# 10 "The Human Need to Fiddle" – Tinkering with Technology

Technology and tools – the material basis of DIY biology and medicine – are foundational for the spread of DIY techniques. But they are also intimately related to the overarching premises and ideology of DIY biology. What characterizes the use of tools and technology in DIY biology is their fluidity: Parts are recombined, 'misappropriated' in creative ways, shifting and changing in relation to the user's goals, a playful engagement with one's material surroundings, biology and body. "In light of the human need to fiddle," Wohlsen asks, "why would someone not want to [tinker with biology]?" (43) This playfulness, however, should not cloud the serious nature and transformative potential of those tools and technologies in action.

Tools have always been a primary condition for making: As Gelber has noted, the first wave of DIY as home improvements was facilitated and supported by the increasing availability and affordability of the necessary tools, machineries and materials to perform those improvements yourself: power-drills, fast-drying paint, pre-cut wallpaper, kits and instructions made it possible also for 'lay' users to take on projects in their home (cf. Gelber, Watson and Shove 73). Low-cost training and trial workshops to sell tools as well as classes to teach their use expanded the simple possession of tools with knowledge on how to correctly and safely use them, Gelber narrates. A similar development is visible in the area of DIY biology and medicine: Declining prices for electronics and biotechnology make the needed equipment more accessible and affordable, for DTC uses and DIY projects. Community workspaces, maker spaces and bio labs but also online tutorials and discussion boards have become spaces in which interested people are taught about their safe and correct uses. More than that: Inspired by DIY's third wave biohackers are beginning to redesign tools and create cheaper versions, instead of waiting for companies to provide tools redesigned with consumers in mind (Watson and Shove 73). Tools and technology, thus, become powerful agents of transformation, education and empowerment.

As such they have also drawn the attention of some of the scholars looking at the DIY movement. Morgan Meyer, for example, specifically focuses on the geography and spatiality of DIY bio in connection to its materiality: Through his focus on tools and ma-

terials, he looks at the spaces where DIY bio is practiced as well as the boundaries that are constructed or demolished (*Domesticating*). Meyer argues that "the circulability, the affordability and the mutability of objects play a key role" in DIY biology by contributing to the recent emergence of a "citizen biotech-economy" ("Build Your Own" n.p.). These „citizen biotech-economies" are open, decentralized, collective, and accessible: They not only grant individuals material access to knowledge, objects, and infrastructure, but also imply a socio-political openness. By doing so, they try to foster "a material re-distribution, a democratisation, and an alternative to established, technoscience" (Meyer, "Build" n.p.). In these citizen biotech-economies tools and knowledge flow freely from institutionalized science towards citizen applications (and back as I would add), are distributed, used, rearranged, hacked, reconfigured, and recreated (Meyer, *Domesticating* 13). The case studies in this chapter exemplify parts of these alternative biotech-economies.

Moreover, Meyer's concept already points to a core concern when it comes to the approach to tools and technologies in DIY biology and medicine: Playfulness, experimentation, curiosity about how they can be used differently – "tinkering with technology" as it is often described. For example, Wohlsen writes that the goal of DIY biology is to "'increase the tinkerability' of biology" (24). "Tinkering," in this context, is used as a label to designate a certain approach, a certain type of inquiry. The nature and character of tinkering, according to Keulartz and van den Belt, can be inferred from a distinction made by French anthropologist Claude Lévi-Strauss in in *La Pensée Sauvage* (1962): Lévi-Strauss differentiates between "two modes of scientific thought," a "modern-day 'science of the abstract' based on 'domesticated' modes of thought" and a long-standing tradition of a "'science of the concrete' based on 'wild' thought" (cited in Keulartz and van den Belt 6). "Whereas abstract science proceeds according to the methods of the engineer," Keulartz and van den Belt summarize, "the modus operandi of concrete science is that of the bricoleur or tinkerer" (6). Abstract science or engineering, for them, follows a plan, a goal according to which the materials used are designed. Tinkering or wild science, on the other hand, "works without a clear plan by making creative and resourceful use of whatever materials are at hand to produce new objects that possess some kind of unexpected functionality" (Keulartz and van den Belt 6). The epistemological approach of DIY biology, for Keulartz and van den Belt, is closer to Lévi-Strauss' concrete science of the bricoleur – practical, following a "hands-on imperative" taken from hacker culture with its emphasis on free access to tools and information, knowledge sharing and cheaper solutions (5-10). But DIY biology, as is visible in the citizen techno-economies, also uses tools available through and from institutionalized biology. What we have in DIY biology and medicine, thus, is a fruitful coexistence of both epistemic practices. Mann uses the designation "tinquiry" to capture the idea of "tinkering as inquiry" (29), an approach that also combines inquisitive engineering principles with the resourcefulness and playfulness of tinkering.

According to Delgado and Callen tinkering exhibits the "exploratory and fun dimension of hacking," it is characterized by openly trying things, sometimes repeatedly, in unconventional ways (189). Tinkering, therefore, is not distinct from hacking but rather a part of it. The exploratory and playful approach of tinkering is also visible in Heidi Ledford's notion of "creative work-arounds" (651). Ledford does not provide a defini-

tion for these "work-arounds" or improvisations but she seems to try to capture the creative potential and unconventional nature of some of the technological solutions in DIY biology. Morgan Meyer takes Ledford's "creative workarounds" to denote "inventive ways to work without conventional and expensive material." These workarounds for him happen in two ways: first, the transformation and combination of objects in unusual ways, and second, the circumvention of established scientific institutions and industrial economies, for example when equipment is imitated or donated (*Domesticating* 14). Tinkering, thus, is characterized by creativity, ingenuity, resourcefulness, inquisitiveness. This approach is reflected in how tools are built, used, distributed and shared. But it also influences how technology is approached as a resource that individuals can shape and use according to their needs and wishes – with creativity and openness, not fixed but fluid.

Meyer argues that DIY biology unites the individual – the yourself – with the collectives around them (*Domesticating* 18). An individual's hack, the outcome of their tinkering, is seen as providing a benefit for the larger community. In this sense, DIY biology is not as much about individuals but more about their communities and collaborations. The 'yourself' is not a concrete individual using technologies on themselves, but an abstract idea of empowerment. DIY here is still often driven by curios minds or individuals, but more than that, it is a community approach and collaborative process. As I have argued in previous chapters and case studies, it is this social nature of DIY biology that brings us closer to its political nature. Delgado and Callen argue that hacking and DIY are technical as well as political demonstrations. They write: "What is hacked is not only a site that was inaccessible before (i.e. biology or electronics) but also the way of accessing it. By exposing themselves as easy and unsettled, hacks work as tangible demonstrations that '*you can also do it*'. In doing so, such demonstrations are not only technical but also political." (189) DIY biology opens up not only different alternatives of doing something but also demonstrate that 'you' can do them too: DIY hacks "tangibly *show* that realities can be modified and that '*you*' can do it" (Delgado and Callen 181). This is true for all the examples in the case studies under consideration here.

In this chapter I have chosen to focus on two different types of using, making and (re-)combining technology to create cheap, functional and practical solutions. Case study IX "Cheap and Functional," approaches DIY biology from a technical side, by looking at tools that are created in and for DIY labs. I look at the spaces and tools of the biohacking lab through their cultural representations and self-presentation. Case study X "Practical Solutions" then combines this view with projects that connect DIY tool-tinkering to medical uses, more specifically, two 'hacks' for DIY medical devices that were developed in the diabetes community – direct interventions into the body using a playful amalgamation of hacked, commercially available and self-made parts. This chapter thus shows real examples of how the DIY, maker, and hacker ethos is fruitfully employed in the area of biology and medicine. It nonetheless, of course, shares and exemplifies some of the core themes of DIY biology, such as access, open-source ideology, hacking and collaboration.

## Case Study IX: Cheap and Functional – Making Tools for the Biohacking Lab

Cheaper, easy to use and nonetheless highly accurate – those are the goals for many of the hacked solutions in DIY biology and medicine. This case study looks at its basics: the spaces and tools needed to perform biology yourself. More than mere examples of DIY possibilities, these reflect some of the most fundamental concerns of biohacking: materiality, domestication, simplicity, openness, access, as well as its social and political nature. In this case study I try to access these examples through their cultural representations, more precisely, the narrative that Marcus Wohlsen creates around them for his book *Biopunk* as well as some of their self-descriptions on the Web. Wohlsen's *Biopunk*, which I have mentioned a few times already, is one of the first comprehensive overviews of DIY biology in the non-fiction science sector. A trained journalist, Wohlsen has set out to describe the biohacking and DIY biology movement in its different facets – 'translating' practices and knowledge for his reader along the way. For this discussion, four of his chapters are particularly relevant because they look at ways in which technology is used, hacked and created. Already their titles can tell us a lot about how Wohlsen frames the biohacker's use of technology: Chapter 2, "Outsider Innovation," points to the distinction between institutionalized and 'domesticated' science as well as the hacker's position outside of the system; Chapter 4, "Make/Do," refers to the hands-on and creative approach to biology that is typical of tinkering; Chapter 5, "Field Testing," alludes to the possible scope of DIY innovations and with it questions of (global) access; Chapter 6, "Cheap is Life," indicates the goal of affordability – and thus access – as well as DIY's potential to save lives with its reconstructed tools for high-tech biology. At the heart of these chapters are specific tools designed and built by the DIY community as well as their makers.

Technology and tools for academics, journalists and practitioners alike have been crucial for the development of DIY biology and will continue to shape how it is practiced and by whom. Famous maker Chris Anderson includes an introduction to DIYbio in his description of the maker movement. What stands out is his pronounced focus on the cheaper, more accessible and modifiable lab tools produced by DIY biology: He argues that so far DIYbio has been "less about doing new science than about democratizing the tools of science" (C. Anderson 221-22). This democratization has taken different forms. On the one hand, we have the redistribution of technology that Meyer described: As a result of technological innovation and rapid price drops for biological technologies combined with the crisis of 'Big Bio' during the last recession, Delgado and Callen summarize, cheap and second-hand equipment has become more widely available on sites like *eBay*, making it easier and cheaper to set up laboratories (180). On the other hand, biohackers have taken on the challenge of creating alternative solutions to expensive technologies. Science journalist Erin Biba writes in her article for *Wired* that "thanks to the DIY revolution" and its open-source technologies like Arduino, biohackers can take a shot at "reverse engineering the big-budget tools" and then share their approaches: "Behind the scenes, engineers and science enthusiasts are teaming up to mod tools and technologies and then sell their inventions—or simply share tips on how to build them—to anyone interested," she writes (Biba, n.p.). Technologies are modified, recombined or copied and then brought into the community of biohackers.

Wohlsen acknowledges this crucial role of tools for DIY biology as well. He references biohacker Mackenzie Cowell's believe that "the DIYbio approach will put the tools they need within reach." Simple, low-cost tools and techniques built by the amateur community, for Cowell, will lower the costs of setting up a lab tremendously (22). This focus on affordability and access is combined by Wohlsen with considerations of epistemic approaches – the often-referenced playfulness – as well as places such as garages and bars as new spheres where "science can happen." (23-24).

In fact, Wohlsen's second chapter opens with this very idea of new places and spaces for biotechnology, or more precisely, with the common image of two separate spheres: the lab and domestic spaces.

> Labs are where science gets done. The home and the lab are separate places symbolizing separate realms of knowledge, separate practices, priorities, and precautions. This feeling holds especially true for molecular biology. Anything the size of a cell or smaller is out of scale with domestic life, where the only cell visible to the naked eye is the chicken egg in the refrigerator. (Wohlsen 18, my italics)

This passage alludes to the spaces in which science *should* be practiced but also the uneasiness about potentially invisible molecular agents in domesticated spaces like the home. His focus on symbolism is especially interesting since he references cultural norms and values, not just about what a 'lab' and a 'home' mean but also about different epistemic practices in science and outside of science. The home seems to represent 'wild science,' tinkering, while the lab stands for institutionalized science, engineering. This distinction between lab and home, I would argue, also corresponds to boundaries between home and work, private and public life that biology as a hobby – and not a profession – promises to derail. Very present as the narrator of his account, Wohlsen himself seems to be rather cautious about this new conflation of long-set cultural boundaries, as he demonstrates in the closing paragraph of this chapter:

> Biohackers want to make the rest of us okay with the *counterintuitive coming together of biotech and basements, of DNA and dinner tables*. They not only believe the mass migration of biotech out of the lab and into the home should happen. They believe it will happen soon and that we all should pretty much not worry. *But the sell may not be easy*. (Wohlsen 27, my italics)

He implicitly positions himself and the reader as apart from the biohacking scene, as cautious and critical voices against a "counterintuitive" foray of biohackers. Choosing this narrative frame – opening and closing the chapter with the same cautious objections – perpetuates the culturally entrenched uneasiness about the conflation of those 'separate' spheres.

Interestingly, his uneasiness about the mix-up of labs and homes does not seem to extend to community workshops, another primary site of biohacking and the main focus of Wohlsen's chapter. A community biohacking lab, we could presume, can also for Wohlsen become a new designated space of biology just like the industrial and research laboratories in Big Bio. "Outsider Innovation" is dominated by detailed descriptions of a maker space/community-based biology workshop called Sprout & Company in a suburb of Boston, Massachusetts:

> The space holds everything a budding biohacker would crave. Two machines for Xeroxing DNA. A squat, steel, sterilizing autoclave, the biolab equivalent of a pressure cooker, complete with a vintage *Mad Men*-era analog pressure gauge sticking off the lid. A electric stirring rod. Tiny centrifuges. A hulking microscope, a rack of pipettes, a deep freezer to calm squirming microbes, and a bright-orange cabinet labeled FLAMMABLE LIQUID STORAGE covered in magnetic poetry. On a high shelf sit bottles of the wet lab's wet stuff. Distilled water. Sodium thiosulfate, a chemistry lab standby. Contact lens solution. An old vodka bottle labeled with an indecipherable chemical formula. A bottle of agarose pellets to make the nutrient-rich gelatin broth that nourishes cells and allows them to multiply in petri dishes. (Wohlsen 21)

This paragraph familiarizes the reader with not just biohacking labs but science labs more generally. It does not only provide a detailed view into the lab with its tools, technologies, cabinets, bottles, pipettes and chemicals but also tries to 'translate' what these tools and chemicals do for a lay audience. Good examples are the "Xerox machine" for DNA, the pressure cooker, or the nutrient-rich, nourishing broth. At the same time, the scientific feel of the lab is interrupted with references to objects that are normally not expected in a lab – the magnetic poetry, contact lens solution, a repurposed vodka bottle. Whether or not tools like these are used in prototypical science labs, these objects do not conform to the standard, sterilized image of a laboratory and thus serve to underline the 'hacker' ethos of a DIY biology lab. They represent the blurring of boundaries that is so prevalent in DIY biology as well as the creative, make-shift solutions facilitated by its approach.

It is not surprising that how biohackers frame their research and approach their projects is also addressed by Wohlsen. An important figure for him is the "tinker." "Make/Do" addresses this underlying approach of DIY biology most explicitly. "In the hands of the most gifted practitioners," Wohlsen writes, "tinkering is an essential form of creativity. But it is a different brand of creativity, practiced in a different spirit, than the kind suggested by the romantic image of the lone artist or genius inventor trying to wrestle inspiration out of nothing." (40) Tinkering, Wohlsen argues, goes against individual technological innovation, against the tradition in the Western imagination of science and technology as a "heroic march of great (mostly) men and their work of genius" (40).[1] For hackers, Wohlsen claims, it is the action that counts, the hack: "Their innovators are not heroes. They are mischief makers. And these tricksters do not sweat

1 This opening for the discussion of tinkering is interesting because even though he does embed them in a larger context, maybe even a group or community, Wohlsen is very much focused on the individuals behind the hacks. This focus, to some degree, evokes the discourse of individual genius typical of scientific knowledge production. Biohackers like Kay Aull, Tito Jankowsky or Meredith Patterson are described in much detail, from their outward appearance, to their educational background, hobbies and marital status. Of course, all these details serve to personalize the DIY biology movement, to give faces to an anonymous mass of, as it is sometimes perceived, potentially dangerous hackers and tinkerers. As such, this narrative approach creates sympathy and to a degree reflects the diversity of the movement. But it could also undermine the focus on community and collaboration, might mold its egalitarian, problem- and solution-oriented approach into standard narratives of scientific invention.

their way to discovery. They tinker." (Wohlsen 41) From the beginning Wohlsen positions tinkering as creative, egalitarian, active, slightly mischievous.

The idea of "mischief makers" leads Wohlsen to the history of the figure of the tinker: This figure has a "rich, complicated history" in Irish and Scottish culture. For centuries, he writes, people at the bottom of the social hierarchy were termed a tinker. "As such, to tinker was to be a vagrant. Tinkering was not the work of an active, contributing member of society. The tinkerer was an outsider, not to be trusted." (41) In Irish literature, for example, the tinker is "a trickster, a rogue, the canny clown" (Wohlsen 41). From a cultural perspective tinkering thus for a long time was seen as rather negative. This negative history – and Wohlsen's use of it – however also emphasizes the re-appropriation of the term, the creative use of all the cultural baggage it carries with it, by turning its negative connotations on their head and reframing the outsider status as an emblem of progress. Today, Wohlsen writes, "[t]inkering has long since taken on a more generic sense of fiddling or tweaking, …But it still retains the idea of work that is not really work. …Tinkering is work you do for fun" (41). Following this reasoning, tinkering becomes a hobby, a work-like pastime, reminiscent of Gelber's description of DIY. Hackers "embrace" the playfulness of tinkering. Yet playing for them is not just entertainment, Wohlsen claims, but an "attitude toward innovation that champions gamesmanship, that prizes intellect applied with competitive vigor and flair" (42). Tinkering in Wohlsen's words becomes a form of material experimentation and an intellectual exercise at the same time. In line with the etymological considerations above, tinkering is thus turned into an epistemic approach and practice.

This intellectual and material experimentation can, according to Wohlsen, have truly transformative effects: "In the same way, the gifted tinkerer can rearrange the already existing engine parts or snippets of computer code in a way that creates something utterly new and potentially transformative" (42). Creative re-arrangements and work-arounds characterize the tinkerer's (and the DIY biologists') approach to technology.[2] The transformation, it seems, does not only take place on the material level of the tinkered object but potentially also on a larger scale. This type of inquiry, experimentation and production for Wohlsen does not only seem to be a particular ethos or approach but, he implies, also a "primal instinct" of the human: "If you believe that using tools is the essential feature that separates us from the other animals, then tinkering may be the most human urge of all – a truly primal instinct. If so, the impulse to biohack starts to seem self-explanatory." (Wohlsen 43) A similar stance is often visible in the maker movement where making is described by some as a fundamental human trait (Hatch). Biohacking becomes just another, self-explanatory way of feeding the human impulse to fiddle and create. In these lines, Wohlsen follows a somewhat naturalistic discourse that stands in contrast to the open, constructivist approach of DIY biology: Tinkering,

2 Despite his largely positive evaluation of tinkering and hacking, Wohlsen also acknowledges that this unusual, "ragged around the edges," creative approach to biotechnology is "source of much of the skepticism directed at outsider biology" because it runs against the "unshakable premise of wet lab work" – ordered, organized, sterile – that is believed to stave of the existential risks of biological experimentations for the research subjects and the wider community (Wohlsen 56).

using tools, here becomes a primary marker of humanness, our biology just another material to use and abuse to feed our own instincts.

The creative use, modification and recombination of technology is one of the ways in which DIY biologists try to fulfil their vision of a democratized and domesticated science. "In DIY subcultures of all kinds," Wohlsen writes, "hacking the costs of materials, equipment, and labor is always a top priority" (60). Part of these efforts to hack the costs is the use of readily available or simpler tools to achieve the same purpose. A good example are common household "chemicals:" They are readily available and relatively affordable. That also means that the "raw materials of biotechnology are always just a supermarket away," as biohackers often observe (Wohlsen 47). Those simple tools, nonetheless, can provide profound and powerful insights:

> Using a few household chemicals, anyone can break open a strawberry cell's walls and isolate its genetic core. At the end, you twirl the stringy stuff of life on the end of a chopstick. Suddenly DNA ceases to be an abstract concept, a sci-fi-tinged computer-animated demo of a double helix. Here it is, right in front of you: the physical crux of everything that lives. (Wohlsen 46)

A household chemical like dish soap can grant you a view into the material basis of life, turning DNA from an abstract concept into a concrete reality. But for many biohackers, using readily available materials simply is not enough: They want to make the high-tech equipment of Big Bio affordable and accessible for the masses.

One example is the "OpenPCR" project by biohackers Tito Jankowski and Josh Perfetto. PCR (Polymerase Chain Reaction) machines, or thermal cyclers, are an essential tool for amplifying DNA in a biological laboratory. Wohlsen describes these machines as a "photocopier" that "did for labs what Xerox machines did for offices" (Wohlsen 65). Basically, what a thermal cycler does is to heat up and cool down reagents and DNA in a specific order for specific periods of time, thereby allowing short DNA strands to be multiplied through polymerase chain reaction. This technique is used, for example, as a first step to map genomes, detect the presence of bacteria and viruses (through their DNA) or diagnose genetic disorders. Since PCR was invented, the machines that perform this work have, in Wohlsen's words, become "more advanced, more precise, more digital" but they also "cost a lot" (65). These high costs have for a long time prevented community laboratories and individuals from using the technology for their own purposes. But because PCR has become one of the most common techniques in molecular biology, DIY biologists have set out to construct their own versions of the machine.

Part of the "growing DIYbio and garage biotech movement" (Kickstarter, *OpenPCR*), Jankowski and Perfetto are two of them. Together, they wanted to create a low-cost, open alternative to this expensive but essential piece of equipment (Ledford 652). Wohlsen describes the OpenPCR as the "size of a toaster," made out of wood instead of plastic, with a digital display that "tracks the heating and cooling cycles" (Wohlsen 66). The "guts" of the machine are build using the open hardware system Arduino, and the "machine will tweet or text you when it's done" (Wohlsen 66). Available since 2011 OpenPCR is sold and distributed by Jankowski and Perfetto's company Chai Biotechnology. But its beginnings were much smaller. After building and improving their first prototypes, Jankowski and Perfetto looked to the crowd for enough capital

to bring OpenPCR into production. In June 2010 they started a fundraising campaign on the famous platform *Kickstarter*. Their plan, they write, is to create an open-source design that anyone can build, that uses "off the shelf parts" and is easy to maintain (Kickstarter, *OpenPCR*). Their campaign was immensely successful. In about 10 days they had reached their initial goal of $6,000 and until July they had doubled their goal. With more than $12,000 the project was officially funded (Kickstarter, *OpenPCR*). Their promise of openness and access seems to have won over the *Kickstarter* crowd and the DIY biology movement. This approach of openness is also emphasized on their website. OpenPCR, they write, is "100% Open Source;" hardware, software and protocols are openly available (Chai Biotechnologies, "OpenPCR - the $499"). Customers can either buy a DIY kit or download the "IKEA-like" open-source instructions. Open source here becomes a facilitator of access but also a means of engaging a community, of making products better by involving the masses.

Openness, for biohackers, equals access. On the OpenPCR website, the machine is described as "A Thermocycler for Anywhere" that due to its low cost and small size "makes PCR accessible to anyone" whether in a small lab on a budget or in the field (Chai Biotechnologies, "OpenPCR - the $499"). Fittingly, their aim is to "democratize access to molecular diagnostics:" They try to make these "fundamental technologies" "universally accessible, without exorbitant costs or intellectual property issues." This universal access, for them, would allow people all over the world to use PCR to address "challenging global issues," for example "point-of-care medical diagnostics in developing countries" (Chai Biotechnologies, "OpenPCR About"). Their vision is a "world where molecular diagnostics are routinely used by all and do not require specialized knowledge" (Chai Biotechnologies, "OpenPCR About"). Here their DIY biology background takes effect: What counts is the use of the technologies, the action, the hack, and not the credentials of the user.[3]

Their motivation, therefore, aligns with broader concerns of distributive justice and globalized access: Who has access to technologies and who is disenfranchised from their use (and benefits)? Wohlsen takes up this concern as well: He tells the story of Guido Núñez-Mujica, a Venezuelan biohacker. Núñez-Mujica is one of the developers of the *LavaAmp*, another tool used to replicate DNA. The *LavaAmp* is a small thermal cycler, a metal box that heats up, cools down, and heats up again making PCR possible. The

3 The *Bento* lab is a similar, somewhat younger and more commercialized alternative: Funded through *Kickstarter* as well (raising thrice their goal in 36 hours), the *Bento* lab is described as a genetics and biology lab for everybody, whose basic version can now be bought for roughly £1,500. What the producers of *Bento* criticize is that despite being "fundamental technologies of life" that "concern all of us," genetics and molecular biology are still the domain of a "small number of experts" with access to laboratories and knowledge. *Bento* is a personal DNA analysis lab, that includes a centrifuge, PCR thermocycler and gel visualization, through which they want to make molecular biology inclusive and accessible, enabling "professionals and non-professionals to engage with genetics in an open and responsible way" (Bento Bioworks). Easy to use and travel with it is meant as a tool for "hands-on" genetics that can be used in different settings: The user reports they provide range from molecular biology as a hobby, to hands-on teaching in schools and colleges, to citizen science efforts. Genetics, it is their wish and promise, can with the *Bento* lab be experienced everywhere by everyone (Bento Bioworks).

*LavaAmp*, according to Wohlsen, is the progress of science boiled down into a simple yet remarkable piece of equipment that will let scientists around the world manipulate DNA "at least about as easily" as in a lab (Wohlsen 55). Núñez-Mujica is himself a trained biologist who wanted to create a new form of test for a disease prevalent in his home region based on the genetic signature of the parasite itself. This test, ideally, would be portable, simple, and off-the-grid, so that it could work as a "rapid response kit" for underserved regions. "Núñez-Mujica," Wohlsen writes, "was inspired by the desire to invent more options for those like himself with access to less" (50-51). Structural factors are important here:

> His stake in making the tools and techniques of biotech accessible to more people is more personal than that of most of his peers in the United States and Europe. *Biohackers in the developed world are typically outsiders by choice.* Companies and schools have the tools, but do-it-yourself biologists are willing to trade that access for the freedom to do what they want the way they want to do it. (Wohlsen 50, my italics)

Núñez-Mujica's university lab, according to Wohlsen, has a lower budget than a typical American school lab. In the face of high prices, they necessarily have to be inventive. Wohlsen's evocation of "outsiders by choice" is particularly interesting because it highlights how biohackers in the "developed world" are privileged despite their own abandonment of this privilege. In other countries, it is implied, biohacking becomes a necessary means of 'doing' biology at all. It is here that DIY biology could leave its biggest mark, by fulfilling the hopes of biohackers like Núñez-Mujica to "make the tools and techniques of biotech truly available to everyone" no matter where in the world they are (Wohlsen 52).

What becomes apparent in Wohlsen's discussions of tools and technology in the biohacking movement is its political nature and potential. DIY biology is portrayed as a bottom-up project with potentially transformative impact. Wohlsen writes:

> Will these playful projects pile up until they reach a mystical critical mass when some alchemy of innovation transforms fun into serious and important work? In Patterson's ideal world, the fruits of creativity will sprout from below rather than fall from above. Moreover, if innovation emerges from the ground up, then perhaps its benefits will come more quickly to those at the bottom. (Wohlsen 48)

This bottom-up approach, Wohlsen communicates, has the potential to include more people into the innovations and transformations that DIY biology brings with it, especially those usually disenfranchised from scientific innovation. In this quote, the bottom-up approach ties into the concern with distributive justice, globalized access and participation in technological change. DIY biology, once more, becomes not necessarily an individualized preoccupation but a social concern.

Tito Jankowski, according to Wohlsen, argues that today we are faced with a new context, in which people want to contribute to biotech in set-ups that differ from typical lab situations, such as those in garages, community labs, or high schools (Wohlsen 68). What is at stake, here, are also questions of literacy and biological education. Erin Biba writes that "people inside the biohacker movement," when asked about where it will have the most impact, "talk about education—being able to do genetics in classrooms"

(n.p.). Jankowski, Wohlsen writes, "hopes to introduce young people to the tools and techniques of biotech in a way that makes gene tweaking as much as part of everyday technology as texting." This educational focus, the aim of increasing the biological and scientific literacy of a broader mass of people, will allow them to "recognize and contribute to" "biotechnology's great promise" (Wohlsen 68). The question of literacy, taken up again and again by Wohlsen and his exemplary biohackers, is one of taking part in social, cultural and political discussions about the (future) uses of biotechnologies. Hands-on approaches as they are promoted in DIY biology and medicine are perceived to be better facilitators of this type of literacy than typical forms of translation, mediation and popularization.

In addition, Wohlsen emphasizes that DIY biology can also be political for the self. "Jankowski," he writes, "hopes that tools like his will help more people overcome the feeling of disconnection they have from their DNA" (68). The alienation from an abstract idea of DNA, according to Jankowski, should and can be overcome through an active engagement with its underlying concepts and ideas. Similarly, Wohlsen writes, Mackenzie Cowell thinks that through DIY biology, "outsiders" can be "shown that they can have fun with science, can play with these tools and ideas that are treated with such gravitas." By facilitating a more playful approach to science, Cowell believes, "they may begin to feel closer to themselves as they unlock the mysteries of their own organic being" (Wohlsen 25). Here, DIY biology – in its different forms of concrete engagement with biological materials – is connected to hope for more self-knowledge and a closer relation to (one´s own) biology. The politics of DIY biology begin to intervene in the personal just as much as the personal can become political due to its embeddedness in social and cultural structures.

## Case Study X: Practical Solutions – Open Medical Devices and the Diabetes Community

The ideology of open access, collaboration and practical solutions that we can witness in DIY biology's use of laboratory tools and technologies also extends to medical problems and assistive devices. In this case study I look at citizen science and maker approaches to medical-technologies that promise individualized solutions.[4] Also here making and do-it-yourself have led to fruitful co-operations, creative approaches and transformative

4 Another example of creative hacks and practical solutions in the realm of DIY medicine are assistive devices produced through collaborations between makers and people with disabilities around the world. With the rise of the maker movement and its technologies for small-scale, digitalized production communities of makers have formed that use their skills to produce cheaper and individualized solutions for people with disabilities. Technologies are used to help those who struggle with physical constraints to navigate an inherently ableist world more easily and to facilitate social participation and autonomy. Making and tinkering with devices and technologies can thus give access to those who usually are *not* the first ones to gain access. Examples include e-NABL, a maker community producing 3D printed prostheses for people with limp differences (Owen and e-NABLE) or Makers Making Change, a Canada-based community (Neil Squire Society/Makers Making Change). Their solutions are shared based on open-source principles, so that everyone around the world can access and use them.

experiences. More than in the examples in case study IX, when medical technologies are concerned the hack materializes in and on human bodies, changing and shaping lives and experiences of embodiment. A special focus is on the Diabetes community who have been actively involved in creating DIY solutions for problems that commercial providers did not (yet) address and have, according to Dana Lewis, been "experimenting and self-modifying diabetes devices and technologies for many decades" to achieve better quality of life results (D. Lewis, "History").

DIY solutions to medical devices are, of course, set in the broader context of the (American) health care system, especially the move towards personalization and domestication of monitoring and therapy previously conducted in health care institutions (N. Fox 138) and the turn towards more patient involvement and responsibility. Today, mobile devices allow "consumers to diagnose and treat their own medical conditions without the presence of a health professional" (Greene 306). Such practices of "DIY Medicine" are getting more common through cheaper and portable technologies such as sensors and genetic tests (Delgado and Callen 179). But more than that, medicine has also become a sphere for hacker involvement, for DIY solutions to unavailable or expensive technologies – as some of the examples in previous case studies have already demonstrated. Delgado and Callen argue that DIY medical makers and hacks are a response to a perceived precariousness and vulnerability of the body in times of reduced state-facilitated health care. As such they can be considered as political demonstrations that reveal the precariousness embedded in the system and at the same time evidence technical ways of coping with it (Delgado and Callen 179). The geographical distribution of medical-technology hacks underlines this proposition: Developing alternatives to established health care practices through DIY practices is more common in the maker/hacker sphere in the US than in European groups (Keulartz and van den Belt 17). In a system of collective health care and welfare DIY initiatives are not as important as in an individualized, market-driven system that routinely excludes people from its services. What is more, these technologies are also often positioned as good alternatives for people in countries that lack comprehensive, accessible and affordable health care around the globe.

DIY medicine, however, is not a completely new phenomenon: Historically, the first DIYers in medicine were clinicians and medical professionals, a generation of post-war "clinician-engineers" that "tinkered" with medical technologies with the aim of making them cheaper and more widely available. According to Greene, "do it" for them meant "the ability of savvy amateurs to build and reengineer their own medical devices" and "yourself" was limited to physicians (Greene 306-07). Today, in contrast, DIY in the context of health care technologies often does not mean a "productive act of building" but "the consumptive act of buying" proprietary software, technology and applications, Greene maintains. "Doing it" equals becoming actively involved in your own diagnosis and treatment, bypassing the doctor, and "yourself" indicates the "patient-consumer" (306-307). While this type of modern DIY does fulfill its "liberatory promise" by freeing the patient from dependence on doctors or the clinic, it also creates a new type of dependence on applications, technologies and the companies that produce them (Greene 306-07).

Between these two, there is room for creativity and experimentation. As Greene argues as well, DIY today can take on another meaning, one between professional engineering and individual consumption: "an expanding community of device hackers and self-experimenting amateurs now use their considerable technological literacy to circumvent physicians, manufacturers, and regulators alike" (307). This third way of DIY medicine – the tinkerers and hackers' way – often includes "strategies for retooling their own devices" such as prostheses or insulin pumps (307). For Greene, despite the risks associated with individuals potentially altering lifesaving medical devices themselves, this is a "powerfully egalitarian" form of DIY medicine that emphasizes the users' role in the production of medical technologies (307). In medicine, this type of 'tinkering' with existing technologies to serve a personalized agenda is one of the main forms of DIY interventions. People use existing tools and reshape them into an individualized solution, subversively reengineering them in the process.

Nick J. Fox takes on personal health technologies (PHTs) as one form of DIY medicine. He explores the assemblages of bodies, technologies, and relations around PHT use in order to assess their micropolitics, also in relation to different stakeholders and future developments.[5] One of his examples is the micropolitics of insulin pumps: A "fully integrated blood glucose monitor/insulin pump" does, he writes, "liberate" people with diabetes from "time-consuming and complex self-management," but it also "fundamentally" changes the relationship between disease, patient and professionals.

> Responsibility for self-management is removed from users, replacing an 'expert patient' (Shaw and Baker, 2004) with sophisticated understanding of his or her disease and its management with a 'dumb patient' who merely has to wear the device and follow any instructions it provides to the user (e.g. to inject an additional insulin bolus if blood glucose goes too high). (N. Fox 142)

Instead of fostering a collaborative connection between patient and professional, it preserves an outdated one, based on passive patients and active medical specialists, manufactures and devices (N. Fox 141-42). In contrast, the practices under discussion in this case study undermine his criticism of "dumb," uninformed users reliant on experts and technology: Instead, they demand a patient that is actively shaping the process, makes themselves familiar with the technology and its potential shortcomings. I will demonstrate that the DIY approach catapults the patient into the role of designer and producer, a specialist on their individual devices. Their disease is not passively managed by machines and professionals but actively intervened in by the patient.

The *Nightscout Project*, a free and open-source solution developed for children and adults with Type 1 Diabetes (T1D), is a prominent example of how commercialized solutions are extended, by patient-specialists, to serve their own needs. It is a DIY modification of a commercially available continuous glucose monitor (CGM), a small device that people with diabetes can use to measure their glucose level – a clinically useful type of

5 Fox focuses on the examples of four different PHTs with differing objectives, from biomedical to independent uses: Blood pressure monitors, Fitbits and self-tracking technologies, insulin pumps as well as implantable cardioverter defibrillators for the monitoring and management of heart arrhythmias (N. J. Fox 139-40).

self-tracking. CGMs work subcutaneously with needle sensors, can be worn for different periods of time and measure the blood glucose level at pre-set intervals of one to five minutes. Older systems had one big disadvantage: They did not allow users to directly view their data or access them remotely. The *Nightscout Project* "allows real time access to CGM data via a personal website, smartwatch viewers, or apps and widgets available for smartphones" (The Nightscout Project). Especially parents of T1D children were looking for more reassurance in monitoring their children´s data while they were out of their immediate reach. The goal of the project, thus, was to "allow remote monitoring of a T1D's glucose level using existing monitoring devices" (The Nightscout Project). *Nightscout*, or alternatively called "CGM in the Cloud," was developed by volunteers to enable those parents "to view their child's glucose level while the child was at school, at daycare, playing sports, at a sleepover, or while traveling overseas" (The Nightscout Foundation, "Our Mission").[6] How does the "CGM in the Cloud" work? It is a simple and creative recombination of off-the shelf technologies. Basically, the CGM continuous to measure the glucose level and sends it to the respective receiver or monitor as usual. Users now attach a device to this monitor, that transmits the readings to the internet, where you can then view the data with other web-connected devices. Today, this type of system can be set up for a range of commercially available CGMs.

The development of the first DIY modification is also often narrativized in media representations of the *Nightscout Project* and its community of users: The entry point, most of the time, are the worries of parents with T1D children, more specifically those of Evan Costik's parents. At four years of age Evan was diagnosed with T1D and his whole family had to adjust to this new situation. His parents had to monitor their son's glucose levels closely, including regular nighttime needle pricks and tests, Mike Bradley writes for *Wired*. Soon after, they switched to a CGM, easing his parents' worries a bit, at least while he was in their immediate reach. "But children, it turns out, sometimes leave the house," narrates Bradley. And in this case, their display unit leaves with them, meaning that parents now have to rely on others to check the devices and care for their child (Bradley). John Costik's first experience of dropping Evan off at daycare, Bradley continues the narrative, was the starting point of his hacked solution: the "lack of information" was so "nerve-wracking" that the programmer started creating a DIY solution, a way to coax the CGM to display the data on the display unit but also send it to a cloud, where he could access them from his computer. "He started tinkering" (Bradley). The result of this tinkering was an "Android app that let him monitor Evan's blood sugar on a phone" – a solution, Bradley writes, "that seems so simple it's crazy it didn't already exist." What he created was an obvious, simple solution that made use of already existing technologies by recombining them in a fruitful way. The narrative of *Nightscout*'s proliferation, as it is most often told, continues as follows: John Costik tweeted a screen

6 A short note on sources: The *Nightscout Foundation* has been created out of the *Nightscout Project* Facebook Group, both implemented in 2014. As a non-profit, it can for example generate donations to fund further research and simplify discussions with other agencies, companies or the FDA. The scope of the foundation is slightly broader, including closed-loop systems like the *OpenAPS* as well. Both homepages, however, can work as information sources for those interested in this DIY technology hack.

shot of his hack on Twitter and, Bradley notes, started a "mini-revolution" among all the parents who had wanted similar access to their childrens' data. As Smith writes in his article "A Do-it-Yourself Revolution in Diabetes Care" for the *New York Times* – note the similar vocabulary – by sharing this photo Costik not only caught the attention of a "legion of parents" willing to create similar homemade solutions, but together they "set in motion a remarkable, egalitarian push for improved technology to manage diabetes care, rarely seen in the top-down world of medical devices" (P. Smith). The *Nightscout Project* as a bottom-up, need-based solution is portrayed as a potentially transformative, political act.

The "legions" of parents willing to try such a system points to one of the central features of the *Nightscout Project*: its community orientation. As the *Nightscout* homepage explains: "There is a community on Facebook with members who are parents of children with T1, partners of T1, and people with T1 from all experience levels who will help you get up to speed on understanding and installing this tool." (The Nightscout Project) As of April 2021, this "CGM in the Cloud" Facebook group had more than 35,000 members. The website emphasizes again and again that the development of *Nightscout*, its many new applications and the support for "newcomers" is the result of a large and active community of volunteers (The Nightscout Project). This community, it seems, is also made visible by the *Nightscout Foundation*: Their welcome page features a collage of alternating pictures of (presumable) users and activists of all ages – younger and older kids, adults, male, female – often with their technologies, mostly in the form of smart watches displaying data. The impression one gets is not just one of a lively, active and diverse community but also one of empowerment, of allowing individuals to participate in everyday life with less restrictions (The Nightscout Foundation, "Home"). The *Nightscout Foundation* is very much community-centered in the narratives they create but also in the potential they see: They believe that taping "into the capabilities and drive of the CGM in the Cloud community and the larger diabetes community" can lead to better approaches in diabetes care (The Nightscout Foundation, "Who are We"). Do-it-yourself, also in this case, equals Do-It-Together.

The capabilities of the diabetes community, of course, have already shown their power in the *Nightscout* system itself. As the website emphasizes, it was „[c]reated for and by people with Type One Diabetes" (The Nightscout Project). They do not only have higher stakes in the development of safer products, but possess a more intimate knowledge about what they and their children actually need. As Smith writes: "Now, as consumer gadgets weave themselves ever more tightly into everyday life, patients and their families are finding homespun solutions to problems medical-device manufacturers originally did not address." (P. Smith) These work-arounds are centered on the patient and their needs not on what a corporation offers and the FDA approves – even though, according to Smith, the movement of user-driven innovation has impelled the FDA to approve new models faster.[7] The personal, here, is tightly integrated into the political, even the commercial: Personal needs are translated into commercial development, activism is used as a blueprint for new devices centered on the patients themselves. The

7 Indeed, today, CGM Monitors are commercially available that display the data in real-time on smartphones or other smart devices.

*Nightscout Foundation*, not surprisingly, is also trying to foster and promote such political engagements: They see a lot of potential for truly "patient-centered research" in this highly active community. They are tapping into this potential by partnering with patients and caregivers from the community to "create opportunities for participatory design, citizen science, and open science diabetes research" (The Nightscout Foundation, "Who are We"). It is this high degree of participation that debunks Fox's thesis on CGMs and integrated systems as fostering uninformed patients reliant on their system. In the case of DIY solutions, the opposite is the case: patients and their caregivers become experts on the technologies, their potential failings and the management of the disease.

To emphasize their idea that you do not *have* to wait to access the tools that could help you the *Nightscout Project* adopted the moniker "#wearenotwaiting" in 2013 (The Nightscout Project; The Nightscout Foundation, "Home"). This moniker also implies a certain impatience with the commercial providers of monitoring devices, FDA regulations and institutional structures that hindered or delayed the availability of commercial tools with similar capabilities. But the DIY approach does not only come from an unwillingness to wait "for the FDA's blessing," as Bradley writes, or a bottom-up "push" for improved technologies through "homemade solutions," as Smith maintains – though both are important and transformative facets of the political nature of *Nightscout*'s approach. Rather, it is the extension of the hacker ideal, the maker ideal towards medical technology. Not for nothing Bradley and Smith both call it a "hack." The *Nightscout Foundation*, they say themselves, is "unique" among diabetes communities for advocating for a "maker movement approach to T1D healthcare" and "citizen science" efforts that use open-source development methods to "create products and projects that offer immediate impact" (*FAQs*). They follow a broader ideal that perfectly aligns with the self-made ethos of DIY biology and medicine. However, this DIY approach, the *Nightscout* website explains, should be carefully considered as people need to be "comfortable configuring and installing [their] own system" (The Nightscout Project). In such a DIY approach, they rightly say, there is no warranty or insurance of any kind:[8] "The quality and performance of the project is with you if you choose to use it." The self is responsible for how well the system works and how they use it.

Another development in diabetes care also goes back to the work done by the *Nightscout* community: the *OpenAPS*. Basically, the *OpenAPS* is one already functional application of a long-standing dream – an artificial, bionic pancreas, a "closed loop." On the technological side, such visions of an artificial pancreas combine a CGM and an insulin pump: Based on the data of the CGM and an algorithm the individual is given adjusted doses of insulin through the pump, which promises to reduce extreme blood sugar highs and lows through automatization. Bradley describes this vision of an "artificial, or bionic, pancreas" that controls "blood sugars automatically, just like

8 In fact, a rather long disclaimer on their website makes this abundantly clear: They stress that the system can fail, that the code is provided for educational use only, that it is a volunteer-based system without formal support, that the system lacks password protection and data security, and that *Nightscout* code or information should not be used for medical decision making.

the biological one is supposed to do" as the "most tantalizing" idea in diabetes care.[9] Here, you might notice, we move closer to the realm of technological integration into the human body, a technological hybridity that carries the grinder's vision of cyborg bodies into medical applications.

The *OpenAPS* is a "basic closed loop APS technology" that is "widely available to anyone with compatible medical devices who is willing to build their own system" (Dana Lewis & the #OpenAPS community, "OpenAPS.org"). On the *OpenAPS* website, it is described as an "open and transparent" effort to make "safe and effective basic Artificial Pancreas System (APS) technology" available to more people, more quickly than commercialized and FDA-approved products. Fittingly, the *OpenAPS* has taken over the moniker #wearenotwaiting from *Nightscout*. The *OpenAPS* community, they write, have already created a "safety-focused reference design, a toolset, and an open-source reference implementation that can be used by any individual – or any medical device manufacturer." The goal is to "reduce the burden of Type 1 diabetes" through open-source and free technology but also to accelerate the innovation and testing process of more advanced APS systems (Dana Lewis & the #OpenAPS community, "OpenAPS.org"). The *OpenAPS* is a DIY solution, that as of February 3, 2021, according to their website, more than "(n=1)*2,211+ individuals around the world" have implemented in some form or other (Dana Lewis & the #OpenAPS community, "Outcomes"). The first DIY closed loop was implemented in December 2014 – a time during which commercial applications of this type were still predicted to be months or years away (Dana Lewis & the #OpenAPS community, "OpenAPS.org").

This uncertainty about when and how such systems will be commercially available is also one of the main motivations for building an *OpenAPS*. On the homepage of the *OpenAPS* we can read: "Individuals who build OpenAPS setups have decided that #WeAreNotWaiting to be able to automatically adjust basal rates to safely keep BGs in range and reduce the burden of living with Type 1 diabetes." (Dana Lewis & the #OpenAPS community, "OpenAPS.org") A need is addressed by these technologies for which individuals do not yet find commercialized and approved answers; it is thus not just fun tinkering but has a serious context. This is also transported in many of the media representations of the *OpenAPS* community and its creation. Often, they position the ability and freedom to choose whether patients want to wait or use a DIY solution as one of the main effects of the *OpenAPS* (D. Lewis, "Experience"; L. Martin). The DIY approach, here, gives people options they previously did not have, it is a demonstration of feasibility as much as a tool of empowerment.

The creation and dissemination of the *OpenAPS* is intimately connected to one name: Dana Lewis. In the media representations she is the voice and face the community as well. The first closed loop was hers. In an article for the *Guardian* Lewis writes about her self-care as a T1D:

9 Commercially available diabetes care is beginning to close this loop as well. Some devices are already available that combine a CGM with a pump so that we are currently moving closer to FDA approved, commercial closed loop systems.

> This process became a little easier when I got an insulin pump, and later a continuous glucose monitor (CGM). The pump continuously infuses insulin into my body, and the CGM sensor can report my blood sugar every five minutes. At night, I relied on the CGM's built-in alarm to wake me if my glucose passed the threshold that required immediate action; but though I tried several CGMs, the alarms were never loud enough, and they couldn't be turned up or changed. I talked to manufacturers, but nothing improved. Once I went to college and lived alone, this became a bigger problem; I was increasingly afraid of going to sleep at night. (D. Lewis, "Experience")

Though she could manage her diabetes fairly well, especially nights were a time during which her CGM did not give her the certainty she desired. Living on her own, the lack of louder alarms increasingly became a source of worry that the commercial devices could not obliterate. While the alarms work for most people, "clearly [she was] not one of those people" (L. Martin). To her frustration, her desire for personalization could not be met by commercialized devices. But one day, the narrative commonly goes, she stumbled over Costik's tweet about his CGM hack. Using his code, she and her partner not only set up a system that would communicate the data to her phone and wake her with louder alarms in case of a low but also informed her partner if she slept through the alarm (D. Lewis, "Experience"). They also created an algorithm that would predict highs and lows and send alarms to her phone or smartwatch. These measures fended of her fear of going to sleep, she writes, but in this "open loop" system, she was still the one who had to take action. Working with others in the open-source diabetes community, she started to try to close the loop. As Martin writes:

> With help from Costik, and an active open source community sharing information on how to access the functionality of CGMs and insulin pumps, Lewis was able to really get started. Within a year she and her boyfriend (now husband) Scott Leibrand moved from creating customizable alarms to creating algorithms to read data from her CGM and send the correct commands to her insulin pump to make proactive dosage adjustments, closing the loop and creating her first DIY pancreas. (L. Martin)

Closing the loop, thus, once more was a community effort in which knowledge about diabetes care met professional knowledge of programming and coding.

Having implemented her own loop, Lewis decided that she wanted to stick to the spirit of the open-source community and provide knowledge on how to do it online:

> Having created something that changed and improved my own life, and having benefited from others' open-source work, I wanted to share our work so other people could use it. This is why we created OpenAPS – the Open Artificial Pancreas System project: to make the code, design and documentation available to others for free, so they can build a "pancreas" of their own. (D. Lewis, "Experience")

The *OpenAPS* is emblematic of what open-source design can do: Not only did Lewis take knowledge that was available open source and develop it further with the help of other people, but she also fed the new device and knowledge that was created back into the community for others to use, extend and improve. This system went from "being a personal project to being an open source, community-focused effort" (L. Martin). A growing

community of interested volunteers and people with closed loops, Lewis writes, is continuing to improve the code and system – in their spare time, for free (D. Lewis, "Experience"). This community also provides advice to those who want to implement their own loops. The internet as a medium to share, connect and inform is particularly important here. Fittingly, for Morgan Meyer the internet plays an important part in the emerging alternative biotech-economies because it is a platform on which tools and equipment can be sold and bought, knowledge and instructions about finding and building alternative tools shared, and people connected to other interested people (*Domesticating* 13). My source, the website, is a case in point: Here people find open reference designs and documentations, mailing lists with troubleshooting guides, chat rooms where "OpenAPS users hang out" and can help answer questions (Dana Lewis & the #OpenAPS community, "OpenAPS.org"). Websites, forums, blogs, videos, according to Meyer, "are part and parcel of the material infrastructure that allows for the circulation of knowledge to take place, for collectives of do-it-yourself biologists to emerge, and for various kinds of boundaries to be overcome" (*Domesticating* 18). The new technologies of the Web 2.0 do not only allow for a proliferation of those ideas and hacks, but they also actively create and reinforce community.

Still, even more than in the *Nightscout Project*, the automatization of a natural biological function raises concerns about its safety. Without human interference, the imagined scenarios go, the system has to be watertight and failsafe for it to be considered secure. The *OpenAPS* takes these concerns into account. The *OpenAPS*, they claim, is built for safety. If the system collapses, parts break or are lost, the other ones can still be used independently and manually. The *OpenAPS*, they write, "follows the same basic diabetes math that a person would do to calculate a needed adjustment to their BG – but it is automated and precise" (Dana Lewis & the #OpenAPS community, "OpenAPS.org"). More than safe, they seem to argue, its automatization and precision makes it less vulnerable to the flaws inherent in human actions. Lewis writes that for her "having a computer make adjustments while I sleep is far safer than trying groggily to make decisions overnight" (D. Lewis, "Experience"). The system, we can read, is also designed to work smoother than humans managing their diabetes manually: instead of infrequent large adjustments, it "makes small adjustments every five minutes" (D. Lewis, "Experience"). This is supposed to minimize spikes and balance glucose levels.

Some of the concern about such open solutions arises from their emphasis on 'do-it-yourself.' People tinkering around with medical devices are in the popular imagination taking part in potentially life-threatening and dangerous endeavors – the circumvention of regulatory bodies and standard protocols. That this type of DIY is actually a highly productive enterprise is often forgotten. "100% DIY," apart from the "existing diabetes devices," this system allows people more options for personalization and customization, because they choose which technologies and algorithms they use (L. Martin). This individualization, however, comes with a cost: As with the *Nightscout* setup it is the individual themselves that is responsible for how well, safe and efficient the system works. The website makes it quite clear that it has to be a self-made solution: "You'll have to build your implementation yourself (no one can/will do it for you!)" (Dana Lewis & the #OpenAPS community, "OpenAPS.org"). You can get help from the community, the message goes, but you will need to do it yourself. In order to do so, of course,

you need to know what you are doing – a fact that helps to make the system safer. The individual is a still required as an active manager of their diabetes: "Overall, it's important to understand that OpenAPS is not a 'set and forget' type of system. You'll still be actively managing your diabetes and doing basic self-care as you were before – this includes everything from meal boluses, checking BG and calibrating the CGM, changing out pump sites, etc." (Dana Lewis & the #OpenAPS community, "OpenAPS.org") The *OpenAPS* is an upgrade of previous self-care regimes, one that can even out glucose levels and provide an extra security net. It does, however, not replace self-responsibility. This, once more, counters Fox's concern of integrated systems creating "dumb" patients reliant on technology and algorithms. The *OpenAPS* becomes a means of empowering people to take their diabetes care into their own hands.

As medical technologies, such hacks leave traces on their user's body. Similar to the implants in the previous chapter, these examples merge the human body and technology: Blood glucose monitors and insulin pumps are integrated into the body, allowing for a closer monitoring of their functions. These technologies inscribe themselves on the bodies that use them, leave their material traces as much as they have social consequences. Lewis communicates some of these physical changes: After her first night with the closed loop system, she "was blown away by how much better [she] felt" (D. Lewis, "Experience"). An automized biochemical adjustment had managed to level out fluctuations in her blood glucose levels that she previously might only have noted subconsciously – it leaves its molecular traces on the body. This effect was so staggering for her that she decided to use the system permanently, thus integrating the technology (temporarily) into her body and possibly conception of self. The open diabetes community has done (self-reported) studies on the health outcomes of DIY closed loops, with reports ranging from better sleep, less mental burden, higher quality of life to less visits to school nurses (D. Lewis, "History").

But more than that *OpenAPS* is also an advocacy project of sorts. *OpenAPS* frames itself as a communication starter, a mediator between different actors in a complex web of commercial, legal and personal interests:

> We are working to demonstrate the need of the community to have closed loop devices; demonstrate the safety of basic closed loop systems and efficacy compared to 'standard of care' without closed loops; and help break down communication barriers between the FDA, these companies, and the community that needs the devices widely available as quickly as possible. (Dana Lewis & the #OpenAPS community, "OpenAPS.org")

They advocate for collaboration between the DIY users and commercial providers, so that in the end all people with Diabetes will profit from their learnings and experience (D. Lewis, "History"). Even if the goal of commercial availability is reached, Lewis explains to Martin, that would not be the end of *OpenAPS* because also those systems might not be perfect or accessible for all (L. Martin). While currently an individual project of people with access to technology, the *OpenAPS* might in the future become a means of granting access to closed systems also to those who lack the financial means to buy them commercially or lack access to a healthcare system that makes them available and reimburses the costs. Here, we come closer to the political potential of DIY medicine.

## To Summarize

Both case studies represent truly bottom-up approaches to biotechnology and medical devices – the tools and technologies of DIY biology and medicine. Tools in biohacking labs are a precondition for DIY biology that has to be met in order to make biology accessible and affordable. These tinkered, collaborative, creative approaches do not only represent a different epistemic approach to biology and medicine, but they also work to enable the participation of all those who are interested in the future of biotechnology. What they aim for, on a broader scale, is the inclusion of those in the processes and practices of cutting-edge science that are usually disenfranchised from them: people in low- and middle-income countries, people with lack of access to comprehensive and affordable health care. As such, it is no wonder that a global perspective comes into play. Cheaper equipment comes with the promise of participation no matter where in the world (citizen) scientists practice their research or satisfy their curiosity. Open medical technologies, similarly, promise access to better management of diseases and technologies that truly meet the users' needs. It is here that we see these DIY solutions interact more closely with individual bodies, leaving their traces and changing experiences of embodiment. Both case studies make biology and medicine deeply personal, stress the individual nature, their hope for a more personalized engagement with and understanding of biology, a familiarization with their own bodies as organic beings on the most minute level. These technologies turn patients and users into more knowledgeable experts on their own bodies: The DIY approach is based on a comprehensive understanding of both the technology and the biological processes to be intervened in.

If we consider the *OpenAPS* system and the assessment that it is not a 'set and forget' type of system but rather a support system for conventional techniques of diabetes self-care, this preoccupation with medical, biological, technological literacy becomes obvious. Especially the *Nightscout Project* and the *OpenAPS* demand a thorough biological and technical literacy for their implementation: In order to set up the system, people need to know how diabetes affects the body, how it is managed, how the technologies used to manage it function and how they can merge different technologies into a working system. Dana Lewis acknowledges this barrier to access as well: "DIY is unfortunately not 100% accessible to all," she writes in a commentary for the *Journal of Diabetes Science and Technology* ("History"). This need for extensive literacy, we should note, in effect stands in marked contrast to their aim – excluding people from participation instead of including them. This question of literacy also ties into concerns about safety: Greene writes that technological literacy determines "whether doing it yourself is ultimately liberating or dangerous." The question for him is how we decide who is "literate" enough to assess the risks of self-experimentation. This problem, however, is also inherent in other technologies, for example expensive wearables with promissory marketing (307-08).

Literacy, as the examples in this chapter have shown, can also depend on the collaborations individuals pursue – information and knowledge can be shared, DIYers educated by other DIYers. In such a context, literacy is something that can be produced in community rather than being an individualist (in)ability. In these new alliances people work together on an equal basis, they are part of a community instead of dependent on commercial providers or governmental regulations. As such these examples could also

be considered as extensive educational efforts. Similarly, many of the tools developed for the DIY laboratory also have an explicit educational focus. They aim at making biology and biotechnology an ordinary part of everyday life, to demystify the processes of biology. Their focus on activity, on hands-on learning, aims to foster the ability to not just understand but actually 'do' biology.