

CITIZEN BIOSCIENCE IN THE AGE OF NEW MEDIA

Marina Levina, PhD
Assistant Professor
Department of Communication
The University of Memphis
mlevina@memphis.edu
www.marinalevina.com

Citizen Bioscience

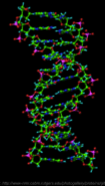
- Citizen bioscience: a community building research initiative that promises to put individuals in control of their – in this case – genetic data and provide greater ability to affect scientific research.
- Genetic information data-tracking - enabled by transitions in new media technologies - produces what is called “actionable personal data”
- Citizen Bioscience projects range from answering surveys on sites such as 23andMe to user-ran studies to biohacking
- From an activist standpoint, citizen bioscience enables its members to participate in scientific research decisions and can affect public policy. However, companies such as 23andMe introduce a particular notion of citizen bioscience – one that promises freedom from institutional power through corporation-enabled control over one’s genetic information.
- Citizen Bioscience conflates discourses of empowerment through the use of new technologies with frustration over the traditional modes of doing science

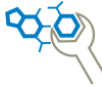


"DYIgenomics (www.DYIgenomics.org) is a new platform bringing citizen scientists together to run peer cohort research studies and conduct novel research linking genetic data and physical biomarkers. Some norms are developing in response to the variety of community-based research issues that arise such as adaptive studies, informed consent, security, anonymity, and study design".

Summary

- DNA sequencing is moving faster than any other technology
- Explosion in the amount of biological information
- Citizen scientists are critical in discovering and implementing new findings
- Tools are now available for genomic citizen scientists





DIY Genomics - www.dyigenomics.org



DIYgenomics ... crowd-sourced clinical trials and personal genome apps

[Mobile apps](#) [Health Risk](#) [Drug Response](#) [Athletic Performance](#) [Studies](#) [Blog](#) [About](#) [Team](#) [Press](#) [Contact](#)

About DIYgenomics

[PDF version](#)

Personal genomics is an exciting new field. There is an urgent opportunity to provide personal health management tools for preventive medicine. DIYgenomics links genomic data streams to phenotypic (biophysical) measurements and interventions in a wide range of areas so that individuals may manage health conditions before the clinical onset of symptoms. DIYgenomics is a non-profit research organization founded in March 2010.

The [first DIYgenomics crowd-sourced research study](#) is currently in process, looking at two mutations in the MTHFR gene which purportedly lead to Vitamin B-12 deficiency and higher homocysteine levels, and may impact about 60% of the population. Citizen scientists are trying a series of interventions with blood tests to measure results at each phase. Each individual serves as their own control by trying all of the interventions sequentially. Final [results](#) are anticipated in August 2010 and ongoing [study participation](#) is welcomed.

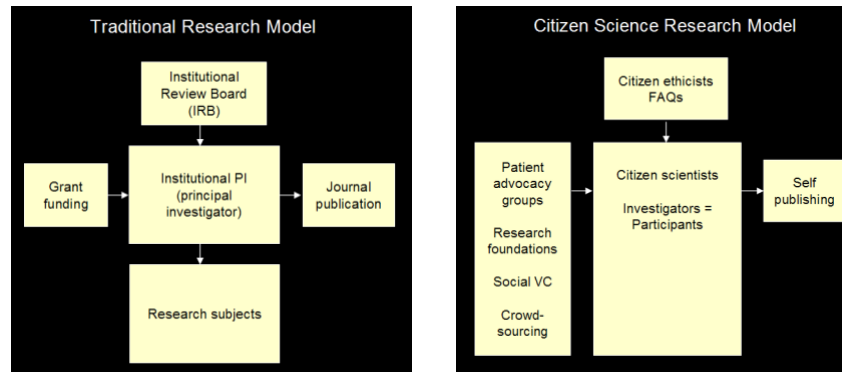
There are several other [studies in design](#), particularly for aging, diabetes, obesity, macular degeneration, and cancer. The methodology is to first identify the genomic risk profiles from already-curated or self-curated genome wide association studies, and determine the corresponding phenotypic markers and potential corrective interventions for the condition. The second part of the methodology is providing accessible means for individuals to review their genomic data, measure their phenotypic markers and explore interventions, in a systematic way and in collaboration with peers.

DIYgenomics has a suite of personal genome apps on the web and mobile platforms, some of which include the ability to [privately upload](#) one's own data file from 23andme for review. The apps feature [health risk](#) (a side-by-side comparison of markers reviewed by consumer genomic companies for the top 20 health conditions), [drug response](#) (identifying markers associated with metabolism and side effects for 250 drugs), athletic performance, and other areas.

Studies are currently run manually and are anticipated to be automated and scaled on a community citizen science platform provided by our partner company, [Genomera](#). At this Facebook/eBay of genomics website, individuals will be able to post the studies they'd like to conduct, attract participants, share data, run studies, and report results.



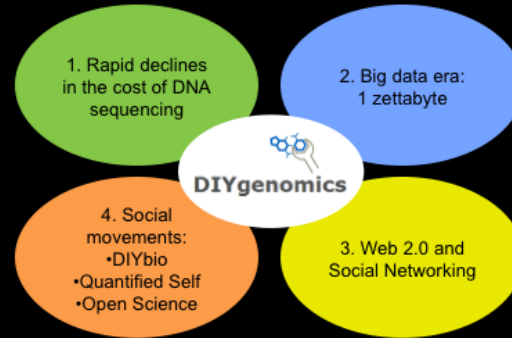
DYI Genomics -Citizen Science Research Model



Source: DYI Genomics - an open platform for citizen bioscience

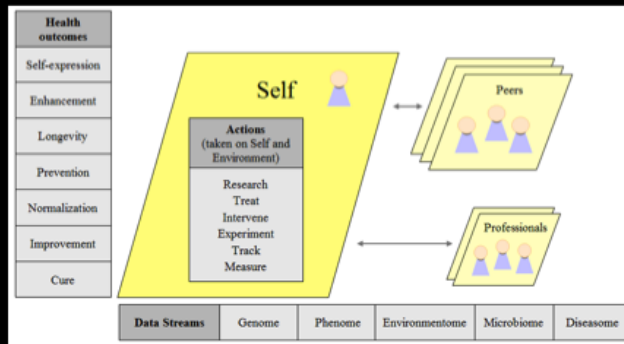


Confluence of factors shaping DIYgenomics



Citizen Bioscience and Biocitizen Identity

A new construct of biocitizen identity



June 12, 2010
DIYgenetics.org

Source: Extended from Saut, M. Emerging patient-driven health care models: an examination of health social networks, consumer personalized medicine and quantified self-tracking. *Int. J. Environ. Res. Public Health* 2009, 7, 490-524, Figure 1.

[order now](#)

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[replay animation]

1866: Gregor Mendel discovers the laws of inheritance.
200,000 years ago: *Homo sapiens* walks the Earth.
2003: The Human Genome Project maps a single person's genome.

2007: 23andMe introduces the first Personal Genome Service.
Unlock the secrets of your own DNA. Today.

175,000 years ago: The mother of all present-day humans is born in Africa.
1953: Watson and Crick uncover the double-helix structure of DNA.

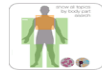
Welcome to 23andMe, a web-based service that helps you read and understand your DNA. After providing a saliva sample using an at-home kit, you can use our interactive tools to shed new light on your distant ancestors, your close family and most of all, yourself.

[Sign up for our Email Newsletter](#)

news **What's new at 23andMe**

May 28, 2008: 23andMe launches 23andMe, a new approach to genetic research, and adds 10 new Gene Journal topics and a search feature to its Personal Genome Service. [Try a demo](#) or [order our service](#) today!

Gene Journal



What do your genes say about you?

Ancestry



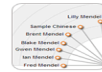
Who were your ancient ancestors?

Family Inheritance



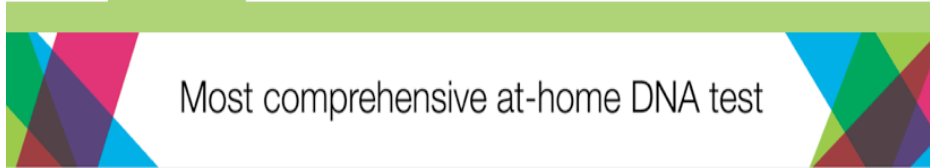
Do you have your mother's sense of taste?

Genome Labs



Would you like to search your genome?

Want to know more? [How the Process Works](#) ▶



Most comprehensive at-home DNA test

When you purchase our complete service, this is what you'll get:

Your risk analyzed for 118 diseases and traits, including:

- Breast Cancer
- Rheumatoid Arthritis
- Type 2 Diabetes

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- Global Similarity
- Maternal and Paternal Ancestry

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Find a disease or trait that we cover:

Select a Disease or Trait

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- Rheumatoid Arthritis
- Psoriasis
- Breast Cancer
- Colorectal Cancer
- Prostate Cancer
- Celiac Disease
- Crohn's Disease
- Hemochromatosis
- Restless Legs Syndrome
- Age-related Macular Degeneration
- Parkinson's Disease
- Coumadin® / Warfarin Sensitivity
- Plavix® Efficacy

[Browse all 118 health and traits topics »](#)



23andWe is a new approach to genetic research.

23andWe is a new way of doing genetic research that has the potential to produce valuable insights more quickly and inexpensively than traditional methods, with the ultimate goal of better understanding ourselves and contributing to improved health care.

[Read more >](#)

Participating is as easy as taking an online survey.

Our surveys don't just ask you questions – sometimes they give you answers, too. After finishing one you might find out how fast your reflexes are, or whether you have perfect pitch. Or you might learn how you compare to everyone else who has taken the same survey. And in addition to being interesting and fun, 23andWe surveys are designed to collect important data for scientific research. [Read more >](#)


Collective action is the key to 23andWe.

Nobody expects to cure cancer by participating in a charity walk or bike ride. Similarly, no single person's survey will tell us everything we need to know to find genes related to Parkinson's disease or migraines. But just as thousands of participants can raise millions of dollars, we believe the combined information these surveys collect could lead to major insights when combined with genetic information from the 23andMe database.

[Read more >](#)

A new paradigm for genetic research.



 [Read our open letter to the science community](#)

23andMe is a new, more efficient way of doing genetic research. Even though new technologies have made it possible to link genes to diseases, traits and conditions more effectively than ever before, collecting the data for this research can be a costly, time-consuming and logistically difficult process. Progress is hindered by the fact that these studies require both genetic and personal information from thousands – sometimes tens of thousands – of people.

23andMe involves our customers in research as collaborators, advisers and contributors by conducting studies that correlate their responses to online surveys with their genetic data. The idea is to enable large studies that would be infeasible using current methods, which typically involve recruiting patients through physicians' practices and other means. We plan to share the results of our research and show you how your contributions are making an impact by posting regular updates on this web site.

[▶▶ Next: How does research work at 23andMe?](#)



Biocitizenship

- Biological Citizenship - "all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as families and lineages, as communities, as population and races, and as a species." (Rose and Novas, 2005)
- Political economy of hope: a social, political and economic system that advances the view of biology as mutable, changeable, and manipulable.
- Communities forming on the Web and outside it as "moral pioneers – we would prefer to say "ethical pioneers" – of a new kind of active biomedical citizenship. They are pioneering a new informed ethics of the self – a set of techniques for managing everyday life in relation to a condition, and in relation to expert knowledge" (Rose, Novas, 2005)

Biocitizenship 2.0.

- Biocitizenship 2.0 - citizens, trained through social-networking technologies and network subjectivity, eager to share information. Their citizen duty is to increase the capacity of network.
- Biocitizenship 2.0 - a product of an unique economic system made possible by a simultaneously emergence of free market economy, which conceives of an individual as “free” to sell access to their biological information, greater general accessibility to scientific research, and new media technologies that allow for faster, easier and increasingly cheaper access to biosocial communities.
- Whereas biological citizenship operates through political economy of hope, biocitizenship 2.0 is embedded in the “free labor” economy of network society.

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Citizen Bioscience, Affect, and Freedom in the Network

- Citizen Bioscience Problematic - to claim a revolutionary position outside of institutional power and capital structure, and, at the same time, accrue financial benefits
- The work performed by users of 23andMe or DYIGenomics is affective in every sense of the word – it is manifested in its ability to produce communities, esteem, but also to enhance bodily capacity to affect and be affected.
- Facilitates active citizen engagement through the use of social media technologies and platforms. Liberatory transition in medical and scientific research that with liberatory transition in social media. Citizen Bioscience uses discourses of control, freedom, and empowerment as produced by new media discourses
- The work of being healthy - The work of being healthy produces citizenship which understands the care of self and which understands the care of self as the care of the network. The goal is to generate more data. Our health is that of the network.

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Do-It-Yourself Revolution in Disease Research



“This summer 23andMe is launching the Research Revolution, a community outreach program that empowers people to drive the direction of genetic research. This program is an opportunity for you to support disease research and positively influence the way it is funded and conducted. We pledge to do research on any disease that enrolls enough patients to ensure a productive study. The research will be conducted by 23andMe scientists, working with outside researchers who have expertise in the particular topics being studied. Our research also requires data from control individuals who have not been diagnosed with the diseases we’re studying. So every person — patient or control — who enrolls in the program will receive a vote to cast for the disease they support. The disease that earns the most supporters by the end of the program will be studied first. By enrolling, you receive access to your own genetic data, including analysis of over 100 diseases and traits. This specially priced Research Edition of the 23andMe service costs \$99.”

- 23andMe, 2010

Citizen Bioscience and Media in Transition

HEALTH 2.0