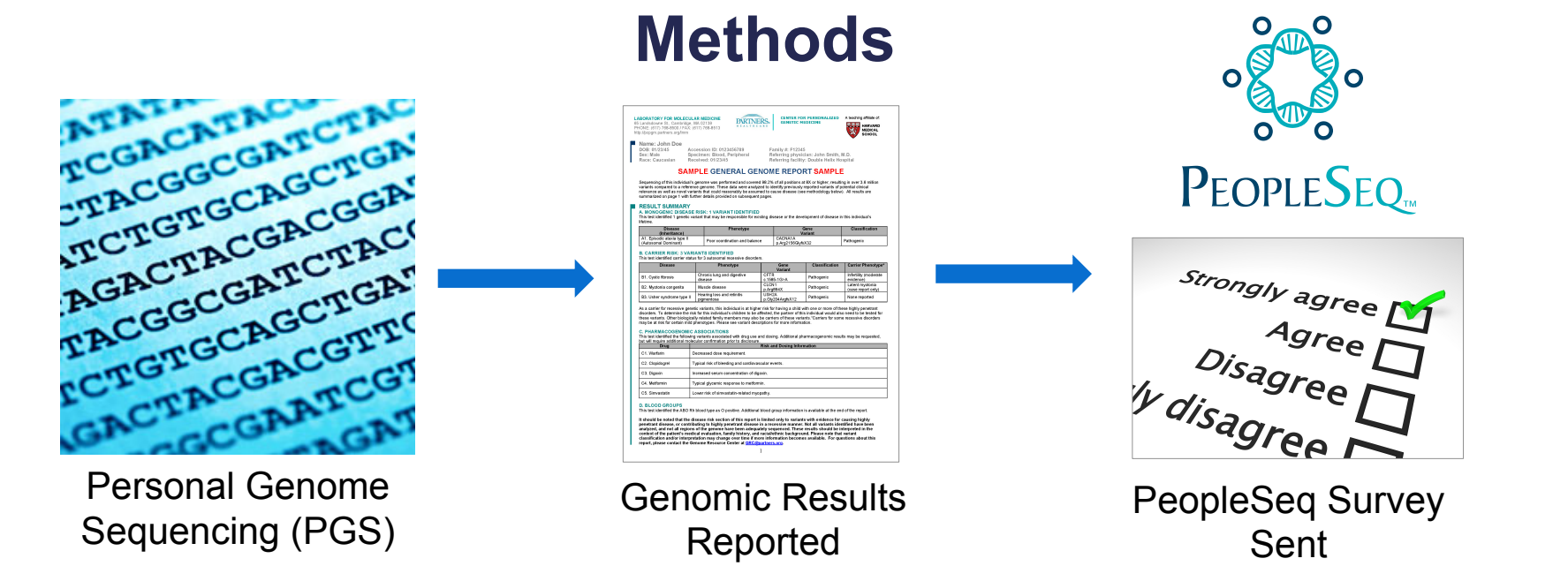


Introduction

- Several programs offer personal genomic sequencing (PGS) to ostensibly healthy adults for education, research and potential health insights.
- 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 and actions after receiving their results.

Methods



- Assessed outcomes using a web-based survey from three PGS cohorts:
 - Illumina's Understand Your Genome (UYG) program – 121 responses
 - Harvard's Personal Genome Project (PGP) – 123 responses
 - Mount Sinai's HealthSeq Study (HealthSeq) – 14 responses

Comparison of PGS Cohort Details

PGS Group	Ordering MD	Return of Results (MD/GC)	Self Exploration	Access to Raw Data
UYG	✓	✓	✓	-
HealthSeq	-	✓	-	✓
PGP	-	-	-	✓

Respondent Characteristics (n=258)

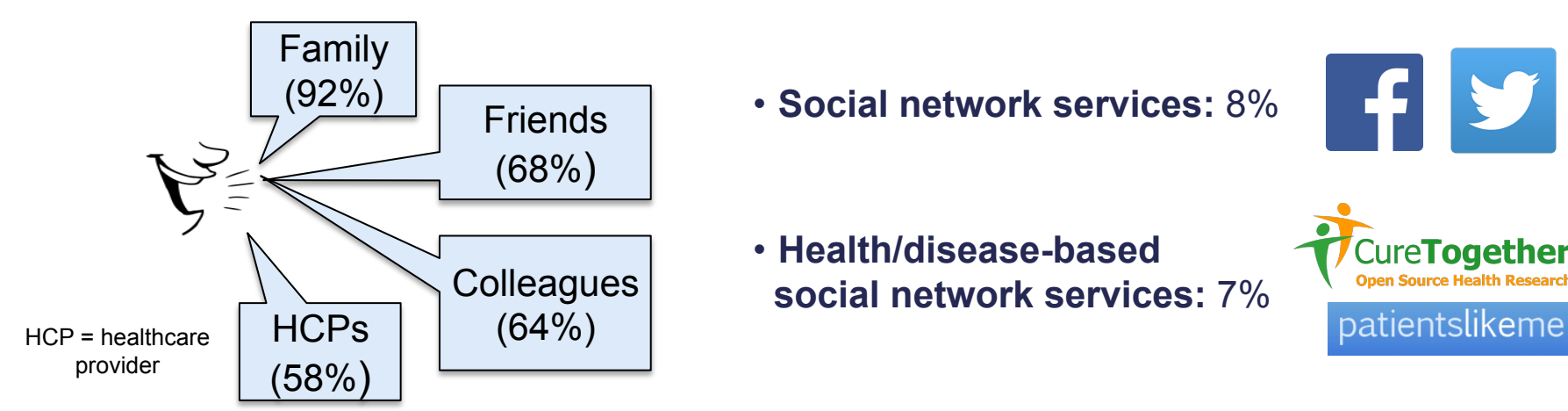
Characteristics	Proportion
Mean Age (Range)	53 (22-92)
Male	67%
Caucasian	85%
Doctorate or Professional Degree	77%
Income ≥ \$100,000	76%
Married	67%
Has Child(ren)	66%
Healthcare Provider or Clinical Researcher	24%

Motivations for Pursuing PGS

Motivations	Proportion (Very/ Somewhat Important)
Personal interest in genetics in general	99%
Curiosity about my genetic make-up	98%
Desire to participate in research to help others	92%
Interest in finding out things to do to improve my health	81%
Interest in learning about my response to medications	81%
It seemed fun and entertaining	77%
Desire to plan for the future	69%
Interest in my ancestry	66%
Interest in finding out about personal disease risk	41%
Concern about family history of possible or confirmed genetic condition*	21%

*Respondents motivated by family history of a possible genetic condition were more likely than others to report learning something from PGS that would improve their health (p=0.003).

Who are you sharing your PGS results with?



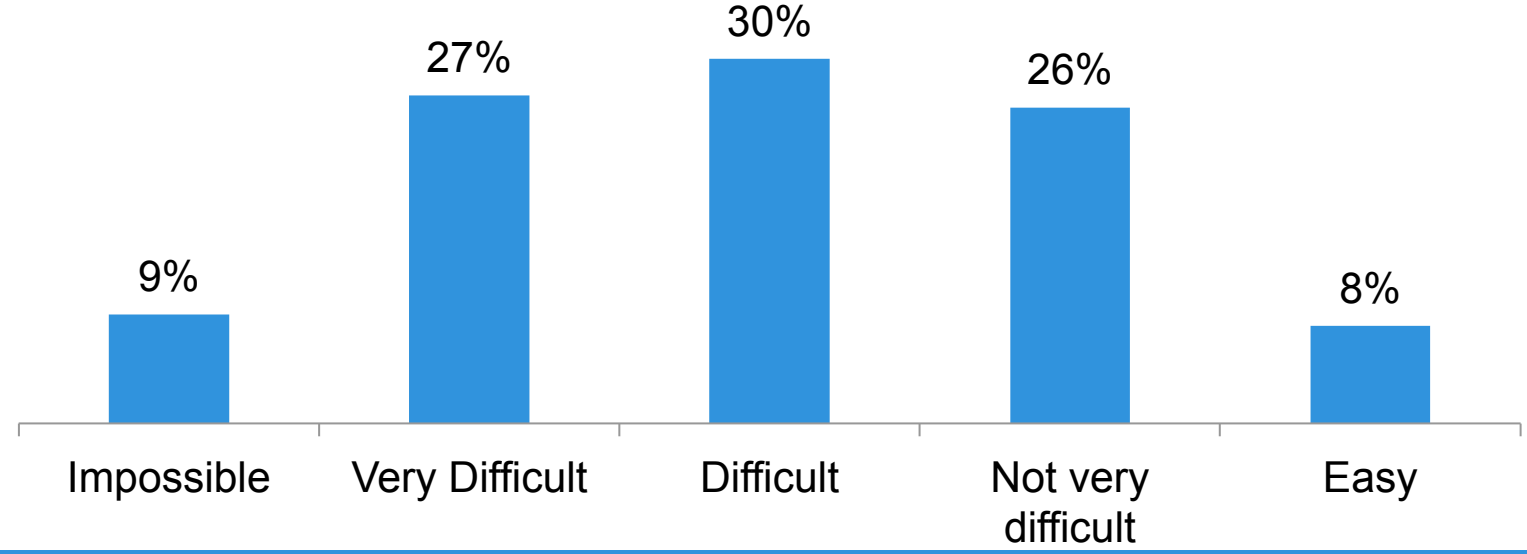
Would you share your genome sequence publicly?

Yes, with my identity attached	37%
Yes, but anonymously	79%

Only 2% indicated they would not share their genome data.

Note: As a requirement for enrollment in PGP, participants agree to have a copy of their Genome Research Report shared publicly. Other sites do not have this requirement.

How difficult do you think it would be for someone to identify you from your genome sequence?

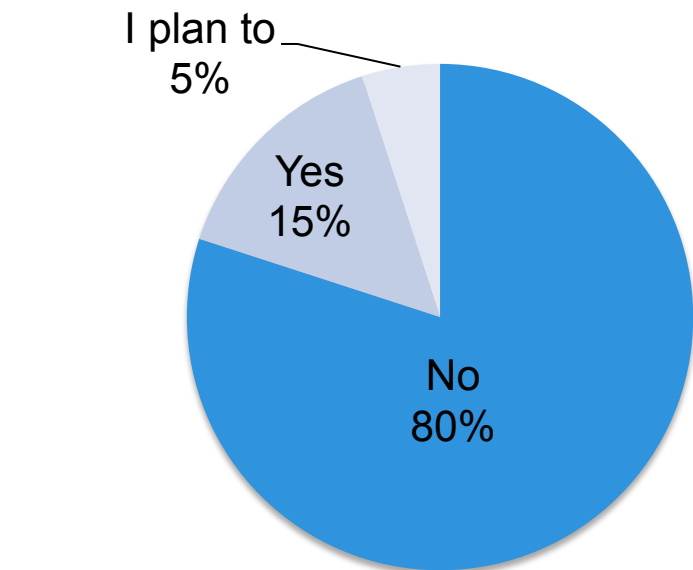


Acknowledgments

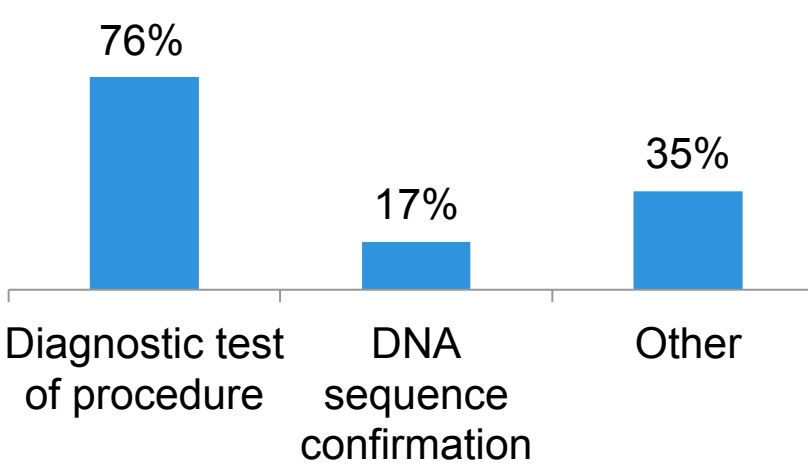
The PeopleSeq Study is funded by NIH grant U01-HG006500 and by an unrestricted grant from Illumina, Inc.

Respondent Actions Post-Disclosure

Have your results prompted you to make an appointment with any healthcare provider(s)?



12% of respondents reported *having* a medical exam or procedure based on their sequencing results.



*Respondents could select more than one option

Differences between HCPs and non-HCPs

Agreement with attitudinal items	HCPs (n=58)	Non-HCPs (n=192)	χ ² p-value
Very comfortable with the idea of sharing genome data	71%	64%	0.32
Discussed results with a healthcare provider	62%	46%	0.04
Health insurance should cover PGS	50%	71%	0.004
Genetic information should be part of a standard medical record	71%	89%	0.001
Tests like these should only be available through a doctor	39%	22%	0.008
People have a right to access their own genetic information without going through a medical professional	62%	86%	<0.0001
The knowledge I gained about PGS through this process has influenced my medical practice	59%	n/a	n/a

Future Directions

- Expand number of PGS cohorts
 - 10,000 potential participants to survey
- Implement pre/post survey design to capture initial impact of PGS
- Create annual follow-up surveys to track outcomes of PGS longitudinally

