

What motivates adopted individuals to pursue elective genetic testing?

Findings from the Sanford Chip Program

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Background

- Elective genetic testing (EGT) may help individuals who are adopted (adoptees) with limited access to family history information understand their inherited risks.
- In 2018, Sanford Health launched the Sanford Chip, an EGT program available to primary care patients that included panel pharmacogenomic testing and optional screening for Mendelian disease risks.

Methods

- A survey was administered upon program enrollment from August 2020 to April 2022.
- Survey items assessed participants' motivations, expectations, and concerns about pursuing testing, as well as demographic characteristics, including adoption status.
- Additional demographic data was collected from the electronic medical record (EMR).
- To be included in analyses, patients must have received EGT results, have answered the adoption status question, and have demographic data available from the EMR.
- Data were analyzed using bivariate analyses.

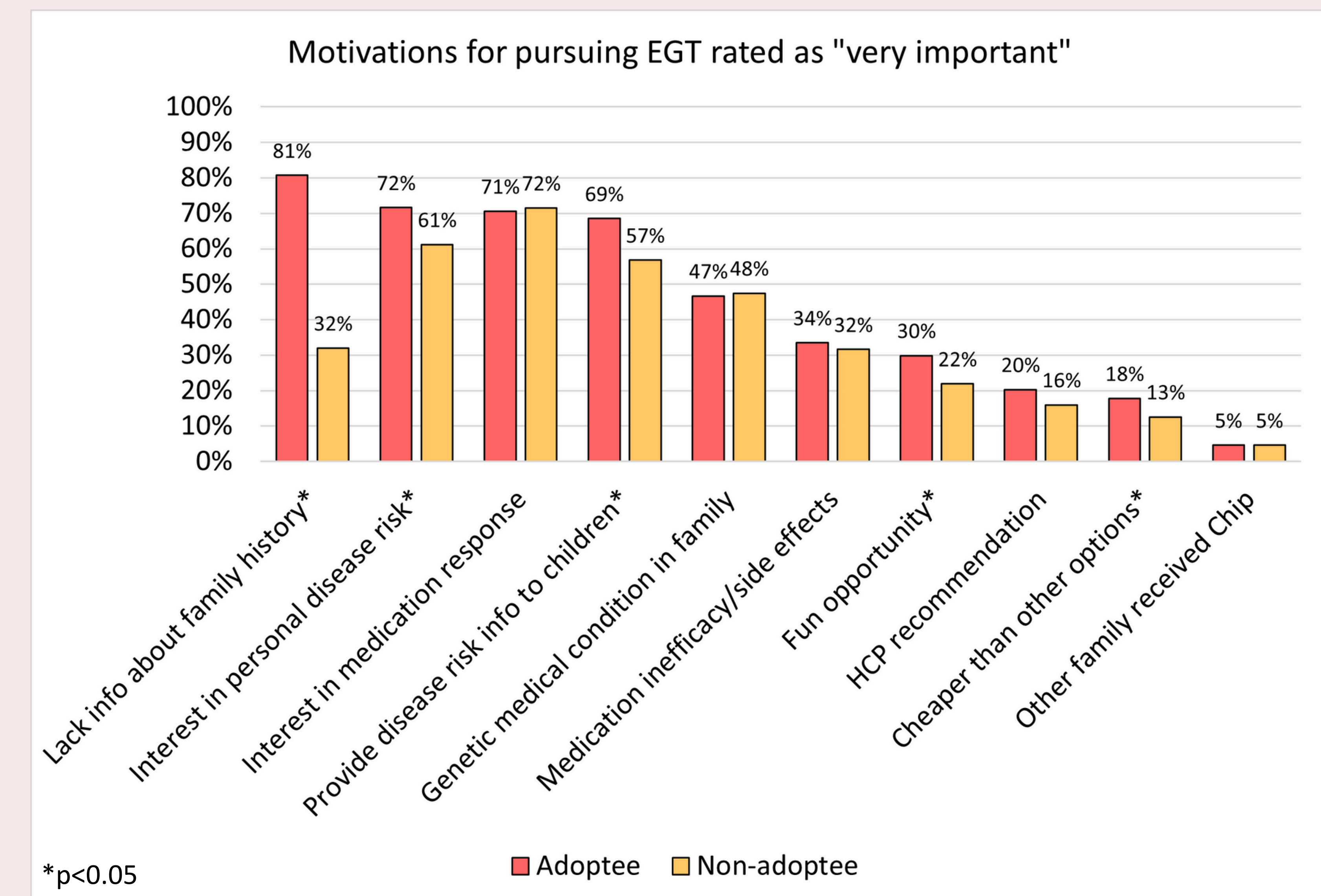
Demographic characteristics

	Adoptee (n=197)	Non-adoptee (n=5,602)	p-value
Age (median, IQR)	48.7 (17.7) years	52.0 (25.9) years	0.044*
Male	119 (60.4%)	3,530 (63.0%)	0.457
Female	78 (39.6%)	2,072 (37.0%)	
BMI, mean (sd)	33.6 (9.1)	31.6 (8.4)	0.001*
Current smoker	31 (15.7%)	418 (7.5%)	<0.001*
Currently married	126 (64.0%)	3,847 (68.7%)	0.170
Number of children, mean (sd)	1.9 (1.4)	1.8 (1.4)	0.477
Self-reported race			<0.001*
American Indian or Alaska Native	8 (4.1%)	25 (<1%)	
Asian	<5 (<3%)	28 (<1%)	
Black or African American	<5 (<3%)	27 (<1%)	
Native Hawaiian or Pacific Islander	<5 (<3%)	<5 (<1%)	
White	170 (86.3%)	5,344 (95.4%)	
Other race	<5 (<3%)	34 (<1%)	
Two or more races	10 (5.1%)	119 (2.1%)	
Self-reported ethnicity			0.008*
Hispanic or Latino	9 (4.6%)	107 (1.9%)	
Non-Hispanic or Latino	186 (94.4%)	5,476 (97.8%)	

*p<0.05

Results

Figure 1



- Adoptees were more likely than non-adoptees to report lack of information about their family history as a very important motivation for pursuing the Sanford Chip (81% vs 32%; p<0.001; Figure 1); moreover, they were more likely to rate it as their most important motivation (45% vs 5%; p<0.001).
- Adoptees were more likely than non-adoptees to expect that the Sanford Chip would explain a family history of disease (52% vs 43%; p=0.004).
- There were no differences in concerns between adoptees and non-adoptees.

Conclusions

- A lack of family history information is an important reason why EGT is pursued by adoptees, who may hope it will identify inherited risks for disease.
- Findings may provide insight into the motivations for pursuing EGT among other populations who may similarly lack family history information, such as donor-conceived individuals.