

Attitudes regarding personal genome sequencing among healthy early adopters: Findings from the PeopleSeq Consortium



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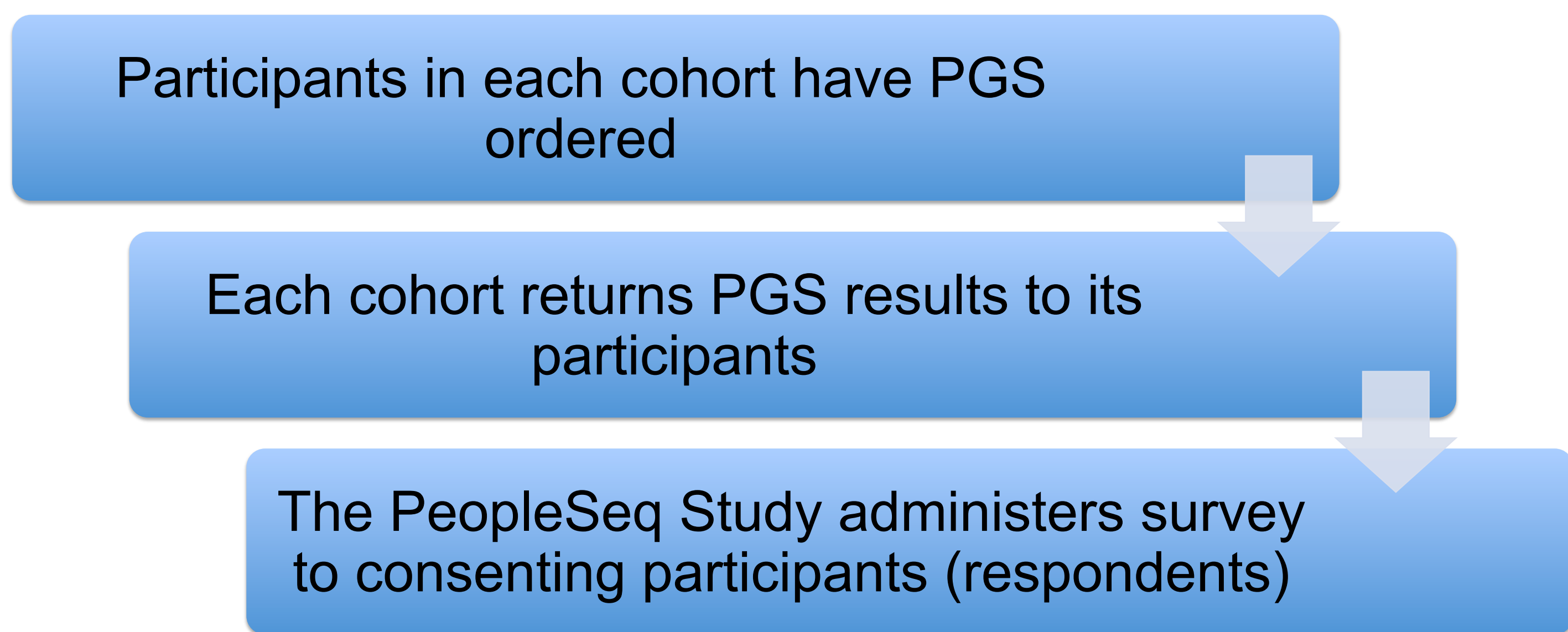
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Introduction

With growing opportunities 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 insight.
- The PeopleSeq Study aims to understand the medical, behavioral and economic impact of PGS among 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.
- Here we present data on healthy respondents' attitudes regarding PGS.

Methods



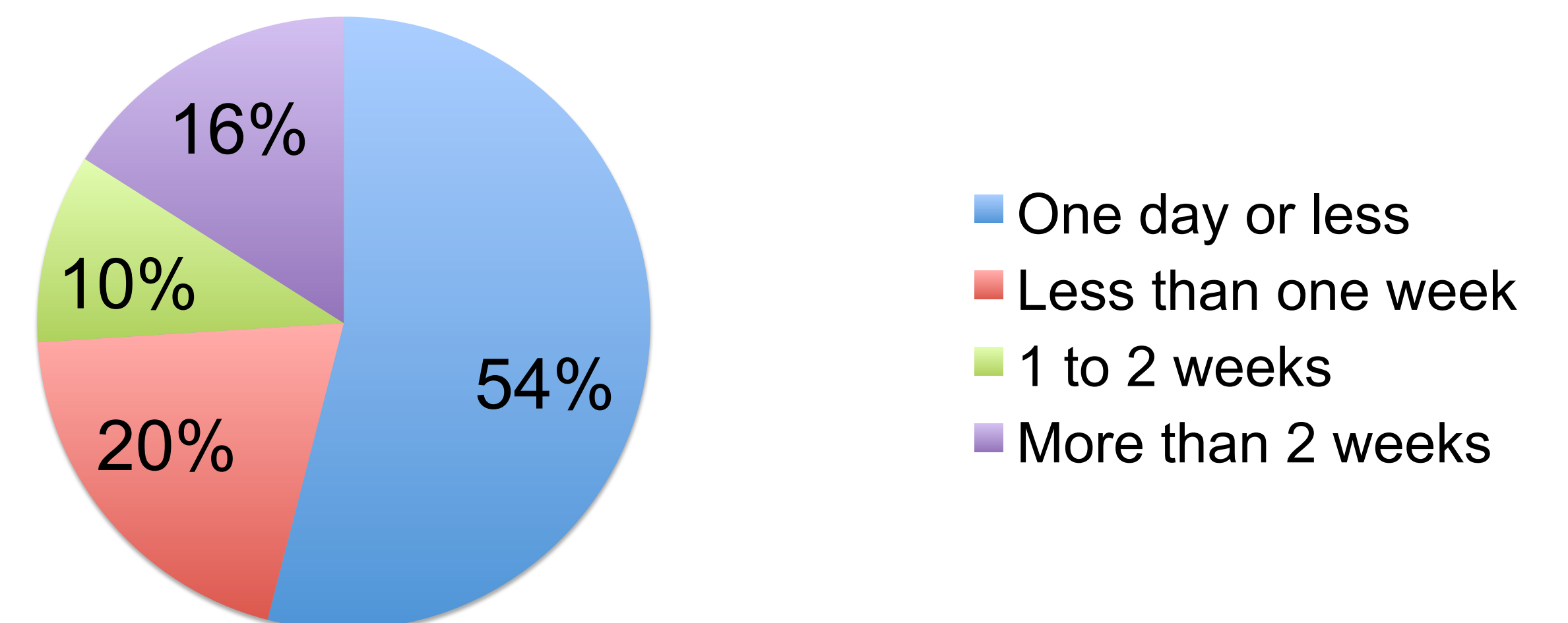
Respondents included in this analysis purchased PGS through Illumina's Understand Your Genome® program, which provides a clinically focused report to participants through an ordering physician, followed by access to their raw genome sequence introduced at an educational symposium. Survey items examine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

Respondent Characteristics (n=237)

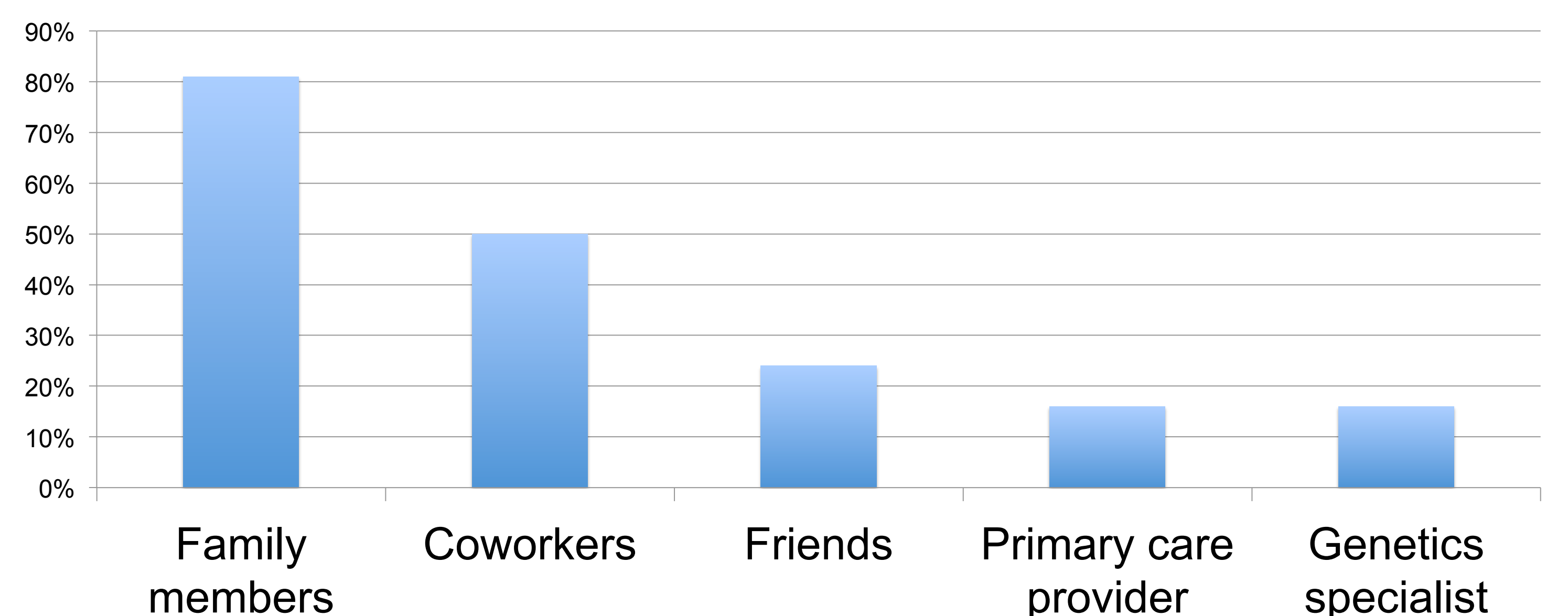
Mean Age (Range)	53 (25-91)
European Ancestry	90%
Doctorate or Professional Degree	61%
Income ≥ \$100,000	89%
Married	52%
Male	58%
Has Child(ren)	76%
Healthcare Providers or Clinical Researchers	41%

Results

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



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



52% 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 favored increased government regulation of PGS (38%)
- Many agreed that there should be insurance coverage for 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 varied PGS cohorts to investigate how attitudes toward PGS in ostensibly healthy individuals vary over time and with increasing public awareness of genome sequencing