

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





Edward D. Esplin¹, Eden Haverfield¹, Daiva E. Nielsen^{2,3,4}, Erica F. Schonman^{2,3}, Erica Ramos⁵, Molly McGinniss⁵, Steven Tucker⁶, Debra G.B. Leonard^{7,8}, Robert C. Green^{2,3,4,9}, for the PeopleSeq Consortium ¹Invitae Corporation, San Francisco, CA. ²Department of Medicine, Division of Genetics, Brigham and Women's Hospital, Boston, MA. ³Harvard Medical School, Boston, MA. ⁴Broad Institute of MIT and Harvard, Cambridge, MA. ⁵Illumina, Inc., San Diego, CA. ⁶Tucker Medical, Singapore, Singapore. ⁷Department of Pathology and Laboratory Medicine, University of Vermont College of Medicine, Burlington, VT. ⁸University of Vermont Health Network, Burlington, VT. ⁹Partners Healthcare Personalized Medicine, Boston, MA.



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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.

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

- 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

Participants in each cohort have PGS ordered

Each cohort returns PGS results to its participants



54%

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

The PeopleSeq Study administers survey to consenting participants (respondents)

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%
Incomo > \$100 000	80%



- 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%)





- 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