Arm chair geneticists looking for enlightenment could provide useful data

Why do people get their whole genomes sequenced at such costs when there's little to be done with that information? In fact, the majority of that information can't even be meaningful deciphered yet. So what, ask Scott Bowen and Muin Khoury at the Center for Disease Control's office for public health genomics, is the draw? According to them sequencing is the highest form of modern narcissism, the "ultimate selfie."

They are not wrong. People are getting their genome sequenced to better know themselves, whether that be through health risks or ancestry. It's an artifact of a self-obsessed world. Instead of studying yoga to explore the very nature of consciousness, we contort and hold poses to journey into the nature of 'me.' We insert our disembodied faces in memorable scenes that a decade ago would have been left as landscapes.

There is obviously a heady genetic component to the personality traits considered to define a 'self.' Extroversion, conscientiousness and the other 'big five' personality traits have a <u>heritable component</u>. But we are far, far away from finding the exact genes involved.

That is the point that Bowen and Khoury rightfully make. Personal genetic information, whether through specific analysis of some known hotspots in the genome (SNPs) or the whole thing, doesn't mean very much right now. We just don't have the breadth and depth of knowledge to make it useful: "While WGS technology provides an unequivocal reflection of personal biology, for most people it could be argued that a common, plate glass mirror provides more useful information for health today."

The mirror is arguably more important in how a person considers herself because it shows us our phenotype, the expression of our genes. We have factivism not FTO activism.

But there are exceptions to what Bowen and Khoury write. Small online communities of people with rare genetic diseases have organized themselves into a supportive niche. Caregivers of these people could also, arguably, be considered to have redefined their selves in terms of the genetics of the people they love.

But most of us will not come into that sort of social identity simply by understanding our genomes. And those who try will be sorely disappointed. We just don't know enough about our genes and their actions on our health, or personality, or even skin tone to say anything meaningful. The list of slam-dunks is quite short, Bowen and Khoury point out.

On the other hand, we need whole genome sequences to get that knowledge. And we need millions of them. "Disease causation is complicated and involves interaction with many genetic and environmental factors. Thus careful population-based research of both aspects is critical for true interpretation," the public health experts write.

Getting to the necessary numbers of sequences will be impossible without data sharing between groups working on the association studies and the inclusion of people outside of academic public health who get

their genomes sequenced for whatever reason. Other endeavors like the American Gut Project, which analyzes the microbiomes of its volunteers, leverage public interest to both fund and participate in their research.

The cautions over the limited predictive power of whole genome sequencing is valid and important. But, maybe genomic public health should look to capitalize on our collective narcissism and the subsequent wave of citizen science to get the millions of data points it so badly requires.

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Additional Resources:

- That 'Precision Medicine' initiative? A Reality Check, Genetic Literacy Project
- What should be done with unsettling 'incidental findings' in gene screens? Genetic Literacy Project
- Will genome sequencing provide impediment to medicine? Conversation