



Attitudes of healthy early adopters toward personal genome sequencing: observations from the PeopleSeq Consortium

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Introduction

As opportunities grow for healthy adults to access personal genome sequencing (PGS), it is increasingly important to understand their attitudes about and intended applications for PGS. The PeopleSeq Consortium is surveying ostensibly healthy individuals who have undergone PGS through commercial or research avenues to understand their attitudes toward and expectations for PGS.

- Several programs offer PGS to healthy adults for education, research, and potential health insights.
- The PeopleSeq Study aims to understand the medical, behavioral, and economic impacts of PGS on healthy adults.
- The PeopleSeq Study works with multiple cohorts that provide whole-genome or whole-exome sequencing to healthy individuals.
- PeopleSeq investigators have collaborated on the development of a standardized survey to query PGS participants about their responses to their results.
- Herein we present data on healthy respondents' attitudes toward PGS.

Methods

Participants in each cohort have PGS ordered.

Each cohort returns PGS results to its participants.

The PeopleSeq Study administers surveys to consenting participants (respondents)

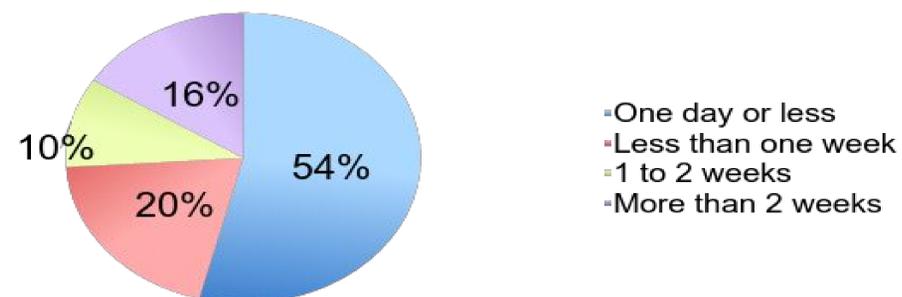
Respondents included in this analysis purchased PGS through Illumina's Understand Your Genome® program, which provides participants with a clinically focused report to participants through an ordering physician followed by access to their raw genome sequence introduced at an educational symposium. Survey items examine decision-making about pursuing PGS and general attitudes about PGS.

Respondent Characteristics (n = 237)

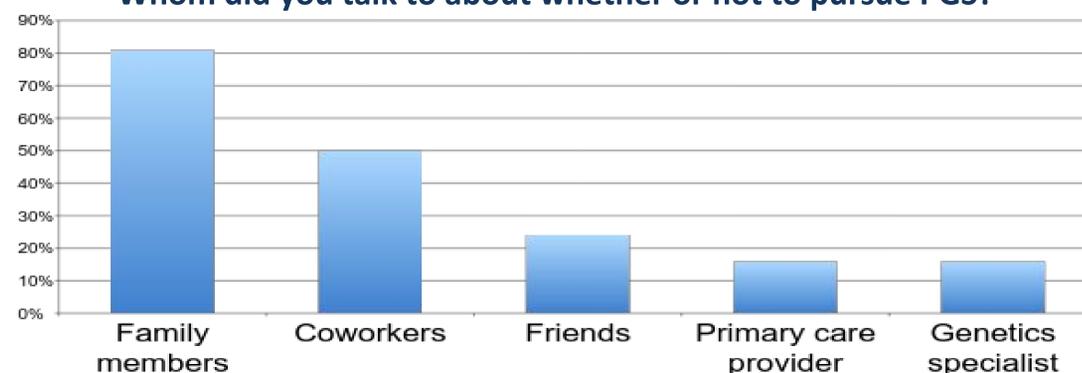
Mean Age (Range)	53 (25–91)
European Ancestry	90%
Doctorate or Professional Degree	61%
Income ≥ \$100,000	89%
Married	52%
Male	58%
Has Child(ren)	76%
Healthcare Providers or Clinical Researchers	41%

Results

How long did it take you to decide to pursue PGS?



Whom did you talk to about whether or not to pursue PGS?



Fifty-two percent of respondents reported talking with someone when making their decision to pursue PGS.

Which factor was the most important in your decision to pursue PGS?



- A minority of respondents favored increased government regulation of PGS (38%).
- Many agreed that health insurance policies should cover PGS (52%).
- Most supported incorporating genomic information into the medical record (62%).

Conclusions

- The majority of PeopleSeq Study respondents made the decision to pursue PGS quickly.
- Many did so with limited medical consultation or counseling.
- We plan to survey and compare additional PGS cohorts to investigate how attitudes toward PGS in ostensibly healthy individuals vary over time and with increasing public awareness of genome sequencing.