87, 12.24)	0.833	6.65 (-5.46, 18.76)	0.278	4.36 (-1.41, 10.13)	0.138
Level 3 vs Level 1	8.00 (3.94, 12.06)	**<0.001**	5.33 (-5.54, 16.21)	0.334	5.35 (-7.13, 17.82)	0.397	6.77 (1.24, 12.30)	**0.017**
Objective Understanding Summary Score	-1.19 (-2.43, 0.04)	0.058	-0.37 (-3.31, 2.58)	0.805	2.53 (-1.82, 6.87)	0.250	-1.21 (-2.88, 0.45)	0.153
Mode of Result Disclosure								
In Person vs Telehealth	1.17 (-2.96, 5.29)	0.579	1.40 (-7.03, 9.84)	0.743	-1.32 (-15.04, 12.41)	0.849	2.95 (-2.90, 8.81)	0.322
Socioeconomic Factors								
Education Level								
HS/GED/Post-HS training vs <HS	0.73 (-3.66, 5.13)	0.744	-1.31 (-23.02, 20.41)	0.906	14.41 (-0.09, 28.91)	0.051	-0.88 (-6.08, 4.32)	0.740
College Graduate vs <HS	-2.85 (-8.18, 2.48)	0.294	0.95 (-21.17, 23.08)	0.932	6.94 (-10.81, 24.69)	0.439	-5.43 (-12.49, 1.63)	0.131
College+ vs <HS	-7.33 (-13.18, -1.48)	**0.014**	0.16 (-21.94, 22.25)	0.989	-6.55 (-25.76, 12.66)	0.500	-9.75 (-19.71, 0.22)	0.055
Survey Language								
Spanish vs English	2.44 (-1.81, 6.69)	0.260	-[b]	-	-[b]	-	-0.18 (-5.15, 4.79)	0.942
Insurance Type								
Private vs Public	-3.09 (-6.62, 0.44)	0.086	-2.05 (-9.285, 5.179)	0.576	0.57 (-9.80, 10.93)	0.914	-4.64 (-10.18, 0.90)	0.101
Health Literacy Score	-0.12 (-0.61, 0.37)	0.632	-1.11 (-2.48, 0.29)	0.119	0.3 (-1.41, 2.01)	0.725	0.12 (-0.493, 0.732)	0.701
Healthcare Distrust								
Values Subscale	-0.27 (-0.80, 0.26)	0.316	0.78 (-0.34, 1.91)	0.171	-1.23 (-2.86, 0.41)	0.139	-0.12 (-0.86, 0.63)	0.755
Competence Subscale	-0.64 (-1.32, 0.04)	0.067	-1.36 (-2.75, 0.03)	0.056	-0.27 (-2.30, 1.77)	0.796	-0.91 (-1.91, 0.09)	0.075
Clinical Factors								
Case-Level Clinical Interpretation								
Positive/Likely Positive vs Negative	7.18 (2.82, 11.54)	**0.001**	9.78 (0.75, 18.80)	**0.034**	1.72 (-13.81, 17.25)	0.827	5.57 (-0.47, 11.60)	0.071
Uncertain vs Negative	-3.48 (-6.93, -0.02)	**0.049**	-3.36 (-11.31, 4.59)	0.405	-11.97 (-23.16, -0.78)	**0.036**	-1.6 (-6.45, 3.26)	0.518
Previous Genetic Testing								
Yes vs No	-2.32 (-5.39, 0.74)	0.137	-9.24 (-15.66, -2.82)	**0.005**	-1.21 (-11.27, 8.86)	0.812	0.77 (-3.63, 5.16)	0.732

[a] While not shown, all models controlled for the genetic counselor who returned the results.
[b] Language omitted from model due to collinearity.

Abbreviations: EA: White or European American; AA: Black or African American; H/L= Hispanic/Latino(a)

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