

## DTC Genetic Testing: Impacts and Actions Taken

Vania Perez Gordillo ([perezgordillov@my.easternct.edu](mailto:perezgordillov@my.easternct.edu)) BIS

Advisor: Dr. Sukeshini Grandhi, Accounting and BIS

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### Background

- Direct to Consumer (DTC) and genetic testing has become very popular over the last few years, with some of the leading services being 23andme and Ancestry.com. These tests provide very extensive details on one's race, ethnicity, possible health predispositions, and even matches you with other people in their database who have similar DNA makeup to you.
- Given these tests go into such depth, there can be expected, unexpected and perhaps even life-altering results from these tests

### Research Questions

- This study aims to understand the impact DTC genetic results have on people
- What impact does DTC genetic testing have on people?
  - What actions do people take in response to their genetic test results?

### Method

- Survey (N=384)
- Participants: 63% Female, 29% Male
- 281 (73%) took a DTC genetic test
- Data Collection: Qualitative Data
  - Participants were asked about the expected and unexpected negative and positive impacts off their test results, as well as any actions taken in response to them
  - Data was analyzed through open coding for predominant themes

### Results [Based on participant responses to open ended questions]

#### Positive Impacts: N=251

- Discovering/meeting with new relatives/a new line of the family tree (N=140)
  - lead to greater understanding of "self",
    - *"greater self-knowledge, sense of who I am, and greater connection to history"*
  - Increased emotional and social connections with family
    - *"Finding and meeting my mom's heretofore unknown families, who have been amazing."*
- Reduced health concerns (N=27): Participants were delighted to know that they had low risk for health issues for self-and/or low risk of passing it to their children
  - *"The 23&Me test indicated that I had a very low risk of certain disease.."*
  - *"..I don't have any identified traits that are life threatening and am not in a position to pass down any nasty traits to my children.."*

#### Negative Impacts: N=131

- Unexpected, dark, or scary information about biological family (N=40)
  - *"A second cousin appeared who was quietly put up for adoption. He was trying to locate birth parents who were NOT interested in pursuing any sort of communication."*
- Low quality of results (N=13)
  - Incorrect information
  - Insufficient information

### Action Taken

- Participants had important conversations about their results not only with family and friends, but also with health care providers and other professionals
- Participants explicitly reached out to family members and met with them, built their family trees and did further research

### Discussion

- More number of positive impacts reported than negative.
- Negative impacts suggest greater attention is needed in how sensitive negative Information is shared by DTC genetic testing companies. Resources and support mechanisms need to be seamlessly integrated into the DTC websites