

8 Test Yourself – Making the Invisible Visible

As Henk ten Have predicted in 2001, this millennium, post-Human Genome Project, is indeed characterized by a widespread availability of predictive knowledge and genetic and molecular information about the self (301). The Human Genome Project had not just popularized genetics for a wider audience – thus changing fundamentally how humans view themselves – but also lead to a cascade of technological innovation that significantly reduced the costs and the time needed to perform genome analysis. Since the first decade of the century, more and more complicated genetic tests are performed and marketed routinely, to physicians but also to consumers themselves (cf. Hamburg and Collins 303). Even though they are probably the most prominent example, tests available to the consumer today are not just limited to genetics but also includes ‘molecular’ testing in the wider sense: Vitamin deficiencies, hormonal status, infections, gut health, all these can be tested from the convenience of your home. They do not need a physician as intermediary but rely on individuals doing the first steps of the test – the needle prick or specimen collection – themselves. You no longer have to consult a medical professional to have blood work ordered, you can do it yourself or, rather, have a company do it for you. The possibilities range from home health tests to companies that offer all-inclusive packages, including recommendations on how to make the best use of your results.¹ They are part of the aim to personalize medicine, to tailor medical interventions to the patient, thus reducing costs and improving outcomes. For some critics, these types of tests can also be considered the “epitome of a particularly individualist or consumerist approach to healthcare” (Turrini and Prainsack 4). Their foundation, thus, lies also in the consumerist ideology of the DIY patient.

As Turrini and Prainsack summarize from different, mostly empirical studies, users and the general public tend to evaluate contemporary (genetic) testing options positively because of their presumed medical importance – presumed in this case because that is how they are marketed to the public – and the potential for positive changes towards a

1 For example, *Amazon.com* offers around 30,000 matches for the search term: “Health Tests.” These range from DNA tests to pH-level tests or sperm count tests for your iPhone, but also include more mundane tests such as blood glucose or iron deficiency (search done: 04.09.2018).

healthier lifestyle (5).² This presumed value is one of the reasons why DTC testing is so popular today. “Genetic testing is capturing the attention, and imagination, of people,” write Anna Harris et al., who not only find their (popular) media littered with molecular breakthroughs and personal experiences with direct-to-consumer (DTC) tests but can now buy these tests conveniently from a multiplicity of sources via the internet, the primary medium through which they are marketed, sold and shared (60–61). The internet has become a convenient tool to sell tests, built communities of users and popularize their use. However, this growing industry of pre-symptomatic testing and molecular diagnosis is also part of the promissory culture of biotech intervention (Rose, *Politics of Life* 91). Press releases, marketing materials, and public appearances of testing companies promise to provide the consumer with some of the most-thought-after goods of today: (self-)knowledge through science, potential for optimization, confirmations of one’s uniqueness and individuality but also connection and participation in something larger – common concerns that my analysis has revealed.

While some critics rightly celebrate DTC medical testing as a form of patient empowerment, others focus on the negative side effects of this type of empowerment: the risks associated with giving consumers access to highly predictive and uncertain information about their own bodies without the guidance of medical professionals; the new types of responsibility and obligations the patient is ascribed; the uncertainty of the testing procedure itself and the possible impact on the individual; the effects of heightened individualism on social solidarity and society as a whole. The discourses of empowerment are always in stark contrast not just to the new burden of individual and collective responsibility for personal health but also to the new forms of precarity and vulnerability that these types of predictive knowledges about the body can entail.³ These concerns have sparked theoretical and ethical debates, giving rise to new labels for the tested person, such as the “potential sick role” (Lupton, *Medicine* 98–99), the “person at risk” or “susceptible self” (Rose, “Genomic Susceptibility” 147). Such delineations point to the main concern: the individual is placed in a new environment of risks and possibilities, for which they often lack the biological literacy to correctly interpret them themselves, potentially leading to anxiety about the contingency of the body. This feeling of vulnerability to forces beyond one’s control inverts the aim of empowerment and instead promotes new forms of self-government to avoid said vulnerability.

The cultural discourse created is that more knowledge about the inner workings of the body allows us to understand ourselves in new ways but also to optimize those inner workings: Knowledge leads to intervention, to change, to manipulations of those biochemical pathways that were found deficient or lacking. The belief is that new medical technologies can “make the invisible seed of future health or illness visible” (Rose, “Race, Risk” 432). Biomedical tests, thus, are perceived to, in Chrysanthou’s words, give us the

2 In contrast, they also show that evidence for health-related behavior changes cannot be found in many of the studies done with DTC testers (Turrini and Prainsack 5).

3 These vulnerabilities can arise either through the uncertainty of tests results themselves (cf. Stevens 203, 292) – as predictive susceptibilities or numerical assessments of risks, sometimes even based on shaky correlations; the inability to act or intervene (e.g., in untreatable diseases); or through negative psychological reactions (cf. Turrini and Prainsack 4).

“power to render the invisible visible” (475). “Haunted by uncertainty,” the utopian body, for him, needs access to „its own personalized map of its interior landscape” (Chrysanthou 476). The tests, it is believed, can make the material basis of life – with its flaws and individual characteristics – visible, actionable, create a “map” of its interior that the individual can use to reach its goals of fitness, health, or self-knowledge. But the “invisible” here are not just material structures but also possible futures, possible identities.

Testing, as this introduction meant to show, can have a variety of material, psychological, even social effects. When tests are done individually, without the interference of medical professionals, self-prescribed and self-administered, they become a form of DIY biology, a sometimes playful, sometimes serious engagement with one’s own body and the biological building blocks of life. Turning bedrooms, kitchens, and couches into makeshift laboratories, direct-to-consumer testing is the subject of case study V “Welcome to You.” Empirical research about the testing process, the motivations to participate and its psychological and physical outcomes has been underway for quite some time.⁴ What interests me here is not so much the perspective of the user but how the companies represent (and thus market) their tests to the public, how they create promissory discourses of self-knowledge and public participation. I will therefore primarily analyze the individual company’s websites and bring them into conversation with each other. This type of representation draws on common ideologies and desires of the public – it identifies a need and offers a solution. It thus reflects some of the affective structures behind (commercialized) DIY biology.⁵ Due to their desired audience and purpose as a marketing tool, it is fairly easy to find material for rhetorical and contextual analysis and similarities in the discourses they create: discover yourself, improve your quality of life, enhance your performance, get to know yourself with science. However, in this process of self-discovery age old techniques such as introspection and verbalization are replaced by proactive preemption-prevention based on consumerist ideologies. Even though on it is a highly individualized action, direct-to-consumer testing is discursively aligned with DIY biology and citizen science. In the second case study, then, I turn from those tests that rely on laboratories for analysis towards examples in which the testing process is ‘do-it-yourself’ from start to finish, ‘hacked’ and open solutions to biomedical testing. Case study VI, “Make it Personal,” is mainly concerned with the cultural representation of a specific case – Kay Aull’s DIY hemochromatosis test – in Wohlsen’s eponymous non-fiction account of *Biopunk*, interspersed with other examples of how biomedical testing can be realized with a more explicit DIY approach. What both case studies have in common however is the idea that ‘testing’ the molecular make-up of the body will lead to new insights into the self, new forms of (social) connection and possibly avenues for self-enhancement.

4 cf. Turrini and Prainsack for a good summary of recent studies on the motivations and levels of utility of DTC tests.

5 It thus, to a degree, also connects back to the question of DTC advertising and its inherent positive and negative sides, a factor that also turned the stimulants described in the previous chapter into such a cultural commodity.

Case Study V: “Welcome to You” – Direct-to-Consumer Testing and Citizen Science

With the “explosion” of genetic testing companies, “the intersection between genetics and medicine is starting to be tapped by amateur biologists-at-large as well,” writes Elie Dolgin (1953). However, not just genetics is increasingly accessible for DIY biologists but also molecular biology more generally. Probably due to the higher risks and privacy issues connected with the ‘data’ they reveal, genetic tests have received the most widespread attention. Molecular and biochemical DTC tests, however, are no less telling than their famous cousins, especially because the discourses they create are often similar: They all speak to an appeal of self-obtained information, of active participation and curiosity about one’s own biological makeup. Despite debates about their efficiency, accuracy, and safety, the need for professional counseling in the process, or the lack of literacy on the part of those who opt for the tests, their popularity seems to be unbroken, visible in the hundreds of companies that offer DTC test in one way or the other. As I have argued previously, genetics might be the most widely mentioned example of the molecularization of the human body, but it is by far the only one. The ‘inside’ view, the fragmentation of bodily functions and their embedding into molecular and biochemical pathways, is not limited to the genome. Rather, the availability of testing tools for DIY users – from home tests bought on *Amazon* to collection kits analyzed in a lab – speaks to the increasing desire of individuals to gain a deeper insight into and understanding of their bodies on this molecular level. They want to translate the prevalent molecularization in cultural discourses of the body onto a more personal, individualized level and make it ‘actionable’ for their own wellbeing.

The DTC testing industry has been following the same broad premises ever since its inception: Consumers choose and order a kit online, collect their own biological specimen – from stool, to saliva, to blood, the primary difference being the material they work with – and send it to a company for analysis. A few days or weeks later, they receive their results in their (virtual) mailbox. The genetic and molecular testing companies in this case study follow this pattern and range from DNA tests for ancestry and health, to blood tests as well as ‘wellness’ tests on a variety of biological specimen.⁶ Before I go into a more detailed analysis of the semantic characteristics and overall themes, let me provide a bit of general information about the companies and their products one-by-one.

23andMe, of course, is probably one of the best-known providers of personal genomic services in the US and world-wide. Founded in 2006, their tests provide the customer with information on their individual genetic variants – mostly on SNP-level – with respect to their ancestry, their genetic health risks and carrier status, as well

6 Another highly interesting example is DIY testing for sexually transmitted diseases and reproductive health: myLAB Box™ is a company that promises its users discrete and accurate testing for some of the most common STD/STIs, such as Syphilis, HIV, Chlamydia, or yeast infections. They position themselves as a means to take control of your health from the “comfort of your home” (myLAB Box™). What makes it so interesting is the stigma – and thus immense hurdle to seek treatment or get tested – around STDs/STIs.

as their wellness predispositions and individual traits.⁷ Since 2010 uncertainties about their status as medical devices, their FDA approval, and the potential for unverified information and false results had led to debates about the regulation of *23andMe* and similar companies' tests, leading in November 2013 to FDA warning letters to suspend testing. *23andMe* complied and suspended sales for the medical component of their tests, sought FDA approval and now is the first company whose DTC genetic tests were granted FDA authorization in 2015. But more than providing individual information, *23andMe* also invites their users to share and compare their genetic results, find genetic relatives through their platform or participate in genetic research based on their data and health information, which adds a social, collective dimension to their testing (*23andMe*, "DNA Genetic Testing").

InsideTracker is a tool that also Meisel recommends in his guide to biohacking: The company focuses on molecular testing, more specifically they provide bloodwork for their clients and turn the results into "actionable recommendations" to optimize health, wellness and performance. They offer a variety of "plans" in which up to 41 "biomarkers" are analyzed. As part of their marketing strategy, they recommend regular testing to compare results and see which of the changes or recommendations work on the molecular level. By "tracking data" over time, the goal seems to be to create a continuous picture of the "inside," the molecular make-up of the body (Segterra/*InsideTracker*). While *InsideTracker* seems to endorse physical activity and high performance, *Wellnicity*, as the name already suggests, looks at a more abstract notion of "wellness," which in their offers "meets simplicity." They do not only provide molecular testing but also offer to put together a personalized "supplement regime" of "professional-grade Vitamins." In a promotional video that explains the process of testing, *Wellnicity* positions itself as a means to uncover the connection between different symptoms one might experience to one's overall wellness. On their webpage, users can either browse the collection of tests and testing packages they offer or select a kit based on individual health goals, symptoms or concerns. The tests themselves, then, range from brain health, gut health, testosterone, stress, metabolism, thyroid, food sensitivities, Vitamin D, to blood sugar levels. Interestingly, many of the them are named along the same line: "My Stress," "My Metabolism," "My Gut-Health," promoting their "personal" nature to the consumer (*Wellnicity*, "Wellnicity"). The benefits presented by the companies – self-knowledge, the possibility for early intervention, empowerment – as well as potential problems and concerns – uncertainty, results that are not actionable or misleading, lack of treatment options, unintelligible results, lack of literacy, undue responsabilization – are strikingly similar among them.

7 As for all the genetic testing companies, the analysis of DNA samples is mostly based on SNPs. An individual's profile is created to compare variations at single base pairs at known locations where variations often occur. Based on Genome Wide Association Studies (GWAS) and the correlations they found between SNPs and diseases or traits, an individual's disease risks are calculated. When people access the results online, they are provided with information on the location of the variation and their individual probabilities. In recent years, companies like *23andMe* have established measures that allow individuals to choose which information they want to see, especially for diseases like breast cancer, Alzheimer's or Parkinson, where the correlation is relatively certain but treatment options radical or practically nonexistent.

In these tests, “[b]iology is not only mutable, changeable, and manipulable – it is also utterly consumable,” one of the most valuable commodities (Levina 5). What is paid for by the consumer are knowledge and access to their own (genetic) information. DTC tests represent one of the most prominent examples of a downright assimilation of DIY ethics into a consumerist ideology. The focus on knowledge and access is also visible in the rhetoric created by the company websites: Access to knowledge is a form of empowerment necessary for individuals striving to feel their best, as Wellnicity promotes (Wellnicity, “About Us”). Possessing knowledge and information, then, is positioned as enabling people to be “in control” of their body and genetic information. This idea of control is often connected to the notion of “taking action.” Most overtly, *InsideTracker* urges their users to “take action using your blood, your DNA, your habits.” Instead of “guessing” – with its connotation of uncertainty – people should “know” what their bodies need (Segterra/InsideTracker). Information leads to control leads to action, the dominant logic goes. The encouragement to “take action” by all these companies can be read as form of *responsibilization* for one’s own wellbeing; it is the individual that is responsible for using their new knowledge to actively adapt their situation.

This combination of information, action and responsibility in the name of empowerment is visible also in the narratives that *23andMe* uses as customer testimonials. By chance, “Jill” discovered a BRCA-1 mutation in her test report that puts her at higher risk of developing breast cancer. After the test and a clinical risk assessment through her doctors, she opted for a preemptive double mastectomy. In her video she talks about how the experience of using her genetic information to do something about her health was very empowering: “Why wouldn’t you want to know? Why wouldn’t you want to do something?” (23andMe, “Customer Stories”) For her, that knowledge allowed her to make an active decision about her health and (future) wellbeing. That one would react to the information given – even go to drastic lengths to prevent that risk from coming true – seems to be self-explanatory.⁸ DNA information here becomes transformative, even performative for an individual, in the sense that it starts many processes of treatment or changes in lifestyle that may affect their sense of self as a person-at-risk for example or a prudent biological citizen.⁹ The discourses of empowerment and the resulting promotion of the ideology of self-responsibility explicitly or implicitly created by many of the websites promotes the idea and necessity of proactive preemption-prevention. It persuades individuals to actively seek out information about themselves, empower themselves, to then act responsibly in relation to that information by changing their habits and lifestyles. Two prominent problems arise here: First, the information you get is not necessarily actionable, thus turning the accessed knowledge into fun trivia

8 It is also interesting that a lot of the customer story/testimonial videos I looked at for this discussion revolve around the BRCA-1 and -2 mutations, those breast cancer mutations made famous by Angelina Jolie’s decision to undergo a preventative mastectomy in 2013. Not only are those mutations now part of the collective imaginary around genetic health risks, but they are also one of the best examples of serious and thoroughly validated genetic risks that allow the individual to take action – which is not the case with other diseases like Alzheimer’s.

9 I borrow the idea of the performativity of DNA from Roof (162).

without long-reaching effects on health or wellness. This is one of the reasons why companies like *Wellnicity* and *InsideTracker* offer to make it actionable for you. The second problem is one of differentiation: This type of commercialized access might lead to a stratification into those who can afford to test and those who cannot, with consequences for the self and society as a whole.

The idea of taking action is not just integrated in discourses of health and healing (or prevention of disease) but also much more generally in ideas of self-enhancement. As some of the testing companies propagate it, the aim is to optimize one's own well-being and performance. As such, some of the tests can be counted as examples of the much more literal "makeover culture" of beauty (Wegenstein, *Cosmetic Gaze* 111).¹⁰ They are one of the ways in which we are bombarded with messages of potential optimization of different facets of our lives. In essence, the idea of optimization perpetuated here goes back to the same premises of competition, getting an edge, performing better than others, and maximizing life satisfaction through investment in bodily capital and social status, that I have discussed in relation to self-help guides and pharmaceutical optimization. The molecular tests performed by *InsideTracker* are an especially interesting case: Already their different tests exhibit a downright adoption of (neo-liberal) goals of self-management and self-optimization in the name of the market: They have telling names such as "Ultimate" (tag line: "Take control of your destiny"), "Vitality" ("Get the competitive edge"), "High Performance" ("Push your performance past its peak"), "Essentials" ("Improve your body and Mind"), or "InnerAge" ("Gain Life and Vitality") (Segterra/InsideTracker). The discourse created only by those names indicates the main goal of the tests: improving health and performance, reaching goals through individualized action, and a sound foundation in science.¹¹

If we believe the promises made by the web appearances of these DTC testing companies, however, genetic or molecular knowledge can not only help you to optimize the self but also to *discover* yourself. The idea is that you can discover the 'true you,' your essence, through your biology, thereby positioning the self as somehow fixed in the body, determined by its materiality. DTC testing, writes Stevens, delivers on the promise of the Human Genome Project to tell us something about who we are (Stevens 307). Biological 'data' are positioned as a repository of information about the self. The discourse of personalization and individualization is extremely prominent on many of the webpages: *Wellnicity* and *InsideTracker* advertise their "personalized," "individualized" or "customized" solutions. On their saliva collection kit, *23andMe* writes: "Welcome to you." (23andMe, "DNA Genetic Testing").¹² An abstract "you" is the primary addressee

10 Some companies like the internationally operating *DNAfit* take this connection one step further, when they portray genetic information as a source to optimize personal fitness and body shapes by providing information on optimal diets, nutrient needs, exercise responses or recovery profiles (DNAfit Life Sciences Limited/Prenetics).

11 A science-based approach is another joint keyword for many of the companies: Authorization for the tests and the companies comes from industry leaders such as biotech companies or universities, government oversight bodies such as the FDA, industry standards and the culturally entrenched trust in scientific solutions.

12 An individual, for them, is a system of cells that awaits to be explored: "You are made of cells. And the cells in your body have 23 pairs of chromosomes. Your chromosomes are made of DNA, which

of the websites – translated by the reader or user into a very concrete and personal “me.” *InsideTracker* uses a related and highly interesting image: “A *selfie* from the inside. It’s customizable. It’s simple. It’s based on *you*.” (Segterra/InsideTracker, my italics) A primary mode of representing yourself, the selfie has become a pop-cultural icon today.¹³ Here, we find a molecular “selfie,” a molecular representation of the self, of “you” – visible and abstract at the same time, a collection of data points. ‘Yourself’ is thus positioned rhetorically at the center of the testing process. The ‘you’ becomes a stand in, a possibility – “That could be me!” – an affective appeal. Surrounded by images of made-over bodies, claims Wegenstein, we begin to desire a make-over ourselves (*Cosmetic Gaze*, 2). Surrounded by molecularized, mediatized bodies, we begin to desire our own molecularization and the possibilities it might entail. But this ‘you’ is also a celebration of uniqueness: “23 pairs of chromosomes. One unique you.” (23andMe, “DNA Genetic Testing”), “No two bodies are the same.” (Segterra/InsideTracker), “Wellness is...a personal journey unique to each individual.” (Wellnicity, “Wellnicity”). In DTC testing, it is implied, the focus is on you, your individuality, your personal “uniqueness.” Consuming apparently individualized solutions becomes a means to ascertain one’s own individuality and uniqueness in a time of increasing uncertainty and loss of traditional anchors of identity.

Nordgren and Juengst argue that the webpages of genetic testing companies link genetic and personal identity by adopting the rhetoric of “personalized medicine,” which suggests that the information they provide is uniquely tailored for an individual or will provide new (fundamental) insights into their identities, in relation to themselves and their family lineage or group membership. In this way, they claim, in the discourses created by the testing companies “the genome can perform all the philosophical functions of the soul in providing an ontological basis for our unique identities” (159-60). This appeal to the genome as a secular substitute of the “soul” is one of the reasons why such companies are so appealing to consumers: Nordgren and Juengst claim that their business models draw together three different ideological streams in contemporary Euro-American culture: “the distinctly pre-modern search for a naturalistic understanding of individual identity in a pluralistic world, the thoroughly modern cachet of genomics as a science, and the post-modern emphasis on radical individual self-determination” (157-58). These three ideologies – the search for a naturalistic identity based on biology, the belief in science, and the emphasis on self-determination – flow together in 23andMe’s campaign “this is me®” that they use for their “customer stories” and “genetic journeys.” Grounding the self firmly in its biology, such a genetic statement of also implies a long-forgone form of genetic essentialism (cf. Nordgren and Juengst 157-58). But it is also a form of self-declaration, a form of storytelling about the self based on its molecular make-up.

can tell you a lot about you. Explore your 23 pairs today.” Apart from this apparent molecularization of the body, 23andMe positions their tests as “easy ways to discover you” (23andMe, *DNA Genetic Testing*) – finding the self in its molecules.

- 13 We could argue that this analogy to a selfie – a medium prone to sharing – also buys into a similar ideology: The molecular selfie, as much as the visual one, is meant to be shared, liked and commented on by others – thus providing another example of the collective nature of individualized testing.

Turrini and Prainsack see identity making as one of the possible uses and values of DTC tests: DTC testing becomes a means of “exhibiting and speaking about” one’s genetic self, it serves as a “starting point to tell a story about ourselves.” As such, DTC testing is also “inherently relational:” “when genomic data are used to explore or reiterate one’s identity, these activities simultaneously build, change, and reinforce relations to others” (Turrini and Prainsack 5-6). It is not just a story about the self that is told but also one about those close to the self, living and dead, even society as a whole.¹⁴ This is visible in DTC testing for health, as the results often concern also current and future family members, but even more so in testing for ancestry. DNA testing is positioned as a way to look into the past and uncover all those connections to other people on the globe – an individual’s group connections and tribal belongings.¹⁵ *23andMe* also encourages their clients to test several individuals from one family for comparison and to search for relatives through their website: A “DNA-based versions of social networking in which connections can be made on the basis of matching genotypes,” claims Stevens (304). On their webpage, *23andMe* advertises for their ancestry testing not just with the possibility of experiencing one’s ancestry in a new way – gain new genetic knowledge – but also by promising possible connections with “DNA relatives” (*23andMe*, “DNA Genetic Testing”).¹⁶ In this way, genomic research becomes, in Levina’s words, a “social-networking” activity (4). This *ethos of sharing*, one can argue, has also taken inspiration from the sharing culture propagated by social networks like Facebook and Twitter (cf. Levina 4) and perfectly aligns with some of the values of the maker movement and DIY biology. According to Stevens, linking genomics with the internet and social media – through its digitization, and I would argue, the discourses created by genetic testing companies – “encourages” individuals to think of their genomes as similar to those types of information about the self that are today routinely shared online (307-08). This positioning

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- 14 Genetic genealogy is a highly debated issue that has received more and more media coverage in the past years: Some public DNA databases on which people have uploaded their DNA for genealogical inquiries, have allowed law enforcement agencies to use their databases to solve unsolved criminal cases. From DNA hits in the databases genealogists can infer whole family trees and identify possible subjects based on their DNA, a prominent example was the capture of the “Golden State Killer” in 2019, almost 30 years after his crimes (H. Murphy). A big issue that arises is that of informed consent: If one member of a family uploads their DNA profile, parts of their relative’s DNA is revealed as well – possibly without their consent.
- 15 Not only is genomic testing for ancestry not an exact science (cf. Balding et al.), it also has possible racial implications. In *Private Bodies/Public Texts* (2011) Karla F. Holloway criticizes how despite the claims that race is not discoverable, it does “inform” genomic science (79): Social assumptions, for example, are carried from (racialized) language to the data, scientists often have to make “arbitrary choices” about designations and migratory patterns (81). Seemingly “benign” ancestry testing contributes to the growth of DNA databases, whose private and public uses, for now, remain opaque (88-89). We do not know how companies will use these databases in the future, if privacy and confidentiality are observed, or whether they will be misused, for example by law enforcement agencies, as described above. Against the backdrop of prevailing stereotypes, assumptions and racial discrimination such misuses could disproportionately affect African-Americans, for example in race-based DNA sweeps (Holloway).
- 16 Similar discourses are created by other companies that provide ancestry testing, such as Texas-based Dynamic DNA Laboratories, who that their testing allows you to “discover who your ancestors were” and “connect with relatives from around the world” (Dynamic DNA Laboratories).

makes the sharing of this most intimate information seem more normal and harmless than it might be. It is also through this ethos and normalization of sharing that the highly individualistic and personal nature of the test results gains a dimension of collectivity and collaboration.¹⁷

Very broadly, Marina Levina argues that personal genomics takes “advantage” of social media technology and network subjectivity – the idea that individuals are always already part of and contributing to a network through the sharing of information – to promote *new, collaborative forms of doing research*: Personal genomics, she argues, is discursively positioned as part of a “social-networking culture” in which a perpetual sharing of the self is standard, so much so that the generation of data and sharing of information is positioned as an act of (biological) citizenship (1–2, 5). Similarly, Delfanti argues that their social media websites and “discourses of participation and inclusion” are used by genetic testing companies like *23andMe* to encourage “active engagement with genetic research” (*Biohackers* 46–47). In 2009, for example, *23andMe* proclaimed their so-called “Research Revolution” – “a Do-It-Yourself Revolution in Disease Research” – to “empower more people to jumpstart genetic research into the diseases that affect them and the people they love” (*23andMe*, “Introducing”). The aim were large-scale genomic studies for ten diseases in which people could participate through a special “23andMe Personal Genome Service Research Edition” that also gave them insights into their own genome, a cheaper version of the test at that time. This “research revolution” marked the first time that *23andMe* tried to draw customers into genetic research. In 2018, *23andMe*’s information page on research claims that they give people the opportunity to “becom[e] part of something bigger” and “make a difference by participating in a *new kind of research—online, from anywhere*” (*23andMe*, *Research*; my italics). By answering online surveys and connecting them to genetic data, researchers can use customer contributions to “help drive scientific discoveries” (*23andMe*, “Research”).¹⁸ *23andMe*, according to Levina, is one of the examples that introduces a form of “research 2.0,” a model that creates and sells 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” (3).

This type of citizen science promoted by *23andMe*, of course, could be seen as empowering people to take part in research but it also is a form of appropriation of its ideals in which individuals relinquish their control over their data to the companies in question. According to Turrini and Prainsack, despite the company’s “strong rhetoric around participation and democratization, the degree to which the company is transparent to its users is very different from the degree to which its users are transparent to the company” and control over how the company uses their data is limited (7). In fact, in this type of citizen bioscience, individuals are used as a source of “free labor”

17 The personal nature of the results, however, also has a collective dimension if we look closer at how those results are created: The Genome Wide Association Studies (GWAS) that form the basis for many of the correlations compare genetic variants and phenotypes between large cohorts of the population – they therefore always have an element of collectivity.

18 The patient-consumer is free to „opt-out“ or “opt-in“ to this type of data use at any time, claims *23andMe*.

(Levina 5) in the biomedical market, a free research commodity facilitated through a discursively created (moral) obligation to participate and share information (Delfanti, *Biohackers* 46–47). The access to their biology that people grant the companies as well as the labor they perform – pricking blood, collecting saliva or other biological specimen – become “biological resources” that produce “economic value” (Harris et al. 73). A noteworthy example of such value-production from genomic data is the cooperation between *23andMe* and *GlaxoSmythKline* (started in 2018), in which they use genetic samples out of the former’s large genetic data base and filled out questionnaires to find possible targets for new drugs – that could then be used for commercial development (*23andMe*, “Note Collaboration”). This is not just questionable from a data privacy standpoint but also ethically: The only people, who will not benefit from this arrangement financially are those who opted-in to sharing their data for research (cf. Ducharme).

A strong incentive to participate in this type of free labor, according to Turrini and Prainsack is the possibility to contribute to collective scientific knowledge. They claim that for many respondents in empirical studies, curiosity about new technologies and a keen “interest in participating in biomedical research” where motivational factors for their use of DTC testing (5). The discourse of participation and collective impact is also employed by *23andMe*: “With the help of our *23andMe* community we believe we can *accelerate research* and *make an impact* with our genetic data.” (*23andMe*, *Research*, my italics). Accelerating research (possibly helping other people) and making an impact (leaving a mark) are used as incentives for customers to ‘opt into’ research. One factor in Turrini and Prainsack’s discussion of the several layers of utility or value of DTC testing for the customer, thus, is a social one, both by creating new forms of identity articulation towards and in relation to others and by creating larger social value by contributing their information to genomic databases and research efforts (6-7).¹⁹ The large-scale studies that *23andMe* is helping with, they claim, “are poised to transform medical research and empower more people to join more studies” (*23andMe*, “Research”). All this is buttressed by a “rhetoric of scientific democratization” (Turrini and Prainsack 6), in which customer-patients are active contributors to scientific advancements as well as proponents for a new, open form of doing science.

While it is far from open-source approaches, DTC (genetic) testing is here aligned with discourses of citizen science, empowerment, participation and democratization of research – making it accessible, allowing also ‘lay’ people to contribute what they want and can. Here, a commercialized form of DIY focused on individual choice and self-administration is discursively merged with amateur biological research. A somewhat related example is the *Personal Genome Project*: This non-commercial project strives to make whole genomes of participants accessible for researchers and the public alike.

19 Turrini and Prainsack, in their discussion of the utility of DTC genetics, argue that taking a DTC test is not the individualistic activity it is often seen as but done with or with reference to others: friends, family, significant others, society as a whole. “In this sense,” they claim, “genomic information is personal and social at the same time: it is personal, but for more than one person” (5). The value of personal genomic information for them is thus “intrinsically social” (7). Moreover, the new forms of identity articulation have a parallel in the emergence of standardized clothing sizes: They prompted individuals to rethink the self and body in numbers – numbers that invited and were created through comparison with others.

Participants must demonstrate that they do indeed understand the basics of genetics as well as the repercussions that the sharing of their genetic and trait data might have for them, because no anonymity is promised (Harvard Medical School/Wyss Institute). While this is not exactly a DIY technique, indeed rather a highly mediated one, it is nonetheless a perfect example for genetic citizen science based on open-source principles. It is the exact opposite of those closed off, inaccessible databases of the genetic testing companies, a sharing for the greater good instead of company profits.

Still, DTC testing has found its place among DIY biologists, in their practices and cultural representations. For example, journalist Marcus Wohlsen includes personalized medicine and DTC genomics in his discussion of *Biopunk* (2012). Wohlsen dedicates a chapter to the increasing ability to “read” DNA, amongst other things through DTC tests offered by companies like *23andMe*. In this chapter, he includes the story of Raymond McCauley, a bioinformatics professional, who in his free time has turned to DIYbio and DIY solutions for his passion projects and potential innovations: To satisfy his curiosity as a “hacker,” McCauley took a DTC genetic test to find out more about himself. Not only did his results have actual material consequences on his body – he lost seventy pounds to improve his odds for some of the more worrisome test results – but he did not stop there: McCauley connected with four other “gene hackers” to start a DIY clinical trial to find out if a mutation in a gene McCauley carries may impair his body’s ability to use folic acid. Spread throughout the US, the four ‘test subjects’ went to an online doctor to get a prescription for a blood test which they had done in nearby clinics. After receiving their initial results, they started a period in which they “washed out” folic acid from their bodies before testing the effects of both a regular off-the-shelf product and a better-tailored vitamin, checking their folic acid levels regularly for comparison. The results showed that McCauley’s body could process the tailored vitamin better. Apart from this personally useful piece of information, for McCauley the “most powerful achievement of the so-called citizen science effort was the fact that it could be done at all” (Wohlsen 133-40).²⁰ Without cheaper access to one’s own genetic data through DTC tests, Wohlsen argues, this type of citizen science and biohacking effort would not be possible. He predicts that with the new tools at our disposal, amongst which he counts not only DTC options but also crowdsourced data bases and genetic interpretation programs, consumers might in the future become DIYers (121). For him, thus, DTC and DIY are not two distinct approaches; rather, they can influence and inform each other, be combined in DIY biology projects in a way that is meaningful and practical for the ‘biohacker.’

20 *DIYgenomics*, a non-profit research organization that wants to realize personalized medicine through crowdsourced health research studies, is an online platform that uses approaches such as McCauley’s on a broader scale. Since 2010, people can choose studies and participate in them, by trying a set series of interventions and measuring the results with blood tests, including for example studies on vitamin deficiency, aging and mental performance (*DIYgenomics*). After receiving more press coverage in 2011/2012, it has been quieter around *DIYgenomics* in the past years – their website and studies, however, are still active.

Case Study VI: Make it Personal – Do-It-Yourself Testing

„In a sense,” Wohlsen writes, “we will all become DNA tinkerers, making decisions about our lives and lifestyles in an effort to tweak our futures based on what our genes appear to have in store for us” (125). “DNA tinkering,” in this case study, is taken much more literally as we turn to Wohlsen’s representation of a biohacker’s efforts to DIY the genetic testing process. This account is dominated by considerations of access to knowledge, self-understanding and self-awareness, as well as, interestingly, bodily modifications and self-enhancement. In this case, the DIY testing process becomes truly personal: The test is conceptualized, implemented and analyzed by the individual affected and the results are poised to confirm or deny the existence of a genetic mutation in the tested and testing individual themselves, personal knowledge about personal risks. The goal is not a complete genomic picture but knowledge about a specific mutation. The narrative Wohlsen includes is that of Katherine “Kay” Aull, a professional bioinformatician with a background in synthetic biology, cancer research, and immunology, who in 2009 at 23 years of age set up a biology lab in her closet in order to test her own DNA. Aull’s story, apart from providing insights into the DIY biology movement, has become a staple reference point for both journalistic and academic authors – and it is also this prominence that has led me to include her story as well. Let me first recount what happened, following Wohlsen’s narrative.

In 2008 Aull had received her Bachelor of Science in Biological Engineering from the Massachusetts Institute of Technology (MIT) and afterwards started to work in a wet-lab for a synthetic biology company in Cambridge, MA. It is here that her story unfolds, a small apartment in Cambridgeport that Aull shared with three roommates and her cat.²¹ Using rather “basic tools” (Keulartz and van den Belt 7) Aull set up a wet-lab for roughly \$1000 that would both fit into her closet and could be used to test her own DNA. Why did she go to that length? Aull wanted to find out if she carried a genetic mutation connected to hemochromatosis, a hereditary disease common in the US. In Kay Aull’s family, the men tended to die young, narrates Wohlsen. When her father was sixty, his doctor noticed high counts of liver enzyme. When his numbers did not go down but increased despite alcohol abstinence, a blood test revealed something unusual: thick and viscous blood that caused the doctors to perform more tests. Connecting the thick blood and grating joint pain her father had experienced for years, he was finally diagnosed with an advanced case of hemochromatosis, a condition that causes the body to absorb and store too much iron, which builds up and leads to chronic damage. The treatment is simple: Since his diagnosis her father had to give blood every month to remove the excess iron (13). About ten years earlier, researchers had isolated the gene for iron absorption and its mutations causing hemochromatosis, making this hard to diagnose condition easier to identify without a doubt (13). This test is expensive and usually other possibilities need to be ruled out before an insurance company would pay for it (14). But “Aull wanted to know if she ran the risk of contracting hemochromatosis too,” writes Wohlsen. So instead of waiting and monitoring her health or demanding an expensive genetic test, she decided to “swab her cheek with a Q-tip, mix it with her

21 I deliberately follow Wohlsen’s account here and will go into detail for some of his points later on.

primer, and stick it in the thermal cycler in the closet” (Wohlsen 14-15). Using tools from her kitchen and second-hand gear from *eBay*, Aull built a gene test herself: In an effort of truly personal genotyping, she decided to extract her own DNA, amplify it, and using a genetic primer ordered online detect possible mutations in her DNA.²² She bought an “antique” thermal cycler on *eBay*, used a rice cooker and whiskey tumbler to make distilled water, and even tried to build her own electrophoresis box from a picture frame and a plastic box (Delgado 70; Keulartz and van den Belt 7). The test was successful, it worked. But it also showed that she indeed carried the mutation. According to Delgado, “Aull wants to have control over her future, and she wants to have it now. So a sense of personal history comes together with an aim at anticipating the future and taking action now” (70). Kay Aull did not want to wait but instead let herself be guided by her biological curiosity to create a test ‘on the cheap’ herself – a typical narrative frame for biohacker stories.

In this description, we find many elements of a DIY or hacker approach to biology. Aull had to think about what she needed, get or make the equipment, prepare and perform the test and interpret the results herself. Her aim was a cheaper but functional solution, an alternative to expensive tests prescribed by medical professionals under certain preconditions, to show that it is doable in a ‘home lab’ – and she also wanted to know something about herself. Wohlsen emphasizes the ‘hacker approach’ by including not just the tools and setting but also Aull’s motivations and mind-set into his narrative, to which I will come later. As is common for DIY biology, the tools she used are simple solutions, either makeshift or second-hand: A rice cooker, a whiskey tumbler, a used thermal cycler, and other household items. She used what was readily available and profited from the availability of used gear after the last economic crisis: the new, as Morgan Meyer called it, “citizen biotech-economies” emerging through the redistribution and democratization of material resources (“Build” n.p.).²³ The setting, as is typical for ‘garage biology,’ is domestic, a kitchen, an apartment in this case. Wohlsen highlights this domesticity when he describes her apartment in “a traditionally working-class neighborhood in Cambridge downslope from MIT along the Charles River,” in which “[t]he lab shared space with her three roommates and her cat” (14), who works as “her chief safety officer (‘If he can’t play with it, I can’t either’)” as well (11). Close to but also distant from the elitist science at MIT, Aull’s experiment does not take place in the confines of the ‘ivory tower’ but in a personal space, a shared space between different people and animals. This setting emits a certain casualness, a harmlessness of this type of DIY testing. Her cat as the “chief safety officer” also conforms to this image: The materials she uses, in general, are safe for living beings – a certain form of self-regulation often propagated by the DIY biology community. However, more than in DTC tests, in this case a kitchen, a home is turned into a laboratory, not just for the collection of a biological specimen but for the whole of the testing process. In this reframing of the home, such molecular tests also gain a spatial dimension: Close to home, they are

22 This primer is designed to bind to genes with the mutations for hemochromatosis, resulting in longer strands of DNA that can be made visible using a process called gel electrophoresis in which DNA strands are sorted according to length.

23 More on Meyer’s “citizen-biotech-economies” in Chapter 10.

a symbol of convenience, access, empowerment, but they might also get too close for comfort. Not just that the public once more impinges on the private (or that through the obligation to share the private is made public), but also the results might be too close to home, the own body, for comfort: they might reveal uncomfortable truths. This is true for DTC testing as much as for Aull's DIY solution, its experience – the vulnerabilities, obligations, uncertainties and subjectifications – as much as its public evaluation.²⁴

Kay Aull is by far the only DIY biologists who has performed genetic experiments on herself. In fact, for DIY bio community labs the extraction of workshop participant's and DIY beginner's DNA is a common experiment – Delfanti writes that in New York DIY biologists were “extracting and genotyping people's DNA at public events” (*Biohackers* 116) – and other experienced bio-hackers claim to have performed genetic therapies on themselves (cf. Quartz). But Kay Aull has become a staple reference point for journalists like Wohlsen and academics interested in DIY bio. Most academics are aware of her fame: Delgado, for example, acknowledges that Aull has gained a lot of media attention for developing her “homemade genetic test” (70).²⁵ One possible explanation for this fame is that her experiment was performed quite early in the DIY bio movement's trajectory: In a phase during which the movement was still finding its place and garnering support, a noteworthy experiment like hers was bound to draw some attention, also among the hackers themselves. Moreover, Aull is also emblematic of the whole movement: Like many of the early (and current) DIY biologists, she has a professional background in biology and the respective insights into how to plan and perform such an experiment. For her, it was more of a question of ‘downsizing’ the needed equipment than of gaining access and scientific literacy to do it herself. Aull is not a “novice” as Delgado calls it (70). Her MIT degree is also often included in references to her ‘hack,’ so one could also argue that this institutional authorization is appealing for journalists and the media: She knows what she does and has the credentials to prove it.

However, apart from her scientific background, Aull's story is also a deeply personal one, full of genetic responsibility and biosocial connections. Visible in Wohlsen's account, her ‘self-experimentation’ combines a DIY ethos with a personal ‘tragedy.’ In his narrative, he seems to endow Aull with four different identities: an “evil genius,” a professional biologist, a hacker/tinkerer, and a personal victim. Wohlsen starts his narrative as follows: “For an evil genius, Kay Aull comes off as very self-effacing. In fact, the twenty-three-year-old MIT grad has no malicious intentions, unless you consider her desire to grow a tail a crime against nature.” (9) This positioning as an “evil genius,” a nice and modest one at that, seems to combine her identities as a hacker/tinkerer and professional scientist: “She also speaks with the crisp confidence of someone accustomed to knowing more about her area of expertise than anyone else in the room – and she probably does.” (9) Wohlsen acknowledges her expertise that does not just come from being the one to do this test but also from her educational background.

24 Wohlsen also thematizes the contradiction between the home and lab as spaces where biology is practiced, drawing on the common evaluation that the home is not a safe space for molecular agents (18). For more on Wohlsen's different valuations of the spaces of biology cf. Case Study IX.

25 cf. also Wolinsky, Keulartz and van den Belt, Meyer (“Hacking”).

However, it is the focus on her family history and the personal nature of her DIY endeavor that makes her most relatable for the reader. We find glimpses into how the rest of her family coped with the diagnosis: from her parents' search for information online to Aull testing herself. The medical background of the story and her personal stakes in it, allow Aull to also be framed as a "patient advocate" (Jen 134). Her experiment, thus, combines a new trend with an old narrative frame, one that is inherently human: the repercussions of a new medical diagnosis.

In Wohlsen's narrative the result of the test seems to turn Aull into a somewhat tragic figure, torn between the implications of what she now knows and the scientific spirit that led her to the discovery, her emotional reaction and her rational approach as a scientist:

Aull said the mutation she carries still means that there is a less than 50 percent chance that she will contract the disease. *Yet I could see her enthusiasm for the test was blunted as she talked about the results.* As with genetic tests for Huntington's disease or Parkinson's, Aull could do little about what she found out other than watch and wait. She is the same twenty-three-year-old she was before the test, but now genetically *haunted by a possible future over which she has little control*, except for knowing to tell a doctor about her genetic pre-disposition if suspicious symptoms appear. 'Everyone has these deep dark genetic secrets. That's just how it is,' Aull said. *'Knowledge is complicated, but ignorance is not better.'* (Wohlsen 15, my italics)

The reality of the test, it seems, had "blunted" her enthusiasm. In this quote, Wohlsen's impressions seem to dominate the account and he seems to make use of a common narrative of genetic testing: the patient-in-waiting, the uncertainty that arises out of genetic knowledge, especially with tests for diseases that lack a cure. In Wohlsen's account, the test that Aull herself sees as a form of empowerment becomes a genetic "ghost" that will haunt this young girl for the rest of her life. An act meant to take control makes her lose control. The value of such a test suddenly seems to be ambivalent. Likewise, for Delgado the result of the test means that "her present seems to be trapped in between her genetic past and her risky future" (70). Both journalist and academic seem to draw on the same basic narrative of genetic risk. But for Aull herself this narrative seems to be beside the point: For her, satisfying her curiosity seemed to come with an inherent warning that she has to accept, even embrace, as a scientist: Knowledge, no matter how complicated, is always better; what counts is the experiment, the solution, the hack. Aull's own voice seems to be drowned out by culturally sanctioned narratives and expected reactions that stand in contrast to – or cannot yet integrate – her overarching goal and ideology.²⁶

However, Wohlsen nonetheless seems to endorse personalized medicine and genetic testing, also self-made testing, as means to gain in self-awareness:

Aull sought to *learn something profound about herself*. Through sheer inventiveness, she tinkered her way to that knowledge. She hacked her genes, and she *gained in self-aware-*

26 We could, of course, also do a feminist reading of this passage in which the male narrator silences the female voice and subordinates her reading of a situation to his own.

ness. Perhaps do-it-yourself biology will someday mean a *new kind of introspection*: the ability to *self-examine with more depth and precision* than Socrates could have dreamed. (Wohlsen 16, my italics)

From tinkering and hacking, from material practices with rough edges and work-arounds, he seamlessly moves to broader issues of self-awareness and self-understanding. DIY tests, he speculates, could become avenues for profound self-examination reminiscent of previous forms of introspection. The material equivalent of Socrates' 'know thyself.'²⁷ By including this reference to internal forms of self-examination – conscious reflections on one's sense of self and mind – Wohlsen also seems to endorse some form of genetic essentialism: The results of a gene test can reveal to you your inner essence, your inner truth more precisely than ever before. Also in a cultural representation like Wohlsen's account of *Biopunk*, self-knowledge and self-reflection seem to be an intrinsic part of the testing process: This, of course, repeats the discourses of self-knowledge so present also in DTC testing, truth about the self wrought from the material body.

Wohlsen, however, does not stop there. Instead, he chooses to end his chapter on a notion that he implies at the beginning: Self-modification, self-enhancement. There is nothing in her experiment that suggests any form of enhancement as the end goal, but still he arrives at that conclusion. A somewhat lengthy quote shows how he connects DIY biology with the ability to "write" genes, thus making biopunk phantasies of enhanced or altered bodies seem in reach:

Perhaps DIY biotech also means a new kind of freedom, where hacking your way to greater understanding of yourself is just the first step. Synthetic biology promises the ability not just to read genes but to write them, like printing out letters on a page in a pattern that creates a picture no one has ever seen before. In biophrophe't's wildest imaginings, hacking human genes could mean making yourself more than human. Then again, inventing ourselves anew is the essence of individualism. Maybe giving ourselves tails or wings or chlorophyll-covered skin is just being human, fully realized, free to make ourselves into whomever or whatever we want to be. Maybe that freedom means we will not have to wait for nature anymore. This may or may not be desirable, but these are the dreams that stoke the biopunk imagination, fueled by *Blade Runner*, radical libertarianism, Newton, Darwin, and a fierce will to power and transcendence. (Wohlsen 16-17, my italics)

In Wohlsen's account it seems like self-enhancement, "making yourself more than human," flows naturally from self-knowledge. In fact, he argues that "inventing ourselves anew" is deeply imbricated in our notions of individualism: The freedom to choose whoever we want to be. Biotechnology, or DIY biology as its most individualistic and open form, could give us the freedom to do so by also altering the material basis of our

27 "Know thyself!" – this maxim of self-knowledge, of course, has a long cultural history: from the Ancient Greek "γνώθι σεαυτόν," transliterated "gnōthi seauton," as one of the Delphic Maxims inscribed in the forecourt of the Temple of Apollon at Delphi to the Latin phrase "nosce te ipsum" and their uses by Franklin, Rousseau or Emerson, to name a few, it has been part of a long legacy of philosophical debate and thinking.

bodies. He does, however, hint at that conclusion, thus preparing the reader, already in the opening lines of the chapter when he references Aull's desire to "grow a tail." This paragraph also shows the close connection between DIY biology and transhumanism, also in the cultural imaginary.

What is even more telling is that this chapter is not the only one that ends with the transhumanist-biohacker's 'dream' of modifying and enhancing the human species. It seems, that what Wohlsen in part wants to convey is that self-modification is the ultimate goal behind biohacking and DIY biology but also behind society more generally. His reference to the cultural ideal of individualism tells us that he does indeed see this fantasy as a result not just of technological innovation but also of the direction American culture is headed more generally. What is more, Wohlsen thus provides us with a perfect example of how DIY biology, medicine or biotechnology is intrinsically connected to ideas of self-enhancement in its practitioners, its representations and cultural discourse more generally: The logical conclusion to all kinds of new knowledge or new technologies seems to be a way to use them to serve our human inclination to make ourselves better than we currently are. DIY biology and medicine, Wohlsen implies, are no exception here.

While this DIY approach and the DTC examples above are two sides of the same coin, a DIY test nonetheless represents a new epistemological approach to how science is conducted, a practice-based, experimental one. To set the test up, according to Wohlsen is also an intellectual and creative challenge. Wohlsen writes, "[Aull] clearly relished the challenge of doing the work at home – for cheap, relying only on her wits and creativity." (11) Aull "challenged herself" to build that test only with the makeshift tools she had (14). Her mind-set is that of a maker and hacker: affordability, ingenuity, creativity, fun. This approach is described by Wohlsen as a *different form of practicing science*: "a more pure kind of science, a curious mind engaged passionately with nature, free of any of the most common ulterior motives" of career, profit or prestige (11). It is an idealist, utopian version of science in contrast to that represented by the looming shadow of MIT, her alma mater down the Charles River. This type of science is portrayed as a return to her origins, the amateur beginnings of all future scientists: "By resurrecting her inner nine-year-old, the girl who cross-bred houseplants while her peers played Nintendo, Aull appeared to be purposely stoking her primal scientific impulse, the driving energy of discovery." (Wohlsen 11) Wohlsen describes Aull as a scientist by nature not just by training. In pursuing her own research, she is returning to her roots, the impulses of curiosity that once drove her to 'discover' science as a hobby and profession. For her, Wohlsen cites, this process is inherently connected to a 'do-er' ethos: it is not just about understanding but about doing it, "poking it with a stick" (11). As a 'purer,' more practical approach, such a DIY set-up is also poised to provide new knowledge, not just about the self but also about how science can be approached as an everyday occurrence.

For Aull her DIY test is a form of demystification: "I think the most important thing about DIYbio is it's something *you can do too*. It's not magic. It's chemistry,' Aull said. 'Doing it in the sink *demystifies the process*.'" (Wohlsen 14-15, my italics) Here Aull does not just perpetuate a mainstay of the DIY movement – that you *can* do it yourself – but also speaks to the broader social relevance of DIY biology as a form of science com-

munication: Turning it from opaque “magic” into a daily occurrence. This process of demystification also shines a light on another distinguishing factor of a DIY set-up that connects back to the question of literacy. When the testing process is controlled and carried out by the tested person themselves the individual has to reach a higher level of literacy where they do not only understand the biological basis but can actually *do* biology. If you manage to genotype yourself chances are high that on the way to get there you picked up enough knowledge to properly contextualize the results. A DIY testing process thus might obliterate the concern that people cannot properly understand the results they get from DTC tests.

What it comes down to, therefore, is scientific literacy, the ability to not just understand but perform biological experiments. This type of literacy or engagement with medicine/biology starts with the collection of biological knowledge from online sources like *Google* – a means to educate oneself that Aull’s father pursued – and reaches into the actual performance of genetic tests. Aull, Wohlsen claims, thinks people are responsible for knowing, for taking advantage of the decades of research and information that are out there for everyone to find (cf. Wohlsen 14). DIY experimentation’s transformative potential could thus also mean a broader public understanding of science. While the hacks he discusses are practical examples of learning-by-doing, in fact Wohlsen’s book can be read as his own attempt at science communication and translation, at increasing the scientific literacy of his reader: He is eager to give explanations or translations of what Aull did, to make the process of testing and its theoretical premises understandable also for a lay audience. To do so, he does not shy away from a scientific explanation of the history, theory and practice of gene splicing, though in a rather unscientific language (apart from specialized key terms). Here, he resorts back to the old and trusted language metaphor of DNA as a ‘genetic alphabet’ and simplifications in the name of comprehension.

However, we also need to acknowledge the potential for stratification inherent in a ‘start-to-finish’ DIY test. In theory, DTC tests are an easy – and today increasingly affordable – version of genetic or molecular ‘experimentation’ that many people can carry out without specialized knowledge. DIY on the other hand, as of now is rather elitist: DIY’s goal of making it accessible for everyone is not yet the case. Some crowd-sourced endeavors and start-ups, however, strive to change that. One example is *Promethease*, a literature retrieval system that uses “SNPedia” – an open-source wiki for human genetics²⁸ – as the foundation for personal DNA reports. If you have your raw genetic data, for example from a DTC testing company, you can use *Promethease* to learn more about your DNA, independent of the company and their interpretation. For \$10 you can get what I would call a ‘second opinion’ on your genetic data in the form of your own, independent DNA report. Both of these tools, in fact, were good DIY alternatives during the time in which *23andMe* was prohibited by the FDA to reveal genetic health information:

28 *SNPedia* is a wiki for human genetics that lists a range of SNPs and the research connected to them (Cariaso and Lennon, SNPedia). Like *Wikipedia*, *SNPedia* works on an open-source basis, so that everyone who has a scientific reference for the information can put in new SNPs. Dolgin claims that *SNPedia* can help people to get more information from their genetic data than the interpretations by the companies (955).

You could just upload your raw data, which of course included that information, and run it through *Promethease* or look up variants on *SNPedia* – if you did not mind the extra work you had to put in yourself. These types of services can provide users of DTC tests with more knowledge on the cheap, thus constituting a middle road between DTC and DIY testing.

To Summarize

As a practice of DIY biology and medicine, testing the molecular make-up of the body is portrayed in cultural representations as a path to new insights into the self and potentially new means to optimize and improve one's health, wellness and life, and this is true for commercial and maker solutions. These tests, their process and insights – the new 'molecularized self' they promise to reveal – become starting points for personal storytelling. In their study of DTC testing, Harris et al. look at *YouTube* videos shot and posted by individuals who did DTC genetic testing for disease: They performed narrative analysis of these videos and found a new form of storytelling they refer to as "autobiology," "the study of, and story about, one's own organism" told on a molecular level – self-making and sensemaking through biological practices. Autobiologies, they argue, are characterized by their playfulness and casual engagement with the technology but also bound up with consumer culture (61-62, 73). The settings of these videos, interestingly, for them become "at-home biological 'laboratories'" – referencing the domestication of biological labor and research so prominent in DIY biology and medicine. However, this playful and fun experience with biology can also have negative sides. Molecular testing, also in the rhetoric used by the companies, participates in and perpetuates discourses of self-knowledge, personal responsibility, and prevention. Gaining molecular knowledge of the body, through testing, is coupled with an obligation to react to the results, to change one's body, one's lifestyle to better alleviate risks and promote health. This responsabilization runs the risk of perpetuating an ableist culture, with a hyper-focus on able bodies, stratified between those who can afford the testing and those who cannot.

Still, the case studies in this chapter have demonstrated that commercialized interventions and hacked solutions are not two opposing ends of a pole. Rather, they can be fruitfully integrated into each other, as the cultural artefacts under analysis have shown: Direct-to-consumer testing is rhetorically and ideologically positioned as a possibility for participation and citizen science, while Wohlsen's account connects a DIY test back to values of individualism and enhancement so prevalent in representations of DTC testing. In the cultural imaginary, such practices are enmeshed, work with and alongside each other. They are different routes to a similar result. Where they stand apart are the levels of biological literacy needed to succeed (with the concomitant possibilities for stratification): Are people in DTC testing settings presented with enough information to set their results into context? Do they have enough (genetic) literacy to do so? When people opt for commercial tests, it is not necessarily a given that they can, for example, interpret the results of a gene test correctly, set the risk ratio they are given

into context.²⁹ Kay Aull's example shows that a DIY test needs a certain degree of scientific literacy or a setting in which a lay individual is provided with both. Community laboratories could provide such spaces.

While a DIY test like Aull's is currently probably not on the road to mainstream, it nonetheless has symbolic potential. Keulartz and van den Belt argue that the test, of course, is not a scientific break-through but that its main premises – reduction of costs for biotech equipment – can have a “transformative impact” on how society deals with science (7). Wohlsen narrative includes a similar claim: The drastic reduction in costs reflects a “change in sensibility.” Aull's test is not a break-through or drastic innovation but “a new way of doing science:” “A practical piece of biotechnology” that though using some of the most sophisticated science of its time was built at home, in a closet, with cheap tools (Wohlsen 15). It is, to relate it to the overall DIY movement, not new but experienced as new, gains a new quality. Wohlsen connects this development to a well-known example all of us have experienced ourselves: Mobile phones. Once they became cheap, they became ubiquitous and changed the expectations of communication and reachability in US culture and world-wide (16). Digital technology transformed culture “not only by what it could do but by how cheaply it could do it” (16). By choosing this example Wohlsen not only makes the processes easier to relate to for the reader, but also acknowledges the cultural force of biotech, especially its democratizing potential. “The power of Aull's project,” Wohlsen writes, “lies not so much in what it can do but in how little it cost” (16). In Wohlsen's narrative the DIY approach becomes a symbol, whose potential, similar to the DIY EpiPencil, lies not so much in the project itself but in what it signifies.

29 Some companies seem to actively embrace their role as translators and mediators of knowledge, including easy-to-understand information on their webpages and offering free consultation services for their customers. *23andMe*, for example, has a whole section on their webpage dedicated to their literacy efforts where they try to familiarize people with the concepts, terms and ideas behind the genetic information we use in our daily lives, cf. also *23andMe* (“Education”).

