

11 Discussing DIY

“As biohackers it is our responsibility to act as emissaries of science, creating new scientists out of everyone we meet.” (*Patterson n.p.*)

Through hacking, making and tinkering, DIY biologists have necessarily become political actors – as Meredith Patterson writes in her *Biopunk Manifesto* (n.p.).¹ Their practices draw on and question larger sociocultural concerns, make political claims and perpetuate ideologies of power, participation and division. Some DIY techniques create deep uncertainties about how individual bodies should and can be managed, about their social implications, about problematic consequences for the personal and public spheres of life. From a feminist technoscience view, the individualist rhetoric of ‘do-it-yourself’ might distort how these practices are part of hierarchies, systems of power and ideologies, that they are not just individual concerns but deeply political – to follow Pitts, they create privileges and constraints, shape the access to and control of biotechnologies, are embedded in political and social contexts and systems of power (cf. 160). In a similar way that numbers in the Quantified Self movement are not neutral but embedded in social dynamics and power relations, DIY activities are political in that they can also be “constructive of subjects, identities and communities” (Lupton, *Quantified Self* 96). As cultural phenomenon and socio-political activism DIY biology creates spaces and possibilities for wider public dialogue about biotechnology and biology, their technologies as well as their broader implications for individuals and society (Stevens 355).

In his expansive analysis of biohacking, Alessandro Delfanti summarizes the discourses that have been spun around DIY biology as follows:

DIY biology has been described in terms of open and peer knowledge production, a danger to public health, a co-optation phenomenon, a democratic (or apocalyptic) change in the relationship between experts and non-experts, an ethical dilemma and an experiment in public engagement with science. (*Biohackers* 113)

1 This *Biopunk Manifesto* was presented as a speech for a symposium titled “Outlaw Biology? Public Participation in the Age of Big Bio” at the UCLA Center for Society and Genetics in January 2010. Patterson subsequently posted the text on her personal blog. I will use quotes from this political statement to open my reflections in this chapter.

While this list is certainly not all-encompassing, all of these descriptions are visible also in my case studies: DIY is variously a vehicle for knowledge production and dissemination, a danger to personal and public safety, a form of commercialization, an impetus for change and transformation, and a type of self-directed engagement with science and biology. These different configurations are owed to the diversity of practices, approaches, methods in DIY biology and medicine that is reflected in their representations in popular culture. This chapter aims to take a step back from this diversity and arrive at some of the broader consequences of and contested issues around DIY biology and medicine that point to its political, social, cultural and material effects. By doing so, it connects back to the theoretical discussions in the beginning as well as the cultural context of DIY. Here, we also come to some of the core questions of the humanities – power, discrimination, class, justice, embodiment, agency. In this reflection I want to move across scales – from the individual to the collective and institutional, from the molecular to the structural and systematic.

On the basis of the case studies, I delineated concerns and public discussions that weave themselves through the narratives and should be part of a critical assessment of DIY biology and medicine's culture: a deep concern with questions of access, literacy and democratization (11.1); a trend towards commercialization and possible exploitation of its promises (11.2); concern about the security and safety of DIY techniques on a personal as well as public level (11.2); a shift in power relations and expertise (11.3); new forms of vulnerability and uncertainty (11.3); a belief in individualist solutions that undermine community principles and create new forms of differentiation but (conversely) also a tendency towards collaboration, sharing and community-formation (11.4). While not all of these areas of problematization are relevant for all DIY techniques discussed in Part III, many do share them to differing degrees. These concerns are also the scaffolding for the four parts of this discussion.² They are fleshed out with questions for further debate: What is DIY biology and medicine's potential for social change? How can DIY shape access to equipment, knowledge, power? How will the increasing consumerization of modern society affect DIY? What are the effects of DIY on the definitions of lay people and experts? Can individualism and collectivity be brought into a fruitful combination? Because DIY biology and medicine is an emergent phenomenon, none of the questions can today be answered with certainty: Rather, we need to raise them and keep them in mind to assess future developments and shape discussions.

11.1 “Power to the People” – Access and Participation, Literacy and Democracy

“Scientific literacy is necessary for a functioning society in the modern age. Scientific literacy is not science education. A person educated in science can understand science; a scientifically literate person can *do* science.” (*Patterson n.p.*)

2 The division into thematic complexes that I have arrived at might seem artificial because there is definite overlap between the different parts. I have, however, tried to set these concerns into dialogue with each other to map out some of the main problematizations.

Is or can DIY biology and medicine be a political movement? As the case studies in the previous section have shown, all of the buzzwords in the subtitle – participation, access, literacy, democracy – are in one way or another part of the discourses and practices around different DIY techniques in biology and medicine. They are either part of their ideological scaffoldings (participation, access) or an important outcome (literacy, democracy). The goals of widespread scientific literacy, of greater citizen involvement in bioscience, of more equality in the production and use of biological knowledge and tools, is one that points to the deep political roots of this discussion. But is this ‘DIY democracy’ more than a rhetorical configuration or promissory narrative?

We increasingly rely on practical applications of science and technology for the management of our everyday life. Scientific solutions to *everyday problems*, also of the body and self, tantalize us with their claims of truth value, neutrality, objectivity, rigorous testing and experimentation. Scientific knowledge is perceived as “better than other forms of knowledge” because it is “external, neutral and separate from society,” a means of accessing “truth” (Erickson 216). Scientism gives science, medicine and technology privileged access and authority over the body. DIY biology and medicine can be considered as one expression of this scientism in contemporary culture. Science, as the case studies have shown, is the backbone of the hacking of biological materials, a prerequisite to engage with one’s own biology and that of one’s environment. DIY, it seems, is positioned as a way for every individual to not only rely on science, have one’s life shaped by science, but to actively engage with it. However, science itself, its modes and spaces of knowledge production are also often perceived as elite, separate from day-to-day life – it is this perceived demarcation that makes it indispensable to tear down barriers, both real and imagined.

Knowledge as a Publicly-Owned Good

DIY biology draws on scientism and science’s authority, but it also – crucially – questions this core assertion that ‘science’ can only be practiced by people with specialized training in specialized rooms and environments. Traditionally, research in universities and industry laboratories requires college education, credentials, and long, rigorous training, thus essentially excluding large portions of society from partaking in it. In contrast, DIY biology claims that science can be done by everyone, to differing degrees, that engagement with science is a necessity, even a fundamental right in a technoscientific society. To do so, of course, people need to be granted or rather *claim* access. Affordable equipment, like the *OpenPCR* machine or *Bento* lab, allows DIY biology groups to conduct outreach programs that provide the lay public with hands-on training and education. Access literally and figuratively ‘opens’ the doors of science for a broader public and enables them to participate. As the case studies have shown, this participation in DIY biology and medicine can take different forms: from partaking in discussions around the use of biotechnologies online or in person to the actual use of them. The important part is that more people are enabled to understand and use the tools of science. DIY biology, also for Kay Aull, is a way to democratize science and give people access to their own biology “in the most direct way possible” (Wolinsky 684). This

access, we have seen, is framed as both ideological and spatial: Access to information and knowledge as well as access to tools, resources and infrastructure.

With the notion of ‘access’ we are also entering a territory that can be regarded as inherently American, as it draws on fundamental values of equality and self-sufficiency, the ideal of liberty. If we take the Civil Rights Movement, Feminist activism or the Disability Rights Movement as examples, similar questions of access have been widely debated in American culture for the last century: access to rights, access to places, access to privileges, on an abstract level, have inflected these debates as well.³ In these movements, disenfranchised parts of the population struggle(d) for social participation, political representation and shifting scales of power. Similarly, the type of access and participation facilitated by DIY biology can also, following Meyer, be regarded as a form of “counter-power” in the hands of citizens that allows them to shape the use of biomedical technologies (Delfanti, *Biohackers* 125; Meyer, “Build”). In the struggle over access and power, DIY biology and medicine, thus is part of a historical continuity of political movements.

But we can also take this idea of access further and critically question if access in this case can and should be granted to everyone. This is not just a moral or ideological but also a practical question: Should everyone be able to fiddle with biological materials and what would be the consequences? Is the DIY approach even aiming at access for all? Are not the complexity and costs naturally disenfranchising some? I am thinking, for example, about people with (learning) disabilities, those with lower incomes or underprivileged class backgrounds, less schooling or access to education, questions of differentiation I will come to later. The current make-up of the DIYbio movement – people with high levels of education, often white, middle-class (men) with enough disposable income (cf. Jen 127) – is a case in point. What the discussion of access, in its essence, goes back to are questions of authority that as of today are deeply discriminatory: Who has the right to use or ‘do’ science? Are there conditions for doing science? Who should be involved in the discussions around the use of science? Who has and who should have the authority to decide? Christopher Kelty argues that much of the anxiety around “outlaw biology” or DIY biology hinges on the demarcations of who a ‘real’ scientist is, who gets to practice science, who is allowed to tinker, and who regulates scientific activity. The main struggle, for him, is one of *legitimacy*: Who gets to decide the future of biology? What counts as knowledge? Who can create knowledge? (3) Citing widely-known biohacker Rob Carlson, journalist Sigal Samuel includes this question of legitimacy into his article: Calling its practitioners “hackers,” for Carlson, is a way of delegitimizing them, categorizing them as Other. For Samuel, this is “actually a bigger societal question: Who’s qualified to do anything?” (“How Biohackers” n.p.).

3 Think, for example, about access to education (thus knowledge) for women and people of color, voting rights and equal access to desegregated spaces, physical access and accommodations for people with disabilities. All these hinge on the question of whether or not disenfranchised populations are allowed – by the majority – to participate equally in public life and to gain access to spaces previously closed from their view. In DIY biology the majority is disenfranchised from participation and access, while a small minority of people (those in science industries) have the privileges the former claim for themselves.

DIY biologists would argue for a “popular ownership” (Steinberg 54) of techniques and knowledge. While Deborah Steinberg uses the phrase “popular ownership” only in passing, I want to elaborate a bit more on this idea because I think it is very much applicable here: Popular ownership of knowledge in my understanding means that this knowledge is in the hands of the general public not experts or specialists – that everyone has the *right* to have access to that knowledge. Knowledge becomes a public property, with all the rights and responsibilities that come along with that.⁴ “Popularly” or publicly owned knowledge is not restricted to experts, and more so, its use is not restricted to experts. This popular ownership is necessary because it allows a broader public to engage in the discussions also around the practical application of biological knowledge: As Henk ten Have argues, before knowledge is applied goals need to be identified, benefits and harms balanced, and norms and values that need to be respected should be delineated (295). This is a process that needs to be public and held among a diverse group because most biological applications today might have broader consequences for human life and embodiment, the social fabric and solidarity. Thus, as publicly-owned goods the tools, technologies and knowledge of science are reframed as a concern for all of us. They should therefore not be proprietary or locked away but visible, usable, debatable. Science and its applications are turned into a public good, something that has to be discussed in the public sphere. But they also seem to promise a form of utopia that as of now seems far from reach. Does DIY really increase participation on such a large scale?

Despite some promising beginnings, this question, as of today, cannot be answered with certainty. Rather, the polarization of public discourse visible at the current moment in time – the debates around ‘fake news,’ the opinion making and targeted manipulations, conspiracy theories and mistrust of scientific advice – should raise the question whether broad-scale access would be used, also by anti-experts, for fraudulent manipulation or exploitation, whether the legitimacy and standards of science would be disfigured beyond recognition. Can openness and access foster trust in science, or will they contribute to more skepticism? Boyd argues that when scientific discoveries and debates play out in the spotlight, they demonstrate the fallibility of the scientific process, visible for example during the Covid-19 pandemic or in climate change research. The realization that an “institution” previously believed to deliver facts and certainty is uncertain itself, debates findings and revokes theories, might impact the public’s trust in this institution. However, Boyd’s argument relies heavily on (paternalistic) distinctions between experts and non-experts that risk increasing skepticism of science. Access to similar information, he argues, risks making individuals feel “as though they ought to be participants in dialogue as opposed to mere recipients of imperatives” (12). I would claim that especially in times of biological crises such a dialogical form of communication might be better suited to foster trust: Making people feel heard and acknowledged and making the scientific process transparent and accessible – as is the goal of DIY

4 The idea of property of course is also ambiguous because today biological materials or biological knowledge can actually be the ‘property’ of companies through patenting. This, of course, contradicts my conception of biological knowledge as a public property and is something I see deeply critical.

biology groups. Still, what this assumption hinges on is the willingness of people to take part, their interest and concern: A generalized rejection of scientific findings will most likely not be overcome by simply opening the doors of science. That would require collaborative efforts across all sectors of society and institutionalized possibilities for dialogue and exchange.

What we can discern, however, is the inherent *potential* of this shift towards access and participation. The dominant principles and ideologies of openness, access, and creativity turn DIY into a new form of generating knowledge based on make-shift solutions, creativity, tinkering, fun, trial and error and characterized by hands-on, active and engaged education. What is created is an “open, bottom-up, collaborative model” (C. Anderson 78). Even though his argument, of course, is much broader, some of J. Dewey’s insights into political inquiry (1927) can prompt a further discussion here. According to Dewey questions of common concern should in a democracy be deliberated on by exactly such a process of experimentation and exploratory action: a creative, imaginative, collective approach to “knowledge-making” that for him is “intrinsic” to political action, with the potential to break with old, problematic orders in favor of “unforeseen possibilities” (cited by Delgado and Callen 181). Following this line of thinking, DIY biology and medicine, through their transformation of how knowledge is created and by whom, also open up new potentials for political action and social transformation. They can break not just with the established order of scientific inquiry but potentially create even wider shifts in how subjects understand themselves as political actors. DIY biology and medicine can create a new way of approaching science, not as something apart from your own experience but as potentially an integral – and recognized as such – part of your daily life.⁵ In this “epistemology of participation” (Delfanti, “Users and Peers” 3) science becomes something that *you can do yourself*, in whatever way you want to: on your own body, in citizen science projects, through experimentation or creative engagement with biological materials. This new epistemological approach can be transformative on many levels. For one, it can change how science is practiced: The generation of knowledge still takes place with standard scientific tools and protocols but on a more personal scale or together with new actors. It can also create new types of knowledge, for example by using the potential of the much-cited ‘crowd,’ the wisdom of the many, to find new solutions and new approaches to problems.⁶ In this shift from individualist, reclusive research enterprises to collaborative and open efforts new, creative ways might be found to address some of the most pressing questions of today, such as cures for human diseases, climate change or species diversity. Most fundamentally, however, it can

5 As I have written above, of course science is an integral part of our everyday lives – be it in the news reports we read, the medical decision we make or simply the technologies we use. Its influence, however, often does not seem to be recognized as substantial. DIY techniques have the potential to much more deeply embed not just the end-products of scientific innovation but also the process of their construction into everyday activities.

6 Crowd-sourced knowledge production has made its way into popular culture as well: Based on her column for the *New York Times*, in the *Netflix* show *Diagnosis Dr. Lisa Sanders* uses the ‘wisdom of the many’ to find diagnoses for mysterious and rare medical conditions. After publishing patient stories in her column, she asks readers from around the world to contribute their own experiences – be it healthcare professionals, researchers or patients with similar symptoms.

transform who is involved in these practices by shifting the site of scientific innovation from elitist institutions to a much broader base.

“It’s Not Magic”

What is needed as a first step for this broader base to make use of the new-found means of participation and knowledge creation is a more detailed understanding of biology and science. Here, DIY biology and medicine, once more, comes into play as a form of translation, mediation and demystification. Meyer argues that with DIY biology the laboratory can “potentially become a place of ‘cultural translation’ between amateurs and professionals” (*Domesticating* 4). In DIY biology and medicine knowledge is communicated to a broader base of people in a language that also lay people understand. The question is how and where should such translation ideally take place? If access to biological knowledge is necessary for political participation, does the state or society have an obligation to facilitate these types of translation practices by, for example, making them part of school curricula? According to Delfanti, educational and social goals are very important for DIY biologists, as can be seen in the “increasing inclusion of DIYbio practices in museum exhibitions, science education projects, and outreach activities for young people” (“Do-It-Yourself” n.p.).

As many of the DIY techniques in the case studies have shown, engaging with your own biology is also a form of demystification: abstract ideas and concepts become concrete, tangible and personal. For example, the *NightScout Project* and the *OpenAPS* require people with T1D to actively engage with not just their diabetes – and the molecular workings of the body in response to low or high blood sugars – but also with the technology they routinely use to monitor their bodies. It is a fundamentally personal project. Similarly, (DTC) genetic or molecular testing ideally requires individuals to become more familiar with the concept of DNA as inherently personal information and the molecular pathways and interactions they are testing for. As such, DIY biology and medicine can become a means of familiarization with science and biology more generally and one’s own biological make-up more specifically. This demystification means that science no longer is imagined as a closed off, magical, mysterious, untouchable realm. Instead, biology, according to Delgado and Callen, is reimagined as “mundane,” no longer holy or exclusive but an inherent part of being human (184). “It’s not magic. It’s chemistry,” as Wohlsen quotes Kay Aull (14-15).

DIY biology and medicine can thus, as an overarching goal, contribute to a higher scientific and biological literacy. Literacy comes up again and again, in academic discussions as well as in the discourses around DIY biology: scientific literacy, data literacy, biological literacy, and technical literacy are evoked to describe citizen’s ability to understand, evaluate and partake in the discussions around techno-scientific innovations. Knowledge and education, it seems, are positioned as some of the most basic things needed to become responsible actors and political subjects. In the last lines of Wohlsen’s *Biopunk*, he arrives at literacy as an important result of biohacking practices as well:

The opening of science, if done well and communicated effectively, brings the possibility of a flourishing of scientific literacy. At the very least, the capacity to inhabit a scientific frame of mind – to weigh facts dispassionately, to test hypotheses, to defer to data – will become crucial for all of us as the scientific knowledge proliferating at our fingertips shapes every aspect of our world. (218)

Likewise, Meredith Patterson, in the introductory quote for this section, includes literacy as a prerequisite for participation in her *Biopunk Manifesto* (2010). Literacy, for her, is not just the ability to understand but also to *practice* science, an ability that will “empower” people to become “active contributors” in “their very interactions with their own bodies and the complex world around them” (n.p.). It is interesting that she chose to start her biopunk manifesto with a reference to scientific literacy. It shows how also members of the DIY community position DIY biology as contributing a great deal to a more wide-spread scientific/biological literacy but also how intrinsically some people in the DIYbio community connect access to knowledge and social participation. Being ‘literate’ allows citizens to *actively* shape their bodies and surroundings.

Literacy is not just needed to make sense of the many different data about the body and private life collected today, but it is also needed to become engaged in molecular discourses of the body. On a personal level, literacy also goes hand in hand with considerations of informed choice – a topic widely debated in relation to healthcare: To be able to consent to medical procedures individuals would ideally require substantial knowledge of risks, side-effects, other treatment options as much as the procedure itself and its biological basis. Only if you understand what is done, you can give true informed consent to procedures or tests. Literacy, thus, should be a prerequisite for (medical) decision making, for example, in genetic testing. However, whether or not a consumer is truly enabled to understand the complexity, scope and short-comings remains relatively irrelevant for the testing process by DTC companies.

Literacy, moreover, is also a political question: As Patterson maintained, you need literacy for participation. Biological and technological processes can only be shaped once they are understood, which is especially important in societies that rely on medicine, biology, technology as much and as hopefully as Western societies do. Because these processes rooted in biology do not only have personal but also social consequences – new differentiations or valuations of life for example – access to resources and literacy to use them can shape social and political developments. For example, DIY’s aim of participation and access questions the existence of a two-class society made up of those actors that possess knowledge and can thus determine (their own) fate and those that are disenfranchised from knowledge and thus cannot question decisions and practices. Increasing the literacy of the “public” is also seen as a means to redress the “democratic deficit,” as Rose and Novas write, that exists when citizens cannot actively engage with and shape the future uses of scientific and technological innovations. Education strategies, thus, for them become a tool for the creation of “biological citizens” (Rose and Novas 445-46).

Performing Citizenship

If we follow Rose, Novas and other scholars in their arguments, “citizenship” today is increasingly defined not just in somatic terms but also in a person’s ability to participate in cultural discourses around the uses of bio-technologies. Levina, for example, in her discussion of network subjectivity in the control society – in the context of genetic testing – argues that (bio-)citizenship can also be enacted through participation in the network, by for example feeding it with new information (5). Williams uses the term “technocitizenship” to denote the “right and responsibility” of individuals to be informed about technological developments and take part in their governance and regulation (16). Citizenship, we can see here, is framed in biological and technological terms, which connects debates around the different uses of technologies to inherently political questions.

One of the most cited examples of these new types of “citizenship” is Nikolas Rose’s and Carlos Novas’ use of “biological citizenship.” Happe et. al., in a 2018 edited collection on “biocitizenship,” write that “biological citizenship” in its essence refers to how political initiatives, bottom-up and top-down ones, as well as technological developments have created “new ways in which bodies shape— and are shaped by— ideas of citizenship” (Happe et al. 1). Biocitizenship, for them, is today redefined as a “broad mode of political action” that is somehow “linked to health, bodies, and life” (Happe et al. 1-2). This definition certainly owes a lot to Rose and Novas’ seminal work in the terrain. Rose and Novas further subdivide their understanding of biological citizenship into “informational bio-citizenship” – the necessity to possess specialized and medical knowledge about one’s condition – “rights bio-citizenship” – involving forms of political activism and campaigning – and “digital bio-citizenship” – those forms of citizenship taking place primarily in the digital sphere (442). These different types of bio-citizenship, I would argue, are also “performed” or “enacted” (Ratto and Boler 3) in the DIY techniques under discussion in my case studies. Inherently physical, material, biological they are concerned with the governance of individual bodies as much as of science and society more generally. DIYers become “bio-citizens,” in Rose and Novas’ use, through self-education and the integration of specialized medical, biological and technological knowledge into their everyday lives; through political activism for openness, access, participation and a more just global distribution of scientific resources and technologies; and the creation of new communities, online and offline, around a common interest in biological materials and bodies. DIY biology, Morgan Meyer writes, creates a “distinct and political form of self” that is actively engaging with their own biological materiality and “making their bodies and ailments more knowable” (“Hacking Life?”) – exactly the type of responsible, involved, self-caring and self-managing self that is required for scientific and biological citizenship.

Through DIY practices, therefore, citizenship is performed. Ratto and Boler look at DIY activities more generally as creating a type of “DIY citizenship:”⁷ DIY activities,

7 John Hartley, in his *Uses of Television*, also uses the expression “DIY citizenship” but for him this type of citizenship is tied to identity formation, in which the DIY citizen has more opportunities to amalgamate an identity and individuality from the available choices. Hartley argues for a flux of

they argue, are political in that they “challenge existing systems [and hierarchies] of authority” and the status quo (5). “DIY citizenship” is used by them as an umbrella term for all sorts of practices that create new “possibilities of political participation” (7). Citizenship is no longer enacted only through what they call “standard political activities” such as voting, advocating or protesting, but has become more “diverse, participatory” and to some degree unexpected, in its locations as much as its practices (7). The maker movement, citizen science and DIY biology can certainly be considered as examples of such participatory and diverse performances of citizenship. Through their materiality they provide “new modes and possibilities for political and social engagement” (Ratto and Boler 16-18). This type of DIY citizenship, similar to Rose’s insistence on biocitizenship’s active nature, is focused on physical doing, on intervention, making, hacking and tinkering (Ratto and Boler 19). But DIY citizenship also continuously has to balance different interests and tensions: “between consumers and citizens, between experts and novices, between individuals and communities, and between politics as performed by governments and politics and DIY grassroots democracy” (Ratto and Boler 5). These tensions are also visible in the case studies in my discussion: the high involvement of lay persons challenges the authority of experts; new bottom-up transformations, as for example the “EpiPencil” or “Circadia” implant, stand in marked contrast to discourses of regulation and control; and DIY is both an act of consumption and a form of creative, political intervention.

However, “citizenship” of course is not immune to critique: According to Ratto and Boler, it is also a contested and loaded term that has often been related to forms of inclusion, exclusion and violence – a differentiation and differential treatment of those who are perceived as belonging, parts of the group of citizens (of a nation) versus those who are denied this right (8). Similarly, we can speculate whether or not DIY as a form of enactment of citizenship despite its promise of inclusion and demolition of boundaries might in reality create new types of differentiation and belonging – those ‘enlightened,’ enabled, active, literate, and responsible citizens versus those who are left out of these transformations (cf. 11.4). Happe et.al. also engage with this problematic nature of (bio)citizenship when they lament that scholarship on the topic often overlooks social inequalities (of race, class, gender, disability) and threatens to abandon collective engagement for individualized consumption (7-8).⁸ Biocitizenship, for them, is problematic because it is based on a “model biocitizen,” who is rational, autonomous, healthy, able-bodied, and privileged, in terms of class and socioeconomic background (6). Tied in with the prevalent market rationality, this ability to care for the self, provide for one’s own needs, makes the biocitizen a “quintessentially neoliberal subject” (Happe et al. 7). Instead of liberation from the decried status quo, DIY as (bio)citizenship might

identity and possibilities to change an identity. According to Ratto and Boler, on the other hand, his conception is very much rooted in Western ideas of self and privileges individualism and individual choice over structural factors (11-12).

- 8 Ruha Benjamin, for example, writes that scholarship on (bio)citizenship often looks at “a more elite strata of people who have the resources and influence to organize around their shared interests” and that “empowerment” is here primarily the ability to consume (17, cited by Happe et al. 7-8).

thus further embed its practitioners in the ideologies they want to abolish, which potentially is visible already in the high prevalence of discourses of optimization and the latent consumerism.⁹ DIY citizenship thus might go hand in hand with problematic responsabilizations of the self instead of a focus on community and might facilitate a new type of coercion to make the self ‘fit’ for the demands of the market. These problematic connotations are not fixed but should rather inflect popular discussions of DIY biology and medicine.

Promising Democracy

Tied to the idea of citizenship, of course, is also the democratizing potential often ascribed to biohacking or DIY activities more generally. DIY can serve as a “democratizing agency,” to borrow Atkinson’s term (1), by leveling playing fields and allowing access for all. Like access, democracy of course is also a fundamentally American theme: Power and sovereignty, the American ideal goes, belongs with the people: “government of the people, by the people, for the people” as Abraham Lincoln famously declared in his Gettysburg Address. Morgan Meyer writes that do-it-yourself biology “is often praised for the potential it holds for democratizing science, ... for the empowerment of ordinary people” (*Domesticating* 2). This democratization, according to him, takes place spatially through domestication, community labs and, I would claim, an ensuing new definition of what a laboratory is or can be; technically, by redesigning technical equipment and creating more accessible alternatives; socially through its openness for everyone; and economically through decreasing costs for equipment (Meyer, “Hacking”). Paul Atkinson reasoned that DIY practices (in general) can work as democratizing agents by providing independence and self-reliance, freeing from professional interferences, allowing individuals to create “more personal meaning in their own environments or self-identity” and opening up boundaries thus granting access to all (5-6). Similar tendencies are observable in DIY biology and medicine: They exert their democratizing potential by creating cheaper, more economic solutions, freeing individuals from medical and professional supervision, fostering self-reliance and independence in research and application, and allowing people to engage more personally and meaningfully with their biological surroundings.

Christopher Kelty argues that biohacking as “new ways of science-making” and engagement with knowledge and tools changes not only science but also our conception of “the public.” In DIY techniques, being part of the public is not passive but “aggressively active” (8). The Habermasian model of a liberal democracy needs “public spheres” in which citizens can discuss and debate matters of public interest (cf. Habermas referenced by Ratto and Boler 12-13).¹⁰ I would claim that community labs, online groups and

9 The discourse of optimization, I want to point out, is used also by biohackers themselves, as the case studies have demonstrated. In fact, some scholars argue that this discourse is quintessential for ‘American’ DIY biology (cf. 11.2).

10 A well-known critique of the Habermasian model comes from Nancy Fraser. She focuses on actual power relations, inclusions, exclusions, and systematic inequalities, the implicit gendering (through Habermas’s strict division between public and private, excluding women from public participation) and the “problematic processes of consensus building,” in Ratto and Bolers’ words,

discussion boards become such “public spheres” in which DIY citizens can deliberate on issues of common concern; but more than that, they become public spheres of activity – of doing, making, tinkering, physical production as much as theoretical deliberation. Though secluded, mystical, outlaw, DIY biology and medicine becomes an inherently public activity in which practitioners affirm their status as biocitizens. The idealized type of ‘DIY democracy’ espoused by DIY biology and medicine, I would argue, is characterized by equality, bottom-up processes of participation, diversity and a multiplicity of voices – a poststructuralist liberation from constraints (biological, social, cultural) and a challenge to established institutions. In this democracy, the self becomes more active in the configuration of all aspects of their life, including their biological foundation. This ideal of DIY citizenship and DIY democracy as an overarching concern of DIY biology and medicine points to the political nature of DIY itself, one that often goes back to questions of *power*, or rather, the subversion of existing structures of power in favor of new ones.

But critical voices need to be heard, as well: Delfanti for example questions whether the opening of physical spaces, the increase in ways of participation, the challenge to mainstream science and the claims of access and democratization truly “consist of a real shift towards democratizing science” (*Biohackers* 120): Do they really change the power structures or only point out their problematic nature? Is, as Clare Jen writes, much of the “democratization project” of bio-making only “discursively produced” (127)? And if so, how much of that discursive production is done deliberately by DIYers and the media? How much democratization is realistic and how much only promissory? While this question is impossible to answer with certainty, it nonetheless points to the hype, the expectations and promises that these discourses of participation, access, and democracy carry with them.

11.2 Can We Buy Safety? – Between Consumerism and Security Concerns

“We reject the popular perception that science is only done in million-dollar university, government, or corporate labs; we assert that the right of freedom of inquiry, to do research and pursue understanding under one’s own direction, is as fundamental a right as that of free speech or freedom of religion.” (*Patterson n.p.*)

With its rise as a hobby in the 1950s and 1960s, DIY and making have also led to new economic possibilities for its practitioners, enthusiasts and service providers. Especially since *hacking* and *making* have entered the mainstream of society in the 1990s and through the maker movement in the 21st century, they have also become embedded in entrepreneurial activities. Selling tools, kits and resources, expertise and advice, access and knowledge have become part of the maker movement. As we can see in the case studies, efforts are underway to commercialize tools and materials and some techniques are already shaped by consumerism. Today, DIY biology, following other forms

required by the Habermasian model (12-13). I would claim that at least one aspect, the problematic division between public and private, is all but erased through the domestication of biology, but still some of the gendered concerns remain.

of DIY, straddles an ambiguous position between consumerism and anti-consumerist activity. I would project that the incorporation into consumerism – the commercialization of DIY approaches and the exploitation of DIY principles for economic gain – is only in its beginnings and can be seen as one of the potentially more controversial aspects of DIY biology and medicine. Similarly, if we look at public discussions around and media representations of DIY biology, commercialized or not, concerns about their safety and security, for individuals and society as a whole, are often central features of the narratives, whether or not such doubts are even warranted.

Commercialization and safety, it seems, are both particularly – but not exclusively – American concerns. Questions of (bio)security are to some degree rooted in American culture, especially American experiences in the 21st century. I am here, of course, referencing 9/11, the anthrax attacks a week later and the ensuing war on (bio)terror. The rhetoric of constant, globalized threats to the safety and welfare of the nation and its people that was wielded in the aftermath of the terrorist attacks, have shaped contemporary American consciousness and have been applied to more and more domains with the increasing globalization and interconnection of the world – including biological materials.¹¹ Concerns about DIY biology and medicine as a potential danger to the whole of the nation, Morgan Meyer writes, are more often voiced in the US (“Hacking” n.p.). Commercialization is a theme that is typical for ‘American’ biohacking as well: Especially in the United States the development of DIY biology and medicine during the past years has been mirrored by a rise in start-ups and other companies offering DIY services or DIY tools.¹² References to such companies are frequent. Their founders are interviewed for media coverage or journalistic representations; they are highly present in the online DIY community and they are referenced in many of the guide books on DIY biology. Keulartz and van den Belt claim that in America there is a higher inclination to use DIY biology as a “launchpad” for start-ups than in Europe because the US model is closer aligned to entrepreneurship, market rationales and personal enhancement (3-5,16). We could maintain that this is due to the entrepreneurial nature of American culture and society, in which entrepreneurial spirit is closely connected to values of self-sufficiency, autonomy and the “good life” (cf. also Ch. 4.1). In the US, DIY culture is part of a start-up culture and vice versa.

In this chapter I first want to discuss these topics separately – weighing their positive and negative sides as well as their potential – before creating a bridge between the spheres: On the first glance unrelated, commercialization and security can work together to spread and solidify the ideological basis of DIY biology. Even though DIY is often positioned in clear opposition to institutional science and Big Bio, this distinction does not hold up. Rather, this movement, this counterculture, has grown in symbiosis

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- 11 Braun's argument, for example, merges biopolitics and geopolitics in the name of biosecurity, by looking at our (molecular) bodies as situated in a „chaotic and unpredictable molecular world” characterized by “exchange and circulation” and “haunted by the spectre of newly emerging or still unspecifiable risks” (14). Melinda Cooper considers the new preoccupation with bioterrorism/biosecurity in US foreign policy after 9/11, in a biological world full of cross-border movements.
- 12 Morgan Meyer, for example, writes that DIY biology today experiences a slow rise in market logics and that companies have begun to form around the needs and demands of the community (*Domesticating* 14).

with the ‘big players’ – with potentially transformative effects for systems of knowledge production in the whole industry. Similarly, as agents of familiarization commercial alternatives integrate unruly and unregulated practices in well-established systems and orders that could be exactly what is needed for the movement to gain momentum and become more ‘mainstream,’ thus moving closer to the ideology of access for all.

The Ups and Downs of Commercialization

Commercialization does provide a clear advantage for DIY biology and medicine, which should not be understated or underestimated: It makes DIY approaches more visible in the public, makes them more accessible to more people and lowers the hurdles of participation. Commercialization can grant new access to knowledge and tools, for example through easy-to-use DIY kits. Instead of having to set up a laboratory at home or finding one of the few in one’s community individuals can purchase such kits or technologies and have all the tools they need to conduct a specific experiment. Through commercialization people can much more easily engage with biology or their own bodies. Consumerism can make DIY even more available, accessible and productive, which would turn it into a key building block for DIY biology’s promise of democratization. Jonathan Bean and Daniela Rosner distinguish between making as a (social) movement and making as a brand. Movements, for them, are social groups focused on a desired (social) change and “creative empowerment” from the bottom up (26-27). Branding’s aim on the other hand is commodification and the attachment of meaning through a top-down approach (26). In the case of making branding, for example, tries to sell making as a mindset, provides possibilities for economic expansion and creates new potential customers for tools, magazines, and other resources (27). Bean and Rosner argue that making has become a good brand, one that sells, one that provides meaning for customers/makers, and one with transformative potential in that it could lead to an ideological shift in which “consummakers” can change the world through production (27). DIY biology and medicine, in this line of thinking, can therefore be both (social) movement and (commercial) brand.

However, this type of branding through commercialization – though successful – could also transform making and DIY from an egalitarian and open movement into a product dominated by the market. In neoliberal societies, consumption is a “technique of the self” (Foucault), a means to perform and signal a certain identity. DIY has become such a “technique of the self” as well. To remain competitive, work on the self is mandatory and this work today is often done in the form of DIY interventions and practices, from fitness tracking to genetic testing or biological experimentation with one’s own body. Through consumption, especially of goods that promise to alter, manipulate or monitor the body, we can ascertain choice in a very direct way – by individually choosing services and goods that we, as consumers, deem necessary and beneficial to our individualized life projects and identity performances. According to Rose, markets and consumerism are also perceived as means of personalization because they (seemingly) increase the power of individuals and allow them to choose desired services, goods, or providers (“Personalized Medicine” 341). But as Rose also contends, this choice might only be superficial: The increasing responsabilization of individuals for their own well-

being and physical health creates not just a market of promises, but also a “market in anxiety” (Chrysanthou 476). Consumption becomes not a choice but a requirement if one wants to partake in the former and avoid the latter. These markets, moreover, are brimming with professionals seeking to make a profit. As some of the case studies have shown, commercialization also leads to the creation of new “experts of the soma” and “economies of vitality” (Rose, *Politics of Life* 6-7, cf. Case Study I). DIY biology gives rise to a new class of professionals dedicated to performing and furthering it. Consultants, teachers, coaches might fill the void left by the shift away from older figures of expertise (such as doctors). Through this ‘side effect’ of commercialization, new economies arise around the individualized concern with the human body, with new means of generating (bio)value.

Conversely, commercialization might also do away with many of the transformative principles of DIY, create new (financial) barriers to access, restrict its openness and hacker ethos. In typical commercialized settings such as the wearable technology industry proprietary software and platforms restrict access to your own information as well as the possible uses and ‘tinkerability’ of the tools. Openness is taken over by profit as a goal. Many of those prototypical commercialized applications of DIY medicine and biology, such as genetic and molecular testing, can also be considered as a form of free labor, the “donation” of work, free time, creativity, data and bodies to the enterprises of businesses, research bodies and start-ups in the name of openness, sharing and distributed innovation (Delgado 72). Such practices of sharing, of course, open questions of data security and privacy, how data are (mis)used, stored and sold. Could they be used by states and other actors for biopolitical strategies and coercive practices? In commercial settings self-gathered data, for example in self-tracking practices or genetic testing, are in the hands of companies and could be misused without the user’s (informed and explicit) consent. Especially in contributory and co-created research models, consumer-oriented systems for data collection pose risks of surveillance, monetization by providers, and lack of informed consent (Wiggins and Wilbanks). Tensions emerge between data ownership, data sharing and data privacy – tensions in which “data philanthropy,” donating data for the greater good, is positioned as the right, the beneficial and solidary thing to do (cf. Ajana). The DIY research “revolution” proclaimed by 23andMe is a good exemplification of such discourses: Sharing your data will benefit society at large by helping to find treatments or cures for diseases. In such cases, these companies use the ‘label’ of DIY without implementing its ideology – similar to the trend towards ‘greenwashing’ in other consumer segments – which might create negative effects: Beguiled by the promise of empowerment and participation, consumers might be trapped in new unequal power relations and interdependencies.

Co-optation’s Transformative Potential

While DIY biology and medicine are often perceived and portrayed as a challenge to traditional approaches in the practice of science and medicine – a form of “counterculture” to biocapitalism with transformative potential (Delfanti, *Biohackers* 112-13, 129) – Delfanti finds that DIY biology cannot clearly be separated from those traditional institutions of science, the medical market or state bodies. Instead, he claims that it is in

relation to all of them, either participating in, relying on or foreshadowing future possibilities (“Do-It-Yourself”). This close connection both to the (biomedical) market and institutionalized forms of science is observed by many scholars analyzing the DIY biology movement.¹³ According to Delfanti biohacking is not working against entrepreneurship and profit, but rather combines it with a new ethos of sharing, distribution, and participation – without however, closing the door to financial gain. Against this backdrop, Keulartz and van den Belt question whether DIY can even become a true alternative to Big Bio or whether it will in the end become part of the vortex of biocapitalism and commodification (16). My case studies have demonstrated this deep entanglement with for-profit efforts as well. DTC genetic testing, once more, is one of the most obvious examples of how money is made from the participation in and donation of personal data in the name of consumption. “So is it disingenuous to build a subculture atop such a massive institutional foundation and call it DIY,” Wohlsen asks (120)?

Delfanti argues that the close connection between biohacking and existing institutions “signals a process of ongoing co-option” in which DIY biology is increasingly incorporated by the bio-industry (“Do-It-Yourself” n.p.). Co-option, he writes is a phenomenon that typically affects social movements that try to effect social change through technological innovations. These technological innovations, often developed with some type of help from industry, are then incorporated into and adapted to industry needs. Because DIY biology’s position in relation to scientific institutions, markets and the state – or rather its enmeshment with these actors – seems to stabilize, Delfanti maintains that DIY biology might undergo exactly such a process of co-optation, potentially resulting in the loss of its “innovative tension” through the absorption of its technologies and practices (“Do-It-Yourself” n.p.). For DIY, this might mean a loss of its transformative potential.

If Delfanti’s prediction proves true, co-optation could lead to larger attempts to integrate the DIY approaches into existing structures and systems of power. But *can* DIY approaches be integrated (productively) into the current economic system without losing their ideology? According to Boltanski and Chiapello (2005) capitalism “feeds” on critical cultures: The incorporation of critical cultures helps “restructure and renew the ideological and organizational logics” of capitalism, as the example of 1960s counterculture has shown (cited in Soderberg and Delfanti 3). Soderberg and Delfanti argue that

13 Ana Delgado claims that DIY bio is characterized by an ambiguous relationship to institutionalized forms of biology, because it depends on and questions them at the same time (67). Keulartz and van den Belt observe this ambiguity as well: While DIY biology’s ethics, values and practices seem to be in contrast to Big Bio’s focus on profit, DIY biology is also dependent on Big Bio as a source of second-hand equipment and rapid technological development and DIY bio community projects are increasingly turned into businesses (3-5). Kelty argues that DIY bio is “enabled by and thrives upon the infrastructure of mainstream biology” (1). For example, there are many personal and professional connections between DIY bio labs and “professional scientists” as many participants are often researchers or students. Meyer also points to the many entanglements of DIY biology with “professional science” and Big Pharma: Despite its critique of the very logics of this industry, its closed off nature and lack of access – an ethos of “do-it-without” as he terms it – DIY biology also relies on it for the purchase of used equipment, tools and products or by accepting donations from companies (“Hacking”).

a similar process is happening with hacker culture and potentially maker culture (3). In *Biohackers*, Delfanti calls this a process of “recuperation” – the instrumentalization of a critical culture (14). Cultural transformations such as DIY and making, that pave the way for a “participatory, cooperative turn of informational capitalism,” can through co-optation and incorporation influence the progress of today’s capitalism (Delfanti, *Biohackers* 50). The end point of such co-optation processes is a situation in which it becomes almost impossible to separate the more radical practices of DIY from those commercialized ones. The boundaries between DIY and DTC have become blurry and both extract commercial value from information, biology and bodies.

Commercialization can be limiting and liberating and also co-optation can have a transformative impact by changing culture on a larger scale. Open biology, following Delfanti, could thus become a “tool of resistance” while at the same time participating in neoliberalism and capitalist value creation (*Biohackers* 14). As some of my case studies have shown, DIY and consumerism can actually be working together, following similar goals. They do not have to be dialectically opposed but can form a fruitful combination. DTC can be a precursor of DIY practices and vice versa, as the integration of DTC testing into DIY, citizen science clinical trials or personalized regimes of self-transformation has shown (cf. Case Studies I and V). The co-optation of DIY principles into neoliberal capitalism could, as the discussion above has shown, actually change the current system into a more participatory, social, egalitarian one, suited to address some of the most pressing concerns of today. I propose to see DIY approaches and DTC approaches as nodes in the same network: Techniques that in their own way further an agenda of participation and empowerment, both with their own drawbacks and downsides. Working together – in their network – they can potentially elicit much more large-scale developments than individually. This combination can also, as we will see, help to alleviate some of the anxieties around DIY biology and medicine in public discussions.

Security and Fear

The contemporary conception of biomolecular life not as fixed but as fluid turns biology from something calculable into a “a dynamic world characterized by ever novel combinations, where entities jump between bodies and cross between species, and where ‘life itself’ continuously confronts us with the new and the unknown” (Braun 17). These biological “unknown unknowns” (18) that could come from everywhere, Braun contends, incite fears and a political rhetoric of threats to life and liberty.¹⁴ The focus on “biosecurity,” thus, can also be considered as a (political) response to the unpredictability of

14 The “unknown unknowns” that Braun takes up here (presumably) go back to a statement made by United States Secretary of Defense Donald Rumsfeld in a Department of Defense news briefing in February 2002 in relation to the war in Iraq and the lack of evidence for the presumption that the government of Iraq supplied terrorist groups with weapons of mass destruction. Rumsfeld argued: “Reports that say that something hasn’t happened are always interesting to me, because as we know, there are known knowns; there are things we know we know. We also know there are known unknowns; that is to say we know there are some things we do not know. But there are also unknown unknowns—the ones we don’t know we don’t know. And if one looks throughout the history of our country and other free countries, it is the latter category that tend to be the

molecular life – also through globalization (Braun 15). Making biology more open and accessible, some critics claim, “also makes it less predictable, raising the specter of unknown dangers” (Bennett et al. 1109): Fear of invisible dangers, concerns about the self-directed nature, worry about the welfare of the nation more generally are part of the public discussions around DIY biology. As Bennett et al. write, “[i]n certain respects, DIYbio is a ‘black swan’ waiting to happen: it portends events whose probability might seem low, but whose negative impact is likely to be quite high” (1110). These security concerns are also shaped by the common understanding of ‘hacking’ as a rather dark, illicit activity. Prominently, these discourses come together in the figure of the (bio)terrorist to emphasize the unpredictable nature of this danger (Meyer, “Hacking”). In the public imagination, DIY biologists, especially those working with those wonderful, minute substances of life, are also potential bioterrorists who work in a black box of elite technology and reclusive hacker ethos.

Often, cultural representations of DIY biology tend to escalate what is done in DIY labs and homes of biohackers, so that we find a stark contrast between the public imagination – genetic engineering, CRISPRing organisms – and the real-life practices of many biohackers. DIY bio activities are represented as both potentially revolutionary and “extremely dangerous” (Aguiton and Tocchetti 834). Media discourses show them as a promise and a threat. For example, the specter of biological engineering is already visible in the treatment of DIY biology in the American show *Designated Survivor* in 2019, but much more prominently in *Biohackers* (2020). The trope of ‘god-like’ powers through synthetic biology is included already in the first episode of the streaming series: “Synthetic biology turns us from creatures to creators,” Prof. Lorenz preaches to a full auditorium.¹⁵ The biohacking that is performed in this show, then, also includes the unregulated genetic engineering of mosquitos as well as self-made genetic treatments for diseases. While these cultural representations are often science fiction, they do speak to a desire that is also prevalent in parts of the DIY biology community. With easier access to sophisticated technology, we are also moving closer to recombinant DNA and genetic engineering – those controversial issues that form the basis for many of the security concerns around DIY biology. Indeed, the availability of more and cheaper tools needed for complex genetic experiments is reflected in what is sold to new biohackers. Josiah Zayner’s company *The ODIN*, for example, sells DIY CRISPR kits that allow people to genetically-modify organisms in their home. Zayner received a lot of media attention for his highly publicized and controversial hacks, such as injecting himself with CRISPR

difficult ones.” (Secretary of Defense Donald H. Rumsfeld, DoD News Briefing, Feb 12, 2002). This statement has gained cultural notoriety since then.

- 15 Her life-long goal, we learn, was to eradicate genetic disease, amongst others with a gene therapy program called “Homo Deus” that was used on embryos – deadly to all recipients but one. This therapy, it turns out, can also give people a stronger immune system. The intent was a cure, the result is an enhancement. Synthetic biology and genetic engineering, as Biohackers fantasizes could give rise to new types of human enhancement that builds inequalities literally into the biological make-up of humans – genetic optimization will become the norm, as Prof. Lorenz maintains. We might also want to note that the name given to this program “Homo Deus” resonates deeply not just with Harari’s eponymous non-fiction book but also the desire he describes in it: to create more perfect beings, God-like humans.

on stage in an attempt to do genetic engineering on humans. The kits sold by *The ODIN* include experiments that would modify non-pathogenic *E. Coli* bacteria to survive on a medium they would usually not survive on or to engineer yeast to become fluorescent (“The ODIN”).¹⁶ Such possibilities, while relatively basic today, feed into the prevalent wariness or even fear of dangerous biological particles and the risks associated with unregulated, DIY experimentation.

In these discourses of risks DIY biology is frequently seen as a danger to public health and environmental safety as well as national and personal security (Meyer, *Domesticating* 3; Wolinsky 683; Gruber). These dangers are reflected in the three kinds of risks that are commonly identified when it comes to synthetic and DIY biology: first, the accidental release of potentially harmful organisms due to lower safety precautions in typical DIY settings; second, a deliberate release with good intentions but unintended or unforeseen side effects on the environment; and third, the deliberate and malicious misuse, for example through the fabrication of new pathogens and their release (Stevens 351-52).¹⁷ Moreover, critics are also concerned about the consequences for individual bodies, for example when untested technology such as the “Circadia” implant is integrated into the body, hacks like the DIY “EpiPencil” used as substitutes for regulated emergency medications, or *The ODIN*’s DIY CRISPR kits used for genetic self-engineering.¹⁸ Interestingly, similar concerns about personal safety were also present during the rise of DIY home improvements in the 1950s and 60s, when the broader availability of power tools also gave rise to concerns about the potential dangers to personal safety that resulted from their use (Gelber 278-82). DIY biologists counter safety concerns with hints at the harmless nature of their experiments and the (as of now) functioning forms of self-regulation in the community. In the US, this often results in a discussion between state interference and freedom of choice, freedom of speech and personal autonomy, because, as Stevens writes, in the age of recombinant DNA and genetic engineering biosecurity would require regulation of information and not just

16 On a side note, the import of DIY genetic engineering kits into Germany – such as those from *The Odin* – is prohibited and their use outside of laboratories can be fined up to 50,000€. German authorities have warned of the CRISPR kits because of disease-transmitting bacteria that were found in them and the FDA has issued a warning not to use self-administered CRISPR kits as well.

17 Almost all researchers that concern themselves with safety and security issues stress that they can happen accidentally as well as intentionally (Wolinsky 683; Bennett et al. 1109-10; Stevens 351-52). However, we also need to take into account that as of today, it is not really feasible to engineer new pathogens from scratch to use them as biological weapons, especially because already existing biological materials, such as anthrax or castor beans, could be used for similar purposes with much less effort. But, as Baumgaertner suggests, with increasing numbers of hackers and sophistication of technologies, the potential for abuse might grow (n.p.). In fact, scientists at research universities have already managed to engineer an extinct pox virus from mail-ordered DNA fragments. The series *Designated Survivor* takes up this cultural imaginary of newly engineered threats.

18 In a report for the *New York Times* from July 2019, Emily Baumgaertner implies that Josiah Zayner, founder of *The ODIN*, is aware, even afraid, of the potential for people to get hurt when people uncontrollably try to “one-up each other” with their hacks. In another report for *VOX* in June 2019, Sigal Samuel (“How Biohackers”) quotes Ellen Jorgensen’s – co-founder of the biohacker space *Genspace* in New York – warning about the potential dangers of DIY CRISPR on human genomes. Biohackers, it seems, are aware of and addressing the potential dangers (“How biohackers”).

materials (Stevens 353) – thus potentially impinging on all of the former. Patterson's argument that freedom of research is as fundamental a right as freedom of speech is a case in point. DIY biology and medicine – or rather the increase in scientific literacy that results when “scientific knowledge seeps into the public domain we all inhabit” – can turn these debates about “scientific risks and benefits” into a collective, social responsibility, as Wohlsen concludes in his afterword to *Biopunk* (217-18).

Familiarizing Biological “Unknown Unknowns”

What the discussion of commercialization and of safety goes back to, I would argue, are questions of location – outside and inside – and approaches – top-down and bottom-up. Consumption often is a top-down approach in which companies decide what becomes available (even though consumers do have a say in types of demand), while DIY solutions are characterized by their bottom-up nature. Moreover, commercial solutions could be characterized as inside (the system), while DIY solutions are typically perceived to be outside of established systems (even though, as we have seen, that is not necessarily true). In the public perception, top-down and inside are associated with safety, regulation, security; while bottom-up and outside are associated with potential danger, rebellion, anarchy. As a consequence, commercial approaches are evaluated as safer and less controversial while DIY approaches are deemed more dangerous and unregulated. Such safety concerns might be countered by co-optation and commercialization: commercial devices are not just subject to stronger regulations but also work as *agents of familiarization*. Unruly DIY practices are integrated into a well-established system; they are no longer out there and dangerous but part of a trusted order.

To some degree, the DIY community in the US has put those distinctions to work for them, even if subconsciously. They have countered fears about the safety of their practices by working with established players and regulatory bodies. The DIYbio movement, for example, has established a strong (working) relationship with the FBI and other government bodies and at the same time positioned itself as an educational community with potential benefits for the whole of society (Delfanti, *Biohackers* 116). Aguiton and Tocchetti focused on the relation between DIYbio and the FBI as an example of the entanglement of promissory biotech and biosecurity risks:¹⁹ During the collaborations between FBI and DIYbio, their argument goes, a “trading zone” was opened up that relies on the “entanglement between promise and risks and enables a relationship of opposing entities to collaborate.” The collaboration with the FBI furthers DIYbio's technological promises by “governing” their activities – quieting down fears about biothreats also in the media and thus enabling the “true” message of DIYbio to be heard and the network to grow – and DIYbio helps the FBI by policing themselves and their

19 According to Aguiton and Tocchetti, this collaboration reached from informal visits of FBI agents to community meetings, presentations by the FBI during conferences and community events, to jointly organized gatherings of global biomarkers. Interestingly, the collaboration between these contradictory actors has also made it into popular culture: The third season of *Designated Survivor*, referenced in the introduction, thematizes the problem of regulation and brings together a CIA agent and a biohacker to counter a possible bio-threat to the United States.

members. They have established a system where suspicious behavior can be reported to the FBI, thus allowing the FBI to more efficiently survey the activities of the community for potential dangers (Aguiton and Tocchetti 829). In this intermediary zone outside and inside mingle so that both parties gain from the collaboration: DIY biology is conferred with the authority of an 'inside' institution that helps mitigate public perceptions of danger, while the FBI gains the trust of an outside and unruly movement. This, however, could also be a form of co-optation because the innovative practices and approaches of DIY biology are integrated into networks of policing and governance that run counter to the creative, unconventional hacker ethos. In the US, on the other hand, this type of co-optation might be necessary for the movement to gain credibility and grow in spite of the present anxiety around bioterrorism.

11.3 “Obligated to be Free” – Empowerment, Choice and Precarity

“Biopunks experiment. We have questions, and we don't see the point in waiting around for someone else to answer them.” (*Patterson n.p.*)

Patience, it seems, is not the strong suit of many biohackers. Instead of passively waiting for technologies that address the questions they have or problems they experience, they want to take an active part in this development. Nowhere is this more apparent than in the *NightScout* and *OpenAPS* movements with their moniker “#wearenotwaiting.” What this impatience points to as well is a pervasive discontent with their current situation, personally as well as structurally. For a long time, (diabetes) patients in this example were expected to wait for the doctor to make their diagnosis, prescribe a therapy and monitor the progression of disease. Armed with the internet as information tool, DTC tests as monitoring devices and DIY instructions for supplementation, lifestyle changes and medical devices, these patients are now more than ever entering an age of empowerment with more choices, more possibilities to actively shape their health (care) – at least so it might seem. In this part, I am turning to the personal consequences for the self that DIY biology and medicine might have. This includes questions of power and empowerment, authority and agency, choice and responsibility, a deeper knowledge of the self as well as a new sense of vulnerability and uncertainty. Are we “obliged to be free” (Rose, *Governing* 217)?

I will argue that the new power granted to individuals through DIY dialectically fosters feelings of vulnerability, precarity and uncertainty. Through the lens of empowerment, DIY becomes a means for individuals to self-determinedly and self-responsibly influence different aspects of their lives. As such, it can become a new means of wielding power in the 21st century. This goes hand in hand with changing relationships between experts and laypeople – as the latter claim more and more authority over the fields of the former as well as their own lives and bodies. A potential downside of this process is the increasing responsabilization of individuals (which always risks neglecting social and structural factors in favor of personal ones) as well as the rise in *horizontal*, peer-controlled power structures. The new authority of laypersons, on the other hand, entails new types of knowledge of the self that give rise to ideas of modification and

optimization. Both the knowledge and the quest for modification can lead to new forms of corporeal precarity that undermine the promise of control and hope perpetuated by the discourses of empowerment. Rather, it leaves the body vulnerable to inside and outside forces. “Precarity” is used by Judith Butler to denote such states of increasing dependency and vulnerability to outside forces, a loss of social rights and material securities (Delgado and Callen 180-90; J. Butler, *Precarious Life*).²⁰ Such a state of precarity is induced by DIY and its discourses of empowerment, agency, responsibility, and self-knowledge in multiple ways, as my discussion will show.

Informal Experts

DIY necessarily raises broader questions of (individual) power as the *do-it-yourself* always implies some sort of empowerment to take on tasks yourself that previously were carried out by professionals. “Taking ownership of their own biology” and the process of demystification are said to be deeply empowering (Wolinsky 683). Through DIY techniques, as my case studies have shown, individuals gain agency over their bodies and choices, take control over different aspects of their lives in which they previously often had felt powerless. This empowerment of marginalized actors – patients, lay persons – also takes place through technology and *knowledge* and is thus inherently related to questions of access and participation. Having knowledge becomes a prerequisite for gaining power and control.²¹ Through its central premises, DIY biology and medicine, thus, becomes a form of playing out and reshuffling power relations, a redistribution that throws into disarray existing structures – or at least is a symptom of the broader changes in the systems of power during the last decades, a new rendition of the discourse of individual empowerment so prevalent in contemporary culture.

Through the increase in individual power and agency, relationships between professionals and lay persons – be it scientists and society, medical professionals and patients – are transformed from paternalistic to egalitarian, an inherent goal of DIY aspirations. Stevens muses that through movements like Do-it-yourself Bio and citizen science clear distinctions between experts and the public might be resolved (11). As “boundary movements” they “obscure” the boundary between experts and laypersons and instead create a space for fluid movements between these worlds of knowledge: Activists in such (social) movements become “informal” experts through the gathering of information or direct engagement with scientists and medical professionals (Brown et al. 597). For example, Lupton writes that the “quantified patient” is an expert on their own body,

20 Precarity, according to Delgado and Callen, is also part of the material conditions of the “DIY scene”: They write, that “[w]hat is rarely emphasised is precarity as the material context of existence of the DIY scene,” amongst which they include the precarity in traditional research institutions – the lack of funding and jobs in academia, the lack of research opportunities for young scholars, and the immense pressure to publish. In this setting low-cost, creative hacking of biology has become an alternative, in which biology and the lab are “owned” and “appropriated” (180-90). But I here want to focus on personal consequences, not broader social contexts, even though I do think that these need to be addressed sooner rather than later.

21 I understand power in a Foucauldian sense as pervasive and differentially distributed power in complex networks of actors, discourses and knowledge practices.

more knowledgeable about it than their doctors, which alters and questions the very foundations of this sacrosanct relationship (*Quantified Self* 78). Similarly, tinkering, the primary mode of inquiry in DIY biology and medicine, is by Christina Dunbar-Hester understood as a form of “cultural production” that aims at producing more egalitarian social relations.

The consequence of these transformations in traditional relationships ranges from less dependence on expertism on the side of the patient or public towards broader structural changes towards egalitarian, cooperative social relations – a dissolution of (knowledge-)elites in favor of a more equal society. These shifts in (power) relations are not only found in traditionally overtly hierarchical power structures such as the doctor-patient relationship. Instead, we also find it in the scientific community, and indeed society, more generally. In science, Erickson demonstrates, we increasingly find a “two-way street” between esoteric and exoteric communities that now work together to produce new knowledge (2-3). The distinguishing feature of the scientific community, the “scientific method,” as it is increasingly recognized, of course can also be employed by lay persons in the pursuit of new insights. DIY biology and the citizen science movement show that it is no longer the exclusive domain of formally trained scientists. The result are new concepts such as the “prosumer” – a hybridization that combines knowledge production and consumption as a new role in the production, dissemination and transfer of knowledge (Brüninghaus and Heyen 63, Toffler 284).²² Through the erosion of these boundaries DIY challenges the very foundation of the differentiation between the scientific communities and society. What does that do to our understanding of science and the belief in scientific solutions? Will it lead to cultural skepticism about the validity of scientific findings, about the quality criteria for research? Will it cement scientism as the dominant epistemology of our time? Or will transparency further distrust and skepticism? These questions remain to be answered.

Despite the many positive outcomes of empowerment and transformations in asymmetric power relationships for the individual and society more generally, also some of its negative sides should not be discounted and in fact might play a crucial role while new principles and guidelines for medico-scientific encounters between different actors are discussed. For one, the loss of power on the one and the increase in power on the other side often does not happen without resistance from those previously in power. Also in the ‘original’ home improvement movement conflicts arose between professionals and DIYers, where professionals urged the DIY community to recognize their limits often with a view to their personal safety (Gelber 275). Similar push-back might arise in parts of the scientific and medical communities. Other concerns include

22 Anne Brüninghaus and Nils Heyen argue that people no longer consume scientific or medical knowledge in order to simply inform themselves or form an opinion, but also in order to take part in the production of knowledge themselves: This leads to new forms and roles of production and consumption of knowledge, in which people become “prosumers” that interact differently with received notions of expertise and knowledge transfer. This shift could potentially change how knowledge is transferred and communicated (Brüninghaus and Heyen 63). This new role somewhere between expert and lay person challenges the clear division between the two and heightens the importance of non-certified expertise. Knowledge production and consumption are no longer a one-way street but active participation is required.

the intentional mis-use of technologies and ‘unprofessional’ uses as well as the potential employment of technologies for negative goals made possible through a lack of professional oversight, leading to slippery slopes in the direction of coercion to comply or new eugenics. An anti-elitist movement risks being exploited also by disingenuous voices: Especially in the case of self-proclaimed experts and hacker ‘gurus,’ the borders between fact- or evidence-based medicine and new forms of quackery become blurred. Body hacks might no longer be backed by science or unproven methods marketed to uninformed audiences for economic gain. The booming wellness industry is a good illustration for such practices, where decisions are often made based on promissory marketing and anecdotal evidence.²³

Fittingly, as Deborah Lupton suggests in her consideration of *Medicine as Culture*, some critics argue that the regulation and “professionalization” of medicine has the positive effect of ensuring a minimum standard of expertise in persons allowed to practice as medical doctors thus protecting patients (109). The medical encounter, proponents of ‘older’ structures claim, depends on the differential distribution of power and knowledge between patient and doctor. Those roles, constituted by practice and discourses of medicine, rely on the doctor being the expert. In their arguments, leveling the power relations destroys the purpose of medicine: Why would people consult medical professionals if they have equal knowledge? If patients continuously question the role and position of the doctor, “how can the doctor-patient relationship exist”? (Lupton, *Medicine* 116-17) Posed in 1994, these questions remain relevant until today, maybe even more so through the easy availability of medical information online. DIY and its focus on collaboration might provide a solution in which both doctors and patients are recognized as experts in their own right that equally participate in and contribute their knowledge to the medical encounter. Whether or not such a solution is feasible on a broader scale, however, is debatable and also hinges on the promised literacy and acceptance in the medical and scientific community.

Vulnerable (by) Choice

What comes with the discourses of empowerment and agency is also a perpetuation of the focus on individual choice and responsibility, criticized already by Rose. Following him, we are today no longer looking at the specter of eugenics with its state directed, top-down interventions into the health of the individual and nation but at a biopolitics based on individual choices, at least on surface value. If the choice lies with the self, the responsibility for the positive or negative outcomes of the choice lies with the self as well. The capacity to “care” for the self is in neoliberalism anchored in the self as a

23 The Netflix documentary *(Un)well* tries to shine a light on the claims and promises made by the wellness industry. *(Un)well* sets out to closer analyze the promises made by the multi-billion wellness industry and asks whether or not its practices actually make us well or unwell. Examples in this 6-episode mini-series include: essential oils, tantra, breast milk for grown-ups, intermittent and water fasting, the hallucinogenic plant-extract ayahuasca, and bee sting therapy (Druckermann et al.). All these examples could be considered as CAM, they are self-chosen and often self-administered – a typical example of DIY values. The series has been criticized for reproducing a false balance by drowning out critical voices with enthusiastic, more benign practitioners.

rational actor (cf. Jen 136). On the first glance, the DIY approach necessarily entails such agentic individuals. But some of these techniques are embedded in larger webs of power and control that extend beyond the individual towards their peers and governments.

What comes to mind is Foucault's concept of "docile bodies." Foucault's studies have shown that power in the medical encounter is more pervasive and subtle than previously thought because it is not just enforced by authoritative figures but also through individual self-surveillance and self-policing. Governmental management was coupled with self-regulation. The "disciplined" or "docile bodies" that arise out of these contemporary, less openly coercive strategies of biopolitics are rendered a target for mechanisms of power that reach into and shape their bodies, desires, identities and concepts of self (cf. Pitts 36-38). Docile bodies are not just disciplined but also self-disciplining (cf. Steinberg 14). Through responsabilization, we increasingly encounter forms of horizontal control between peers in which non-conformity to what ought to be (based on calculations) is punished (Selke). The heightened focus on the self and the body, its comparison to perceived norms and others, makes individuals more aware of their own bodies and invites a *deficit-based thinking*. This type of thinking is already deeply embedded in self-help discourses with their structure of lack and lack-rectified. A focus on our shortcomings and optimization potentials, however, leaves the body in a perpetual state of uncertainty, never enough and always on the verge of becoming better. Health is "recast as a perpetually insecure state" (Schüll 318).²⁴ Deficit-based thinking invites a constant self-surveillance. As "potential patients" we must be constantly alert to bodily changes, whether or not we are sick or healthy (Pitts-Taylor, "Medicine" 164). This surveillance, however, also includes those around us. In a form of "sousveillance" people watch each other, make judgements and compare (Lupton, *Quantified Self* 58-62). In a "net of surveillance" people (users of tracking devices in particular) turn the medical, panoptic gaze upon themselves and their peers through practices of monitoring and sharing (Sharon 98) – leaving individuals in a sphere of constant monitoring and feedback, vulnerable to their own and the other's gaze.

The underlying question, thus, is one that already Braun posed in relation to Rose's ethopolitics: "What does it mean to 'exercise choice' in the self-management of the body?" (12) What defines a choice, how do discourses impede on this choice? Is it really an individual choice when we take into account ideas of horizontal control? How free can choices be in such a context?²⁵ Rose writes that "responsibility is a double edged sword" that "seems to give people more power as individuals" while also obliging them to take on this role as an active, involved, responsible subject ("Personalized Medicine" 349). Choices might be severely constrained by the pressure of peers, social obligations

24 Dumit similarly writes that we have experienced a shift in the conception of illness: Bodies, today, are "inherently ill, whether genetically or through lifestyles or traumas," they are inherently insecure (7). Health and illness, for him, are "epistemic," no longer "states of being" but "states of knowledge" (13-14). As an epistemic practice itself, DIY has and increasingly will become a new avenue through which we can arrive at that state of knowledge.

25 Taking this idea further, the increasing reliance on technology also impinges on the idea of free choice. To make choices about the body individuals increasingly rely on technologies: Schüll even argues that this dependence on technology in wearable tracking turns individuals from an active choosing self into a passive one that needs devices for help (330).

and cultural discourses. For example, in the context of personal genetics, you can, as Henk ten Have writes, no longer claim to be “victim” if you have “deliberately decided” to forgo predictive measures, such as genetic diagnosis – it was your choice “not to know” and “not to eliminate potential disadvantages” (301). The consequences have to be carried by you and no one else. The individual is obliged to act responsibly, choose carefully and it is this obligation that makes them not free but actually very much limited. “The self is not merely enabled to choose,” Rose argues, “but obliged to construe a life in terms of its choices, its powers, and its values. Individuals are expected to construe the course of their life as the outcome of such choices, and to account for their lives in terms of the reasons for those choices” (*Governing* 231). They are “urged to shape their lives through choice” but often lack the knowledge to “navigate” those choices (Schüll 324-25), leaving them with a “double insecurity” of “always being at risk” while “never knowing enough about what one could and should be doing” (Dumit 1-2). If the “obligation to choose” becomes an obligation to act according to what one knows, the “freedom” to choose to know more and potentially optimize what is not going according to norms is not really a freedom at all but an obligation.

The idea of “choice” is most problematic, as in many biopolitical questions, if we take into considerations those who “lack the resources that might enable them to choose:” For them, “the biological self is a precarious entity – bare life, exposed to death – rather than an object of personal reconstruction,” argues Braun (12). The focus on individual choice risks negating social and structural factors that impinge on the body and life choices. The promise of control through technology and/or DIY techniques is often used to amend such feelings and realities of precarity. The belief (almost religiously) in scientific solutions for bodily ailments and limitations is used to come to terms with the inherent vulnerability of the ‘human condition.’ For example, as Lupton asserts, self-tracking – by turning “fleshy sensations” into data – “becomes a way of mastering the uncertainties, inaccuracies and vagaries of human embodiment” (*Quantified Self* 54). Similarly, also other DIY techniques, such as implantable monitors, hacked medical devices or molecular testing, can be used to counter uncertainty with technology.

A Precare Existence

The idea of more control, as Lupton finds, is also based on the availability of more data about the self, a higher degree of self-knowledge that, it is perceived, allows individuals to assert control over their bodies and lives in an unprecedented manner (*Quantified Self* 67-77). The authority individuals gain over more aspect of their lives and bodies comes with more possibilities to explore them in ever more intricate detail, gathering new, deeper knowledge about the self, particularly its materiality. The self is constructed as a “database” – as Schüll demonstrates for continuous self-tracking (324) – that can be explored with technological tools and commercialized services. In some of the case studies DIY has become a means to (re)shape the engagement with one’s own biology through exploration and experimentation. This new type of creative, open, inquisitive engagement creates a more intimate relation to biology and the body. This self-knowledge and self-exploration, as many of the discussions have shown, seems to be culturally connected also to ideas of self-enhancement – not just of an abstract sense of self but of a

material, concrete body. Drawing on discourses of bodily plasticity, in cultural representations self-knowledge becomes an entry point for modifications of the physical status quo, on molar and molecular, cosmetic and curative levels. This possible modification of the body is the most prominent *material consequence* of many of the DIY techniques; at the same time, however, it is a deeply personal, individualized consequence because these modifications are performed by the self on the self according to self-set norms and imaginaries. These self-enhancements do not have to be drastic steps, such as integrating technology into the body to gain extra senses, but can also be more mundane such as reaching a personal feeling of wellness through vitamin supplementation. What is crucial today is that these tools are accepted as new ways to materially re-configure the body.

But the use of technologies, or more precisely information as their desired outcome, also gives rise to new modes of vulnerability: Joseph Dumit and Regula Valérie Burri maintain that today we have information “to the point of excess” (223-24). We should thus also ask ourselves if we can have *too much information*? Do we strive to know more about the self than is good for us? Knowledge about the body and self is often volatile in itself, it creates more uncertainty than certainty. This uncertainty leaves the self in a state of constant possibility, creates patients in waiting, leaves room for interpretation and doubt, apprehension. For example, Dickenson argues that knowledge through DTC testing and the resulting perception of the self as a “patient from cradle to grave” might actually undermine personal agency and choice (60). As Chrysanthou mentions, the availability of information may create information-related illnesses, such as “information anxiety:” The impossibility to keep up with the flux of information about health online can, for example, create further negative health outcomes such as chronic stress and anxiety – especially because the information we want to use to tame our uncertainty about our (physical) condition might be uncertain or misleading itself (473-74). Similarly, Joseph Dumit argues that the insecurity we feel about our physical status quo persists despite our increasing knowledge and research about risks and treatments, “as if the more we know, the more we fear; and the more we fear, the more preventive actions...we need to take” (1-2). A precare existence is the result. Instead of the promised control, the individual realizes that control, like perfection, is a moving target: More, and more minute, knowledge only creates further instances that need to be controlled – thus doing little more than miniaturizing the targets of control. Talking about tracking, Schumacher thus rightly contends that one of the most important questions to be asked is how we as humans deal with the abundance of knowledge about our selves without losing our humanity (51).

Bodies Beyond Hacking

Here we are also reaching the *affective dimensions* of DIY biology and medicine: Affective structures of hopes and promises, fears and anxieties underpin much of the DIY practices under consideration in my case studies – promises of perfection, of control, of wellbeing and comfort, promises of access and participation as much as anxiety about bodily contingency, about uncertainties, about loss of control, about death, disease and

decay, anxieties about being overheard, neglected and mistreated.²⁶ I would argue that the shared “affective atmosphere” (Ben Anderson, “Affective Atmospheres” 77) of hope and desire created also through DIY techniques is used to counter overarching societal moods of fear and anxiety about the contingency of (future) embodiment. In times of overwhelming precarity – in all its different shades and connotations – we follow a fantasy “of one day not being vulnerable” (McCormack and Salmenniemi 8). What is created is a promissory atmosphere, the promise of control over the previously unknown, unruly and untamable: nature, biology, the body. DIY perpetuates the hope of true self-directedness and self-optimization. These promises and fantasies might however fail to materialize, thus perpetuating the very vulnerability they aim to prevent.

In light of this vulnerability, we should also take a minute to look at “forms of life” (Rose, *Politics of Life* 105) already deemed vulnerable today – disability, old age, disease, marginalization – and ask whether these can be hacked as well. Is there a form of life that is not hackable, a *life beyond hacking*? Proponents of biohacking would argue that yes, especially old age is “hackable,” at least if we aim at staving off the frailties associated with old age. But then, but what about the elderly today? Moreover, will improvement culture lead to new forms of eugenics and social Darwinism, in which those who cannot be hacked or opt out are deemed inferior? What happens to those who are not hackable? Or who do not want to hack themselves? Who opt out of improvement culture? These questions lead to problems of discrimination and social stratification, of obligation and a new biopolitics based on an incentive to ‘hack’ the self in ever more ingenious ways – a “regime of bio-making” that according to Jen might be the outcome of today’s DIY practices.²⁷

But here we also once more see how the personal becomes political – a standard assertion of feminist inquiries and activism – how individual choices are embedded in larger cultural concerns and (bio)political considerations. DIY can exacerbate experiences of vulnerability, especially if it becomes a new requirement for participation in the neoliberal market place, an obligation to care for the self yourself because no one else will do so, or a tool used by states and institutions to enforce a bio-politics of participation. On the other hand, Delgado and Callen, for example, claim that DIY is a political action especially because it questions our “dependencies on institutions that do not serve to cope with the precarious condition of life” (180-90). DIY for them

26 For example, a promise of certainty and control drives people to test themselves, but anxiety can possibly influence the “voluntariness” of testing. In a culture that creates more and more anxiety about bodily contingency, testing becomes less voluntary and more of a way to counteract that anxiety and grasp for certainty: It becomes not an action but a re-action.

27 Jen warns of an “emergent bio-making regime.” She writes: “With increased commercialization of bio-maker culture and tighter alliances with biocapitalism and the US military-industry complex, a rising bio-making regime may reconfigure neo-liberal governance in ways that newly discipline subjects to assume bio-making as a moral imperative. This would disparately impact marginalized populations who already encounter barriers to scientific literacy and skills.” (136-37). As a brief historical reference – or rather a historical continuity – this element of obligation shares some characteristics with DIY home improvements in the 1950s. As I have discussed in Chapter 4, also home improvement DIY took on a coercive quality especially for men, when it became an obligation, a standard part of the regime of masculinity, to be a “handy man.”

becomes not a source of precarity but a solution: A creative intervention, as also many of the case studies have shown, that shines a light on exactly those conditions that create precarious conditions of life – dependencies, ideologies, differential distributions of resources and power – and demonstrates ways to subvert them.

11.4 Me versus We - Social Stratification and Collaborative Individualism

“When we work, it is with the betterment of the community in mind -- and that includes our community, your community, and the communities of people that we may never meet. ...The biopunks are actively engaged in making the world a place that everyone can understand. Come, let us research together.” (*Patterson n.p.*)

In this quote, Meredith Patterson voices an explicit invitation, extended to everyone who heard and later on read her *Biopunk Manifesto*. This invitation stresses not just that satisfying curiosity should know no boundaries or barriers, that access to knowledge should extend to everyone, but also invokes a community, a ‘together’ of like-minded and similarly motivated people. On the first glance, this stance seems to stand in marked contrast to the focus on individualism in contemporary biomedicine and biotechnology, the consumerist, almost obsessive nature of individualist desires for health, perfection, and self-improvement, the ‘yourself’ that is an such an explicit part, on the most literal level, of ‘do-it-yourself’ techniques. The discussion here will focus on the social consequences of DIY biology and medicine, more specifically, on the interplay between individualization on the one hand and an ethos of collaboration, community and sharing on the other.

The individualism perpetuated by many DIY techniques can create negative social consequences by negating community principles and creating new forms of differentiation. I will discuss these new types of differentiation as one potential outcome of the trend towards DIY. Who is part of the trend? Who is granted access? Or, as Clare Jen put it, “[f]or whom is bio-making a democratization process? Who remains on the margins of the margins?” (134) And what are the results of this social stratification, locally and globally? These are some of the questions I will touch upon. But as many of the case studies have shown, despite the strong focus on the individual in DIY, DIY biology and medicine can, on closer inspection, be considered also as a collective approach – potentially creating new opportunities to subvert, criticize and resist the consequences of the discourse of individualism. Can this collectivizing moment have broader social ramifications? Can it subvert the differential distribution of resources, tools and knowledge? A second scenario considers DIY biology and medicine’s collaborative nature as a chance for social transformation.

Me Trumps We

The focus on the individual in DIY biology and medicine is visible in most of my case studies – either through the underlying rhetoric of individual responsibility, the self-directed nature of the DIY endeavors or through the focus on the self and body as source

for (molecularized) self-knowledge and biological manipulation. Self-help books, for example, aim at individual optimization, the discourses created by genetic and molecular testing companies explicitly focus on ‘yourself’ as the object of inquiry, and also Wohlson’s narrativization of *Biopunk* takes as its focus individual biohackers and possibilities for *self*-enhancement more often than not. This *individualism* is especially visible in the discussions of personalized medicine and digital health technologies, but it is also the cultural foundation for DIY in the larger sense. Donna Dickenson argues that “Me medicine” has superseded “We medicine” as the dominant frame in healthcare. More precisely, she is concerned that the current focus on “Me Medicine” – those “promissory technologies” that characterize debates around personalized medicine, such as direct-to-consumer genetic testing, pharmacogenomics, private umbilical cord blood banking or enhancement techniques (1; 144) – is surpassing “We Medicine,” public health measures for example. This shift would cause the American “cult of individualism” to undermine the notion that medicine and biotechnology should serve the greater good (2-3).²⁸

During the past centuries, these individualist tendencies in the US have increased: Robert Putnam, in his book *Bowling Alone*, describes how the “heathy tendencies of Americans to make connections and form associations,” especially between people from different backgrounds and social situations that would otherwise not interact with each other, has been declining in the late 20th century (cf. Gauntlett 137). Economic forces, constant competition and a neoliberal ideology of personal freedom have made American society an increasingly individualistic one. If we are concerned only with individual access, individual modification, individual preferences and individual freedoms, however, we lose sight for broader concerns. It is problematic if one of the highest values of a society is individualism because that risks negating social factors, structural problems and inequalities. It is an ethical concern as much as a social, practical, and indeed, in the case of biology and the body, a potentially material one. A focus on the individual blinds us for the collective ramifications. As Lupton claims for self-tracking, the prevalent notion of autonomous individualism means that communality, situatedness in social, political, cultural contexts, participation in social groups, acculturation to certain norms and values, and relationality are often not truly recognized (*Quantified Self* 140). Extreme personalization erodes possibilities for community action and empathy and negates that we as humans are always situated in and shaped by what and who is around us. One example that Peter Conrad discussed already in 2007 are biomedical enhancements: Through their focus on individualist thinking (and individual dissatisfactions) they do not question social standards or expectations on a collective level, he argues. Instead, they risk decreasing the diversity of a society and might bring to the forefront (ethical/moral) conflicts between individual benefits and the public good (*Medicalization* 91-96). Likewise, Lemke claims that genetic diagnosis creates a dynamic in which optimization of individuals takes precedence over the transformation of (dis-

28 Dickenson looks at “threat and contamination,” “narcissism and the ‘bowling alone’ phenomenon,” “corporate interest and political neoliberalism,” “choice and autonomy” as factors that potentially influence the rise of Me Medicine and decline of We Medicine (10-29).

criminating) social contexts: Social progress, he argues, is replaced with a “therapeutic regime of self-improvement” (“Disposition” 558).

Of course, such concerns are also applicable on a larger scale, for example in relation to health care: While individualism and personalization can lead to more cost efficiency, fewer side effects and better targeted therapies, improved quality of life for individuals (Sharon 99), it also comes with tremendous ‘side effects.’ Stevens writes that one of the problems with the vision of individual autonomy and personal responsibility in healthcare is that it changes the public’s view of health care from a social, public, collective responsibility to an individual one in which the individual has to take care of their own well-being: The result is a lack of concern for notions of care – and care work, I would suggest – and the collective responsibility in a community, threatening the “notion of health as a public or social good” (Stevens 308). As Rose writes: “If our medical ‘imaginary’—our image of what healthcare should be—is ‘all about me’ it may well have serious consequences for my willingness to pay for, let alone care about, the health of others who are not related to me—not just others in my town or my country, but others in far away and distant places.” (“Personalized Medicine” 350-51) Instead, such individualization replaces the notion that the state cares for its citizens with a discourse of individual responsibility (and the resulting possibilities for blame), thereby turning from welfare as a public and collective endeavor to an individualized, neoliberal model of governance (Sharon 99). As a result, the utopian body project that Chrysanthou talks about – a healthy body – might create an unhealthy society as the individualization and privatization of health promotion foreclose social, political, and holistic strategies (447). The “rush” towards personalization, individualization, preventive-preemption might divert resources from those health care interventions that are acutely needed and/or have proven effective in the past, those “impersonal, population wide, solidaristic social interventions” that have improved health for all, such as clean air and water, sewage, food control and population-wide vaccination (Rose, “Personalized Medicine” 348, 350-51). The promise of individualism, thus, might turn out to be a burden after all.

Privileged Bodies

The creation of “privileged bodies” is one possible consequence of the focus on individual solutions and the loss of collective responsibility. “The body-in-isolation is, of course, a privileged body,” writes Victoria Pitts. What she refers to with this “body-in-isolation” is exactly the individualized body perpetuated also in DIY culture: the body standing apart from social, economic, political, personal ties, characterized by a “‘right’ to individuality, to standing alone, negotiating to get one’s own, self-defined needs met through technological access.” This body, usually in Western cultures, is flexible, a project, a “body of privilege” (Pitts 191-97). While this privilege is manifold – from physical location, to access, to economic situation – I first want to consider this privilege mainly in its material form, its connection to enhancements.

Especially due to the inherent (social and cultural) connection to some form of optimization, DIY also carries with it the potential of furthering the creation of physically privileged bodies that seems to be an inherent fantasy of biotechnologies today. In the neoliberal need for self-optimization, it is no wonder that also for DIY biology and

medicine the surveillance and modification of the self is a common goal. Even the developers of open-source tools like *OpenPCR*, we have seen, relate DIY biology to a more personal engagement with one's own biology, a familiarization with and monitoring of the previously hidden, material recesses of the self. Might the liberalization of access to biomedical tools, technologies and knowledge actually help perpetuate improvement as a necessity? If the promise of democratization is fulfilled and 'everyone' has access to the technologies of enhancement, there would be even less of an excuse not to use them, at least if you use them in socially desirable ways. A culturally entrenched coercion towards self-improvements could be the result.

DIY improvements potentially create a new type of embodiment, an embodiment of possibilities and openness, highly flexible and modifiable. But modification also always carries with it risks of coercion, exclusion and differentiation: To quote Samuel's journalistic take on biohacking's risks: "What if biohackers' 'upgrades' don't get distributed evenly across the human population?" ("How Biohackers") Will we have new types of exclusion and differentiation, between those enhanced/modified and those who are not? In this scenario, some bodies are made 'better' than others, who get stigmatized, discounted, disvalued. Those who do modify, or who have access to modifications, are privileged through their access and, more substantially, create privileged bodies through their ability to potentially shift their biological materiality according to their personal needs and those of the market.²⁹ In contrast to its promise of democratization, DIY technologies could morph into privileged, to a certain extent exclusive (bio)technologies that often do not recognize or fail to consider questions of social stratification and intersectionality.

Differentiation and Segregation

The privileging of some experiences and bodies as well as the concomitant differentiation of society, might in the long run lead to a new form of *medical or biological segregation*, a type of new, culturally sanctioned discrimination. Here, we have a classical differentiation into who is allowed – or here empowered³⁰ – to participate, who is heard in public debates, whose experiences are denied and whose experiences are included. According to Keulartz and van den Belt, the notion that the "public" in DIY is necessary active, involved, engaged disenfranchises those who are less active, those who are less able to do things because of unequal access to time or resources, those who are physically unable to take part, those who refuse (for moral, cultural or other reasons) to take part (13-14). I want to look at this medical or biological segregation on three different levels: the molecular, the local and the global.

29 Tellingly, Samuel goes on as follows: "Here's another risk associated with biohacking, one I think is even more serious: By making ourselves smarter and stronger and potentially even immortal (a difference of kind, not just of degree), we may create a society in which everyone feels pressure to alter their biology — even if they don't want to. ...In a world of superhumans, it may become increasingly hard to stay 'merely' human." ("How Biohackers" n.p.)

30 Empowered might be a better term here because of the aim of active empowerment through DIY – the idea that the movement actively furthers the participation of lay people, thus potentially also determining who is allowed to participate.

On the molecular level, new forms of molecular differentiation mean that prejudices and discrimination are not necessarily based on gender or race/ethnicity but other criteria related to the body – criteria that today are in constant flux. Not only categories such as ‘normal’ or ‘deviant’ are in perpetual negotiation. An unpredictable shift to new criteria could mean that all social groups might get marginalized as soon as new scientific knowledge or aggregate data find them deviating from the ‘norm.’³¹ Moreover, these new criteria that can potentially be used to divide society into groups are today often located in the body, not visible to the self without the help of technology. For example, the informational body created by (DIY) biomedical testing creates new types of differentiation or *racism* that is not based on “skin- [or surface-]morphology” but based on “information,” a very abstract, non-tangible and invisible basis, that, however, is perceived to be intrinsically linked to identity simply due to its “depth,” its hidden nature and its omnipresence in the discursive construction of bodies as information (cf. Clough 223). Data or information here form the basis for distinctions into groups with some deemed superior and some inferior or at risk. As one potential outcome of such practices, genetic engineering could give rise to new types of human enhancement that *builds inequalities literally into the biological make-up of humans*, creating a more divided society and world. Democracies, as Francis Fukuyama argues, however, are built on the idea of equality, of all beings being created equal. Inequality inscribed into our DNA through enhancements could, thus, undermine democratic principles and human rights. According to Stevens, the outcome of such genetic engineering would be a “radically unequal and divided society” (48). We might not even have to think that far because either on their own or as precursors to other, more radical practices also some of the DIY techniques carry with them seeds of division and inequality: A differentiation into groups based on the molecular make-up of and information produced by the body.

On the local level, we come closer to those categories often associated with questions of discrimination: disability, class, social status, gender, race. Here, differential distributions of access can create new forms of segregation. Physical and cognitive disorder or rather inability, for example, are exclusion criteria for participation in a highly active, knowledge-based ideology such as DIY.³² Moreover, the economic situation of an individual, especially in consumerist DIY, will decide whether or not they can take part in

31 In the context of genetics, this idea of a norm or comparison to a norm, in fact, is highly misleading as there is no ‘standard sequence.’ For the kilogram or time, society has agreed on a physical ‘standard’ to define weight and time. Such a standard can never be set for the genome, which directly impacts questions of ‘normality’ and ‘disease.’

32 As Keulartz and van den Belt have claimed the ideology of active participation also disenfranchises those who are simply not able to participate – physically or mentally. The cooperation of makers and people with disabilities could be read as a positive example of how this type of differentiation can be overcome through the production of competence and expertise in community, the recognition that people with disabilities are experts on their own (individual) embodiment that need to be heard and included when developing new aids and tools. Still, the fact remains that sheer physical or mental difference can easily lead to the exclusion of people with disabilities from the promise of do-it-yourself. Moreover, self-optimizations as they are perpetuated by DIY biology and medicine have a hyper-able subject as the desired and promised outcome – furthering instead of questioning the dominance of an ableist culture.

the narrative and promise of democratization. Already today, a high degree of disposable income is needed to afford the tools and technologies of DIY biology and medicine, which is reflected in the current make-up of the movement: At the moment, DIY biology and medicine is still a very much White, middle-class phenomenon for people with higher degrees of education and income.³³ While more development might make technologies cheaper, chances are high that self-knowledge and self-enhancement in a consumerist society will always come with a price tag. DIY biology here might continue a division in society, where those with higher social status already today have better access to health care, self-knowledge and (medical) interventions. Biopolitical governance is no exception, as it often (re)produces racism and differentiation. Many people are “denied the right to health” and cannot make decisions about their health: “their biological selves are precarious and exposed to illness, injury, death – unavailable for preemptive intervention and optimization” (Krupar and Ehlers 4). Racism, Daniele Lorenzini recounts (following Foucault), is a way to differentiate populations, “the biological continuum,” and create hierarchies between different human groups – some of which will be exposed to risks of death more readily than others (43-44). Differential distributions of value, life chances and vulnerability, thus, are an inherent part of biopolitics and biopolitical governance. According to Krupar and Ehlers, the result is a (deliberate or not) logic of “let die” in which some parts of the population are harmed to protect others. The lines between those groups are sometimes blatantly obvious, but most of the time less so, reproduced by the biopolitical system itself. Practices that “foster life” can at the same time devalue other lives, especially those “at the peripheries of ‘ideal’ citizen/subjecthood” (Krupar and Ehlers 4, 12-13). These differential valuations, of course, affect disabled people and Black, Indigenous, People of Color (BIPoc) more often than others.

In addition, gender can become a source of social stratification if we talk about limits to access. Historically, DIY practices have often been divided along gendered lines. Looking at contemporary “bio-making’s” gendered dimensions, Clare Jen argues that scholarship should also consider classed and gendered barriers to DIY participation, such as educational barriers, the economic situation, surplus time apart from caregiver responsibilities, or unwelcoming community labs (127). She claims that often the narratives, spheres and mythologies of bio-making are male-centered, discounting female biohackers, their contributions and the long history of systematic exclusion from scientific participation. In fact, also many of the protagonists I encountered during my research were male – it is certainly noteworthy how, for example Wohlsen, describes female biohackers in different terms than their male counterparts.³⁴ Such representa-

33 For example, Lupton writes that owners of wearable devices are more likely to have a higher household income (*Quantified Self* 31). The affluent and those who can buy into new developments in healthcare have better access to medical care and could, with the increase in personal health technologies, also have better access to those, leading to a widening gap in healthcare (N. J. Fox 149). A 2006 Report on Human Enhancement (2006) similarly ascertains that more affluent members of society gain access to new technologies, also health technologies and human enhancements, sooner than others, increasing their advantage (Williams 9-10).

34 For example, in Wohlsen’s *Biopunk* Kay Aull seems to have to measure up to traditional images of scientists as male: “Aull is tall and beanpole skinny. She carries herself with the stiff awkwardness

tions, or under-representations, might shape the whole movement going further, leading to a perpetuation instead of a transformation of those traditional exclusions. In contrast to the dominant, male-centered mythologies Jen argues that “feminist biohealth hackers” have contributed a great deal to the movement, citing examples such as Kay Aull and Meredith Patterson (135).

The global dimensions of DIY biology and medicine and its possibility for segregation warrant closer attention for many reasons: DIY is inherently privileged in the US, people opt out of a system by choice, while in other countries DIY might be a necessity simply to be able to take part in biomedical innovations (that save lives); the DIY movement itself has discovered global questions as a valuable concern, and, lastly, the question of access is much more pressing on a global scale. Especially when we look at DIY biology’s newfound interest in global questions of resource distribution and access – with its concomitant projects that try to amend some of the more pressing concerns – we soon realize that despite of good intentions these practices can also be deeply problematic.

For one, “privileged bodies,” as of today, are primarily located in the Western hemisphere: They are the ones benefiting from technological innovation for their own life projects, for them DIY is fun, a hobby.³⁵ Especially when DIY is used for enhancement and optimization, it is not an equalizer but a differentiating force: Underprivileged people(s), in the current frame of DIY biology, might become even more disenfranchised, widening the gaps that already exist today, in relation to ‘biological’ categories like life expectancy, mortality, vulnerability, but also levels of education, employment rates, household incomes, and so forth. In large parts of the world, what we term DIY is an (economic) necessity. Where access to high-priced but potentially lifesaving technologies is missing, DIY solutions might be the most feasible way of granting access to these technologies, as the example of the LavaAmp hack demonstrates (cf. Case Study IX). One could argue that any tool is better than none, especially if they are functioning well; that sometimes the cheaper but ingenious solution is making the best use for the most people out of limited resources. However, allocating DIY solutions to low- and middle-income countries as a replacement for the ‘real thing’ perpetuates problematic distinctions and associations. Should we accept DIY’s make-shift, cheaper, and ‘just-as-good’ solutions as the answer to global problems of resource distribution? DIY here might become an easy-way-out that avoids large scale, controversial – and for large parts of the world also painful – reflections and discussions about privilege, entitlement and the worth of human life. In the global perspective more than the local one we thus also touch upon questions of *distributive justice*. How and where biotechnologies can be used highlights how resources, benefits and burdens are divided unequally between

of an adolescent boy still not used to his overlong limb.” (Wohlsen 9). Why is Wohlsen comparing her to an “adolescent boy” or why is her marital status of more importance than in her male co-biohackers’ descriptions? Even if done subconsciously, Wohlsen seems to treat his male and female interviewees slightly different.

35 What should be noted as well is that DIY biohackers in countries like the US do have a functioning medical system to fall back on, for example if they harm themselves in the process. When such a comprehensive medical system is missing, people are even more vulnerable.

peoples and nations. This of course, is also a moral and philosophical question concerned amongst others with social justice and collaboration on an international scale: What is needed to live a dignified life and who has the responsibility to facilitate that (cf. Nussbaum), how can we ensure that a right to bodily integrity and health (prior to potential optimizations) is guaranteed for everyone, how do resources have to be redistributed to reach a state of equality and equal opportunity around the globe? Or more to the point: For example, the often-claimed access for all would require large scale literacy and education efforts, redistributions of wealth (to allow people to buy into DIY practices) and technologies (to provide the tools), if it were aimed at a global level. These requirements are not met on a national level and even less on a global one.³⁶

Moreover, because DIY biology as a cultural phenomenon has emerged primarily in the Western world and large American and European cities, as Meyer writes (“Build” n.p.), their subsequent spread to other parts of the world could be seen as a new form of American exceptionalism, where American definitions of health, of ideal bodies and lives influence cultures around the globe – and this is especially true for commercialized solutions. As we have seen, numbers, norms, data and technologies shape bodies and experiences of embodiment, and those might not necessarily be built with diversity in mind. Rather, they reflect the worldview, environment and prejudices of their producers, which carries with it tremendous potential for discrimination. If tools are produced by Western biohackers for people in low- and middle-income countries, we also risk perpetuating a new form of *technological colonialism* in which Western hackers are portrayed as the heroes and saviors. Instead of strengthening local solutions, of empowering local amateurs, makers, hackers and ‘need-knowers,’ DIY technologies might be exported by the West. This of course is an inherently negative future trajectory that perpetuates outdated differentiations, negates the competence of other peoples, and buys into an American myth of (moral) superiority and virtue – taking away much of the diversity, creativity and chances provided by DIY.

On the other hand, the opposite might become true as well: DIY and making do take different forms in different countries. Ideally, through DIY local problems can be addressed using a new epistemological practice – *local solutions for local problems*, arrived at through an epistemology based on participation, experimentation and creativity. Jen’s feminist analysis of biohacking practices touches upon such considerations. She argues that alternatives to biomedicalization were often constructed by feminist bio-health hackers out of necessity and the realization that they could cater to their own needs better than the establishment (135).³⁷ Today, this feminist impulse, Jen claims, is visible also in biohacking efforts that replicate PAP smears, a common gynecological diagnostic tool, with vinegar in Thailand (McNeil).³⁸ If we consider access to healthcare and ed-

36 Of course, such question cannot be answered in this short discussion of DIY’s common themes, potentials and downsides. I still want to raise them to point out larger (even though future) considerations and potential outcomes of some of the DIY practices today.

37 Jen includes women’s self-help groups as examples: “Pelvic self-exams, using speculums and mirrors, gained practical and iconic significance as an empowerment tool and technology of resistance.” (135)

38 This “hack” was developed at John Hopkins medical school. Household vinegar can be used as a cheap tool to find and treat pre-cancerous cells, McNeil explains, by simply brushing it on a

ucation as a *universal right*, DIY solutions could unfold a transformative potential that allows people access to both cheap and effective healthcare solutions as well as (science) education to empower local replicators to create their own solutions. People are empowered to create their own solutions because they know what they need and how they need it. DIY and the maker movement, with its possibilities of small-scale and localized production, provide the tools and technologies to make those visions a reality, with the downside of the as of now high costs associated also with DIY. When knowledge is transferred – on an equal basis – the transformative potential of DIY in low-income countries might even be bigger.

In summary, today we do not necessarily find the access touted by DIY biologists. As is visible in the introductory quote for this section, Patterson likewise seems to misjudge the exclusiveness of her own community, driven by ideals that as of now still need to be fulfilled. Intersectional considerations would also be interesting, as the convergences of class, gender, (dis)ability and race/ethnicity might shine a new light on exclusions from DIY's promise. But first we need to recognize DIY as the privilege it is, at least in the form it is done in most of my examples, as a conscious dissociation from the system, a voluntary outsider status. A global perspective on the differentiations produced by DIY biology necessarily also includes broader questions of resource distribution, human rights, and equality. DIY could here be seen as perpetuating the underlying problems of unequal distributions while at the same time providing a possible solution by making the technologies available in the first place. It is, however, on a global scale that I would see the largest downsides to DIY's democratization narrative – from which large parts of the global population are excluded anyway for the simple reason of lack of access to education and capital to buy into its promise.

Collaborative Individualism

So far, this discussion has focused on the negative effects of the individualism that carries DIY practices. But, as many of my case studies have shown, DIY can also be a collaborative effort. Often it is not just the individualism one might expect from DIY techniques that is performed but an interplay of both individualization and collaboration. I would argue that the forms that DIY takes today, in the sectors that I am looking at, manage to integrate both: they combine an individualist, project-centered view with community integration and collaborative inquiry. More so, they depend on each other for success.³⁹

We can here take inspiration, once more, from Nikolas Rose and his work on “biological citizenship” with Carlos Novas. For them, biological citizenship is both individ-

woman's cervix. Pre-cancerous cells turn white and can be treated “frozen off with a metal probe cooled by a tank of carbon dioxide, available from any Coca-Cola bottling plant” (McNeil).

39 Individual projects rely on collective knowledge and sharing, for example, by making use of tutorials or advice groups, using the wisdom of the many to find a suitable approach. At the same time, often collective projects also depend on individuals to take part and refine them: For example, large scale DIY or commercial genomic studies rely on individuals to share their data for a common cause; large scale citizen science efforts rely on individual contributions of time and knowledge.

ualizing – the somatic self and personal responsibilities – and collectivizing through the creation of new forms of “biosociality” (Rabinow), creating new collectivities around biomedical classifications (441-42). This duality is also visible in DIY. Genetic and molecular testing, for example, is based on individualization, personalization and self-knowledge, but it is also inherently relational. Similarly, in many efforts of biomedical tinkering with technology knowledge and literacy are produced through collaboration and community. We experience a growth of new forms of community, new forms of solidarity and social networking in spite of the pervasive rhetoric of personalization (Rose, “Personalized Medicine” 350-51). These include patient and advocacy groups – such as the Open Diabetes Community – and other groups organized around new types of knowledge and new molecular identities and experiences of embodiment (cf. Pavone and Goven 13-14). This new community of practitioners demands new rights to access, participation and knowledge. It is a form of activism similar to those older forms of biosociality. “Making is connecting” is the basic formula that Gauntlett finds for this phenomenon: connecting things, connecting ideas, connecting people (2).

The internet plays a crucial role for this process of community formation in DIY biology and medicine. As a space of exchange, community and empowerment, it provides fertile ground for the formation of not just physical meet-ups but also “virtual communities” (Csordas 178). The boundaries of and membership in these virtual communities, according to Thomas Csordas, are fluid, which makes them perfect tools for collaboration among groups as well as a project-oriented creation of teams with shifting competencies. But those new collectivities are also created and fostered through the media and discourses: Cultural representations work as collectivizing instances that produce community. DIY biology and medicine’s community-oriented nature, therefore, satisfies not just personal scientific curiosity but also an inherent human need for social connection, as I have also discerned in Case Study V. We can borrow aspects of Benedict Anderson’s concept of “imagined communities” to describe the communities that arise out of DIY biology: Even though many of their members will never meet each other, they nonetheless feel a deep connection, “in the minds of each lives the image of their communion” (6). This (imagined) connection is based on similar interests, similar values or similar experiences – depending on the type of community. On different levels, science becomes a collective project, a *social-scientific utopia* in which all stakeholders participate. This collectivity allows for a trickle-down effect that is the basis of DIY’s educational potential: Knowledge is disseminated from those who have it to those who lack it or are currently excluded from it, for example through the structural and personal connections between DIY biology and institutionalized science. As a collective project, DIY biology and medicine also is turned into a form of ‘do-it-with-others’ (DIWO), or ‘do-it-together’ (DIT), new acronyms used to denote collaborative forms of DIY that seem to transcend the individual.

However, the knowledge that is produced in DIY biology and medicine, collaboratively, following scientific standards, is used on individual bodies for individual purposes. What we find here is, what I term a *collaborative individualism* in which people come together to do things individually, in which collectivity and individuality are in constant interplay. While sometimes either one may dominate, they are never really dialectically opposed. Meyer borrows the term “connected individualism” (Flichy) to de-

note this inherent connection between the individual and the collective, “halfway between individual practices and group practices, between the logics of autonomy and the logics of networks.” For him, this connection is visible in how people might perform biology autonomously in their own laboratories but still rely on the “collectives of people, ideas and objects” formed by DIY biology, the new biotech economies he describes (Meyer, *Domesticating* 19). If we want to stick to the designation ‘DIY’ – due to its cultural purchase or historical continuities – it can be useful to rethink the ‘yourself’ not just as the active individual doing biology but as capturing this individual through its inherent relations to the network of other practitioners and institutions (in the broadest sense). Donna Dickenson also acknowledges that “We” is alive and well in biomedicine in certain instances, that the choice to be made does not necessarily have to be between Me and We but that we can also find a way in-between, combining both.

This collaborative nature of DIY biology and medicine can balance some of the concerns connected with individualism: It creates community, instead of erasing it, social questions and relations become part of the equation, and it creates empathy and cohesion. But is this collectivizing moment enough to transform a broader culture shaped so much by individualist thinking? We need to keep in mind that this newly-minted community is still apart from the rest of society, it is still a rather closed-off group of people. In this community, individualism and collectivism are in a constant interplay of competing interests and approaches as well. In the end, we are left with a paradox of individualism and community, that as of today cannot be resolved. Is the collective nature lived reality or merely a promise, a utopia?

