



Defining the Genomics Experience

An Open Report to Personalized Genetic Companies

Overview

With the arrival of low-cost personalized genetic testing and the explosion of new companies offering a peek inside our genes, we are now charting unknown waters in the field of personal health management. Until this decade, determining our own genetic futures has been the stuff of science fiction. While personal genomics offers us the power of knowledge, it also opens up the possibility of abuse, whether from our own mismanagement of that power or other people's access to it. We now suddenly have access to technology only theorized in the past; over the next decade we will determine how that technology will be applied to our lives.

Concept Hatchery conducted a quick and informal conversation exercise to get a glimpse into how people respond to genomics. Certain themes immediately rose to the surface, each presenting its own unique challenges and opportunities. Here are our thoughts on the major human issues around genomics.



Can you find out about the genetics of the guy you're dating? - Jen C.

It doesn't really say that they don't give out your information to Blue Cross. -Karen T.

It would have to be an anonymous service. - Nick B.

Theme: Privacy and Security

The possibility that their genetic information would be “out there” in someone else’s safekeeping caused universal concern. A large part of the worry can be attributed to the understanding that simply knowing of a disease’s probability may preclude you from future insurance coverage. In addition, a general mistrust of how companies handle private information as well as a lack of understanding of existing genetic handling procedures that keep samples anonymous make the issue of privacy and security a deal-breaker for many people.

In order for personal genomics to gain widespread acceptance, people must feel they have security and control of their information, as well as the possibility of anonymity within the secured system.





Opportunities: Privacy and Security

What kinds of electronic information are considered secure, and from what does the perception stem?

How might we highlight the anonymity of existing systems?

How might we give users a sense of control?

What tools should be available to give people access to their information in a way that feels personalized and safe?



I don't know if I really want to know. I mean, it would be stupid not to, but...
- Kathy S.

Knowing it's coming doesn't help me if there's nothing preventative.
- Mo O.

It would be nice if there was a menu you can select from. Because some diseases just freak you out. - Adam F.

Theme: Fatalism

Another universal theme was the belief that some things are better not known, particularly if it is about your own health. People have a surprising amount of fatalism about disease, often seeing genetic predisposition as something fatalistic, while active health such as diet and exercise as choices within their reach. The question of “what will I do with the information” lingers foremost, and where prevention is not possible, people believe they would rather just march ahead and find out as they go.

This illustrates the information gap between the general public and the medical profession about the benefits of early detection and the advances made in disease management. While healthy adults think mainly of prevention, many unpreventable diseases such as arthritis can be diminished through early diagnosis and management, leading to the possibility of a normal life for a longer period of time.





Thoughts: Fatalism

How might we alleviate the fear that comes with learning about genetic predisposition?

Certain diseases - such as breast cancer - have made great headway into promoting early detection. What might we learn from those examples?

How might we increase awareness in the benefits of disease management rather than disease prevention?



For the people I love, I would want to know, so we can take preventative measures.

-Jean C.

I would test my kids (before myself). Because you have a tendency not to care about yourself so much; your focus is on your kids.

-Ken S.

Theme: Caring for Others

Even those people who did not want to know about their own genetic predispositions wavered when it came to loved ones. Their doubts of whether they can handle knowing about their own fate vanished when it came to the future of their spouse and children. This extended to unborn children in the case of pregnant women wanting to give their child the best preparation they can for the life ahead.

When it comes to health management, people think tribally rather than individually. They are often more likely to accept hardship and responsibility for the sake of their family. Parents want to be forewarned of risks to children so that they may be raised with the health habits they need. Couples want to know about each other's risks in order to keep their lifetime companion with them for as long as possible.



Opportunity: Care for Others

How might we structure the service around families rather than individuals?

How might we give people the tools to speak about genetic disease to their children?



Everything will become quantified; we'll just be a number. You won't see the individual behind it.

- Jean C.

In five years you'll get able to get the same information at Walgreens for \$99 and you won't need Navigenics.

- Cliff J.

Theme: Personalized, not Quantified

The subtext of many conversations was unease at the idea of being “quantified.” With genes often described the core of our being, being presented with sets of genetic codes and probabilities is perceived as something that may diminish that individuality.

In addition, the rapid arrival of fast and low-cost genetic sequencing means that soon everyone will have access to genetic information by spitting into a tube at their local pharmacy. Genetic testing is seen as a technology rather than a service, further depersonalizing it.

Movies like “Gattaca” also perpetuate this fear by portraying a genetically driven future in which individual will and effort are suppressed in favor of quantifiable genetic information. People want to hold on to belief that they can be more than the limitations of their genes; personal genomics challenges that belief by portraying genetic knowledge at the center of their personal power.





Opportunity: Personalized, not Quantified

How might we emphasize the uniqueness of people, particularly those thinking of genetic testing?

How might we make personal genomics a tool rather than a fate?

With the approaching future of low-cost testing, how might a high-end service differentiate itself as a health partner rather than a technology provider?



Conclusion

By highlighting these areas of concern and opportunity that we obtained from interviews with real potential customers, we hope to raise awareness of the human issues in this rapidly growing technical field.

Current genomics companies are quick to point out the possibilities, but do little to proactively address the uncertainties and fears in making important life decisions. People who elect to have genomic health screening are embarking on a new and sometimes emotional journey as they learn potentially devastating facts about their own well-being. As providers of the service, genomics companies need to be aware of their impact on a person's mental health as well as physical, and take steps to help people adjust to their newfound information.

Clearly, the number of players in the field of personalized genomic services will quickly narrow down in the next few years as some companies pull into the lead and others drop out. With the foreseeable future of low-cost walk-in genetic screening, how will these leaders maintain their position? We believe in a future where personal genomics is not a technology, but a health partnership, where companies help people proactively manage their well being through genetic testing and other tools.

