

# Assessment of a Video on Genome Testing Expectations and Results: Parent and Adolescent Views and Understanding

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## Background

- ✦ A consenting process is required prior to receiving genetic testing. In clinical settings, consenting is provided in-person by genetic counselors. In research settings, consenting is often provided via paper explanation.
- ✦ Both parents and adolescents need to understand and be adequately informed about expectations in research genomic testing during the consenting process, including limitations to testing, the possibility of secondary findings, and the risks/benefits of receiving positive/negative results.
- ✦ Both parents and adolescents have requested the return of results from research genomic testing, which is currently not required, yet remains an ethical obligation for researchers.
- ✦ Currently, there are not enough genetic counselors available to provide the information needed prior to consenting for both clinical and research purposes.
- ✦ Alternate methods of pre-test counseling to convey information about research genomic testing have been considered such as interactive systems and audiovisual tools.

## Purpose

To assess the views and understanding of parents and adolescents (13-17yrs) to an audiovisual tool developed to explain the expectations and results of genomic testing.

## Methods

The video reviewed in this study was developed through pretests with qualitative focus groups, followed by video production.

### Phase 1

#### Study Population

Ninety-seven healthy parents and an adolescent pairs were recruited for phase 1 from Cincinnati Children's Hospital Medical Center and surrounding locations.

#### Data Collection

- ✦ The video was posted on YouTube for easy access to potential participants in a prospective study about the return of eMERGE (e3) genomic research.
- ✦ Parents and adolescents viewed the video prior to providing written consent.
- ✦ After consenting, participants completed a 14 item questionnaire assessing their understanding of content in the video.

#### Data Analysis

- SPSS Stat 10 software was used to run the following analyses:
- ✦ Two-sided independent t-test to compare average scores between parents and adolescents
  - ✦ Fisher exact tests to compare the number of parents and adolescents answering correctly for each individual question on the questionnaire
  - ✦ Two-sided independent t-tests to compare the average scores among adolescents by age, sex, race and household income

## Methods

### Phase 2

#### Sample Population

Convenient sampling was used to recruit ten healthy adolescents for Phase 2 of this study. Participants had no previous genetic testing, nor been diagnosed with a genetic condition.

#### Data Collection

- Stage 1: Adolescents asked what they expected to learn from a video about genomic testing
- Stage 2: Adolescents watched eMERGE video: Genome Testing: Expectations and Results  
Adolescents filled out 16-item questionnaire to measure understanding
- Stage 3: Adolescents were asked their impressions and feelings about the video, what was memorable, what they felt they learned, and questions concerning negative test results

#### Data Analysis

- ✦ All interviews were audio recorded and transcribed verbatim. Transcripts were coded and analyzed for major themes. Cohen's Kappa inter-rater reliability = 0.743.

## Results: Phase 1

### Sample Characteristics

Phase 1 Demographics (n=97 in each group)			
	Parent n(%)	Adolescent n(%)	
Sex	Male	12 (12.4)	33 (34.0)
	Female	85 (87.6)	63 (65.0)
	Other	0 (0)	1 (1.03)
Age	13-14 years old	-	42 (43.3)
	15-17 years old	-	55 (56.7)
	Mean Age (SD)	44.70 (7.78)	14.76 (1.18)
Race	White	75 (77.3)	73 (75.3)
	Black or African American	17 (17.7)	16 (16.5)
	Asian or Pacific Islander	1 (1.03)	2 (2.06)
	Mixed Race	3 (3.09)	6 (6.19)
	Don't Know or Unsure	1 (1.03)	0 (0)
Ethnicity	Hispanic	3 (3.09)	5 (5.15)
	Not Hispanic	93 (95.8)	86 (88.7)
	Not Sure	1 (1.03)	6 (6.19)
Household Income	< \$15,000 to \$29,999	15 (15.5)	-
	\$30,000 to \$44,999	10 (10.3)	-
	\$45,000 to \$59,999	9 (9.28)	-
	\$60,000 to \$89,999	17 (17.5)	-
	\$90,000 to \$149,999	11 (11.3)	-
	\$150,000 or above	22 (22.7)	-
Prefer not to answer	13 (13.4)	-	
Familiarity with Genetics or DNA	Had a genetic test	18 (18.6)	11 (11.3)
	Told by doctor they had a genetic condition	10 (10.3)	12 (12.4)
	Immediate family with a genetic condition	25 (25.8)	18 (18.7)

### Parent and Adolescent Scores on Post-Video Knowledge Questionnaire

- ✦ There was a significant difference in the average scores between both groups ( $p < 0.001$ ), with parents answering 11 of the 13 post-video knowledge questions correctly, compared to 9.35 from adolescents.

- ✦ There were significant differences in the number of correct parents and adolescents for over half of the questions, including:

"Genetic test results for conditions I choose to receive will become part of my (child's) medical record."	P=0.016
"All gene variations that cause a specific condition will be examined on the gene panel."	P=0.002
"Other researchers may have access to my (child's) genetic information."	P=0.006
"I (My child) is not at risk for the condition."	P=0.002
"I (My child) could still develop the condition."	P=0.037
"The cause of a medical condition I (my child) or others might have could still be genetic but the test was simply not able to find it."	P=0.002
"My (child's) doctor may recommend different screening."	P<0.001
"I can definitely prevent the condition from occurring in me (my child)."	P=0.027

- ✦ Significant differences in average scores were found among adolescents by race and household income.

	Phase 1 Adolescent Score Comparisons			
	Mean Scores	P value <sup>1</sup>	t value	dF
Age Group	Mean (SD)			
	13-14 years old (n=42)	9.6 (2.42)		
15-17 years old (n=55)	9.1 (2.60)	0.378	0.89	94
Sex	Male (n=33)	9.33 (2.37)		
	Female (n=63)	9.37 (2.61)	0.954	-0.06
Race	White (n=72)	9.96 (2.11)		
	Non-White (n=25)	7.60 (2.75)	<0.001*	4.43
Household Income	\$59,999 or less (n=34)	8.68 (2.48)		
	\$60,000 or above (n=50)	9.98 (2.23)	0.014*	-2.51

<sup>1</sup>p-values obtained from 2-sided independent t-tests; 95% CI  
\*Denotes significance

## Results: Phase 2

### Sample Characteristics

Phase 2 Demographics (n=10)		
	Adolescents n(%)	
Sex	Male	5 (50%)
	Female	5 (50%)
Age	13-14 years old	7 (70%)
	15-17 years old	3 (30%)
Race	White	8 (80%)
	Black or African American	1 (10%)
	Mixed Race	1 (10%)
Ethnicity	Hispanic	0 (0%)
	Not Hispanic	9 (90%)
	Not Sure	1 (10%)
Grade Level	Junior high or Middle school (6-8)	5 (50%)
	Some High School	5 (50%)
	Some High School	5 (50%)
Familiarity with Genetics or DNA	Not familiar at all	1 (10%)
	Not very familiar	3 (30%)
	Somewhat familiar	5 (50%)
	Very familiar	1 (10%)

Three questionnaire items were added in phase two. Additional statements included:

"Health insurance companies cannot deny me health insurance coverage based on genetic test results."

and  
"Insurance companies can deny me life, disability, or long-term care insurance based on genetic test results."

The third new item asked for specific video content causing confusion.

On average, adolescents answered 7.53 questions correctly on the questionnaire.

### Reactions to the Video

- ✦ Adolescents mentioned the video being too long or had a hard time recalling its content (n=5).
- ✦ Adolescents expressed confusion in understanding information when the voiceover explained information differently than it was displayed on the screen (n=2).
- ✦ Adolescents interviewed were able to give examples of things they learned from the video, including specific facts about the genome (n=3) and the potential for denial of insurance (n=3).

### Reactions to Genomic Testing

- ✦ Views on whether or not adolescents would get genomic testing were offered (n=5).
- ✦ Those who viewed genomic testing as 'good' thought testing would provide useful information and allow the opportunity to engage in preventive behaviors.
- ✦ Those who viewed genomic testing as 'bad' were fearful of a positive result and unsure what to do in response to one.

### Understanding Test Results

- ✦ Adolescents believed positive results just meant there was a risk of disease (n=4), equaled a disease diagnosis (n=5), or meant other family members could be at risk as well (n=2).
- ✦ Adolescents believed negative result meant they may still be at risk for a condition, or that a gene increasing risk could not be found, but one could still exist (n=7).
- ✦ Some showed a level of understanding of the concept of results, yet lacked confidence in knowledge. Responses were framed as a question or the interviewer was asked to approve their answer.
- ✦ Adolescents explained that results went to a primary care doctor and/or into an individual's medical health record (n=5), with only one interviewee confidently stating this was optional.
- ✦ Adolescents explained that results were perhaps stored and/or compared to those of others (n=5), with someone even suggesting researchers made a "census" of test results.

### Views on Test Utility

- ✦ Adolescents indicated individuals could initiate various lifestyle changes to prevent realizing the risks identified in a genomic test (n=5). One other adolescent suggested the use of medication, while another mentioned using test results to inform other family members of their risk.
- ✦ Adolescents had difficulty defining limitation (n=4), with some responding with, "What limitations? What is that?" or "What do you mean by limitations?"
- ✦ Some adolescents recognized that limitations meant there was room for improving genomic testing (n=3).

## Conclusions & Next Steps

### Conclusions

- ✦ More attention in the genetic testing and consenting process needs to be focused on adolescents.
- ✦ Education of genetics and related concepts may need to be improved in the greater community, and specifically within minority and low-income populations.
- ✦ Adolescent interview responses suggested adolescents lack confidence when explaining video content and thus did not demonstrate substantial learning.
- ✦ Individuals may be encountering this information for the first time, and may need aid in understanding.

### Future Research Suggestions

- ✦ Consider sectioning the video into essential/recommended and optional sections. This may lead to a shorter viewing experience that misses some information but would still highlight key areas for recall.
- ✦ Consider sectioning the video into chapters based on topic, without assigning importance levels.
- ✦ Incorporate repeated exposures and an assessment of knowledge 1) after viewing the video at test consent and 2) after viewing the video at receipt of results.

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