

**THE BLOG** 01/09/2017 05:47 pm ET | Updated Jan 10, 2018

# Genome Sequencing For Healthy People: Early Results



By Robert C. Green, MD, MPH

Doctors are already using genome sequencing to diagnose genetic disorders. Yet the idea of genome sequencing for healthy individuals to preemptively screen for risk factors is still controversial, especially since we do not yet know the short- and long-term outcomes of providing that information to healthy adults.

In a [previous post](#), I introduced the [PeopleSeq Consortium](#), an ambitious project we have started in order to track outcomes in ostensibly healthy people who have obtained their own genome sequence information. This is part of our overall scientific mission to determine how personal genomic sequencing may impact participants' long-term health, behavioral and economic outcomes.

## Genomes2People's PeopleSeq Consortium



While still in its early stages, we do have some very interesting [preliminary results](#) to share with you here.

For example: When asked to rate their motivations for pursuing personal genomic sequencing, 98% of participants reported “curiosity about my genetic make-up” as an important consideration, compared to just 41% who said “interest in finding out about personal disease risk” and 21% who cited “concern about family history of a possible or confirmed genetic condition.” Those last 21% are an especially important group. They went into the personal genomic testing process with health outcomes in mind. And they seemed to find them! After receiving their results, they were also more likely to report improved health because of something they learned from personal genomic sequencing.

But what did respondents actually do with their results? Only 20% said that their results prompted them to make an appointment with a healthcare provider, and 12% reported that they obtained a medical exam or procedure due to their sequencing results (in most cases, follow-up testing). These numbers sounded a bit low to us. After all, in [another study](#) we conducted of direct-to-consumer genetic testing, 63% of customers planned to share their results with a healthcare provider but only 35% actually did so within six months of receiving their results.

Is it worth the cost, the time and the possible anxiety if only 1 in 5 people learn enough to warrant a follow-up appointment? There are plenty of ways to speculatively answer that question. For example, you

could say sequencing results that don't prompt a healthcare follow-up are also valuable because they provide peace of mind. Ultimately, though, we're still working on answering that broader question: "[Is it worth it?](#)"

PeopleSeq Consortium participants weren't keeping their sequencing results to themselves - quite the opposite. Nearly all said that they shared their results with family, and over two thirds shared some of their results with friends. When asked whether they would be willing to share their genome sequence publicly, most said yes, so long as it was done anonymously, and 37% said they wouldn't mind sharing their results publicly with their identity attached. In fact, only 2% of all participants said they would not share their genome data.

Do those responses mean that this group is unconcerned about their genetic privacy? It's hard to say. When asked how difficult they thought it would be for someone to identify them by looking at their genome sequence, 34% said "easy" or "not very difficult" while only 9% thought it would be impossible. This may mean the group has some concern that their genetic information could fall into the wrong hands. However, these numbers also suggest that some participants were willing to share their genome sequence publicly, even though they didn't really believe their information could be truly private.

Who are these early adopters, anyway? Compared to the broader U.S. population, they were a bit older, more likely to be white, male and married, and quite a bit better off financially. In addition, 77% had a doctorate or professional degree, and 24% were a healthcare provider or researcher.

This brings up a very interesting side note. We had anticipated a high proportion of healthcare providers in our cohort; nearly half of the participants came from [a project](#) that especially targets physicians and life sciences professionals. So we decided to take a closer look at where healthcare providers' answers differed from the rest of the respondents. Healthcare providers were more comfortable sharing their genome data than other respondents, yet less likely to agree that the same information should be part of a standard medical record. Healthcare providers were significantly less likely than other participants to say that health insurance should cover personal

genomic sequencing, yet significantly more likely to believe that these tests should only be available through a doctor.

We knew these initial PeopleSeq Consortium participants would be skewed toward highly educated “early adopters,” a group that may be wealthier, more motivated by curiosity and not as leery about sharing their results. But as the PeopleSeq Consortium moves forward and there are more avenues for healthy individuals to become sequenced, we hope to discover greater diversity within our sample, with the overall demographics a bit more representative of the broader population. And we will have many more results to report, especially about what happens after participants get their sequencing results back.

Stay tuned, and we’ll let you know what we find.

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