

Living with
Experimental Neuroprosthetics

THE CONNECTOR



Alexandra Middleton

The Connector





EXPERIMENTAL FUTURES

Technological lives, scientific arts, anthropological voices

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LIVING WITH EXPERIMENTAL
NEUROPROSTHETICS

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Alexandra Middleton

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For Jim, Susan,
Tobias and Ilse

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Prelude

Only a Machine

Louise received the call from Jesper when his left arm was still inside the mouth of the machine.¹ She had just left her overnight shift working as a caretaker at the elderly home in a small town in southern Sweden: a land of lakes and bogs, and home to iron, steel, and glass industries. It was early July 2015 and Louise had just drawn the blackout shades in their bedroom closed, drowning out the blinding *midsommar* light. Moments after she had crawled into bed, her cell phone rang.

“Louise, kan du komma hit? Jag har skadat mig på fabriken. Ambulansen är på väg.”
 (“Louise, can you come? I’ve injured myself at the factory. The ambulance is on the way.”)

Her husband’s voice was calm, unremarkable, as if he were calling to ask what he could pick up at the grocery store on his way home.

“Är det illa?” (“Is it bad?”)

“Ja.” (“Yes.”)

“YOU HAVEN’T SEEN the pictures from the accident yet, have you?” Louise asked me.

We were sitting side by side in a biomedical engineering lab at a university in Sweden, observing tests conducted with Jesper, as we had countless times before. The titanium rod protruding from Jesper’s residual limb, where it ended before an elbow, was plugged into a Bluetooth dongle, effectively connecting the interior of Jesper’s arm to a personal computer, opening up a network of electrical channels read from electrodes surgically implanted in his arm. Signals produced by Jesper’s muscles, their sharp peaks and angular valleys, danced blue-green on the black computer screen, transformed by the lab’s open-source software for pattern recognition.

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The hour was getting late, reaching the point at which Louise, who had until then been raptly attentive to the experiments with Jesper, would typically relax back into the chair, pull out her iPhone, and show me pictures of flea-market furniture they were renovating at home. This time, she had leaned over to whisper to me in a hushed voice, so as not to disturb the experiment.

“I haven’t seen them,” I said, trying to conceal my surprise. “But I would be interested, if you are okay with showing me.”

In the two years since first meeting Jesper and Louise in the hospital waiting room, I had heard snippets hinting at “the other arm,” Jesper’s biological one—the factory, the machine, the hand, lost—but never the entire story. Having worked with people living without a limb for over five years, I had a simple rule: I never asked outright how they lost their arm or leg. Especially in Sweden, one learns not to ask too personal questions, particularly early in a relationship. I adopted the practice out of respect for the trauma of limb loss—not only the loss itself but also how the loss was incurred and how its trauma may live on. Stories of limb loss would come to me, though, sooner or later. Offered in a moment of trust. Sometimes by the individual themselves. More often by a third party, a loved one. But almost always, the intimate details tended to arrive by way of artifacts residing in the home or upon the body: a photo album stashed in a kitchen cupboard, saved images on a phone, the trace of a silken scar.

Jesper’s story arrived on the heels of a late night in the lab, through the vessel of an iPhone. Like many insights about soft-spoken Jesper, it was delivered not by Jesper himself but by his wife. The two operated in the lab spaces in a tandem-like way. While the other patients would visit the lab solo, Louise was the one family member who would accompany her husband to each and every lab and clinic visit. She had the sharp presence of a participant-observer—noting everything, posing pointed questions, taking quickly to engineering terms—and the diligence of a patient-advocate, researching alternative prosthetic hands and making arrangements to optimize Jesper’s care. A caretaker for the elderly and disabled in her professional life, Louise seemed to bring this sensibility to Jesper’s care as well.

I cannot write about Jesper without also writing about Louise, I wrote one day in my fieldnotes. At times it was difficult to disentangle where one stopped and the other began. Louise was, in ways, Jesper’s spokesperson, sometimes to his own chagrin, revealing things he wouldn’t readily: an unsigned release document, an at-home training session missed, the dogged persistence of his phantom limb pain despite treatments. Often, these “revealingings” were met with affectionate jest: by Jesper, the miming of sheepishly being caught undergirded

by a warm appreciation; by Louise, clamping her hand over her mouth as if signaling herself to stop talking.

“Are you sure you want to see them (the pictures)? They won’t disturb you?” Louise hesitated. I assured her they wouldn’t, but only if Jesper felt comfortable. Louise asked Jesper, who nodded, his eyes still fixated on his neuromuscular signals on the screen. Louise procured Jesper’s phone from his jacket pocket. But before opening the “Photos” folder, she returned to the story of the phone call.

JESPER’S LEFT ARM was somewhere inside the machine, a glass pellet blender, when he dialed Louise. He was opening a hatch deep inside the blender when another worker pressed one of three unlabeled buttons, which happened to be the “on” switch. “Whose fault was it actually?” Louise wondered, almost rhetorically. “His? Or the company’s? Or the machine-makers?” The buttons all looked the same.”

With his right hand gripping the cell phone, speaking to Louise in his characteristically calm voice, Jesper still felt each of his left fingers, his left palm. In his worst-case scenario appraisal of the situation, he thought he had broken a few bones. Later, he would come to find out that his hand had already been taken by the machine, separated from his arm. But in this moment, the cell phone in his right hand and Louise on the other line, he distinctly felt his left hand as though it were there. This was Jesper’s first sensory acquaintance with his phantom limb: still inside the machine.

“*Jag kommer,*” Louise said. (“I’m coming.”)

Everything next happened in a blur. Louise swiftly pulled on her clothes and walked downstairs to ask her children, ages five and ten at the time, if they were okay to stay alone as she went to Jesper. “*Vi klarar oss,*” Louise’s ten-year-old daughter replied. (“We’ve got it.”)

The tall multistory factory tower hovered panopticon-like over the town below, and Jesper and the machine were still entangled in it when Louise arrived. The firefighters told her to wait outside. Twenty, thirty minutes passed? It was hard to say exactly; time was moving in a warped way. To Louise, it felt like hours. Eventually, the paramedics cut the machine to free Jesper’s body. He then walked himself down the tower stairs to exit the factory, down the long gravel road to the ring of bystanders, colleagues, the ambulance, and Louise. “Everyone was crying,” Louise recalled.

The first thing Louise noticed when she saw Jesper was not his arm but his head. A long gash ran down his forehead, likely inflicted while trying to free himself from the machine.

“It was only later that I looked down,” she recalled. “Two blue-white bones sticking out. *Inget kött* (‘no meat’ [muscle, tissue]). They (the paramedics) must have cleaned the bones.”

Louise’s eyes were wide as she took a breath. “And then I saw it. No hand.”
“Jesper just looked at me, and said, ‘*Förlåt*.’” (“I’m sorry.”)

RECOUNTING THIS TO ME, Louise’s eyes welled, glassy as tears gathered on her cheeks. She let them linger, momentarily, before briskly wiping them. “I’m so sensitive,” she said apologetically. I placed my hand tentatively on her shoulder. Louise looked down at her lap, picked up Jesper’s phone again, and opened the Photos folder, her thumb scrolling with the slightest hint of a tremble.

The first picture was dated July 6, 2015. “Five days after the accident,” Louise narrated. Several pictures just featured the limb, absent of hand (which both patients and clinicians I worked with referred to as a “stump,” informally, and as a “residual limb,” formally). The skin was mangled, covered in what had to be at least thirty staples, tied together by a bright yellow cord. Then, Jesper started to appear in the frame alongside the limb. His face looked pale, drained, wiped of emotion. I didn’t detect a hint of the characteristic twinkle in his eyes. Louise paused her scroll and continued the story.

THEY ALL BOARDED the ambulance—Jesper in the back with the medics, Louise in the front seat with the driver. “How he screamed,” she recalled, referring to Jesper’s shouts of pain coming from the back of the ambulance. “The ambulance driver was in shock. She was clutching my knee, telling me how brave I was. I told her ‘*Han lever i alla fall*’ (‘At least he is alive’).”

The paramedics had given Louise a plastic bag. Inside it was Jesper’s hand. Louise sat in this way: the bag with Jesper’s hand between her legs, the ambulance driver clutching her knee, Jesper’s screams piercing her ears.

On the way to the nearest hospital, 40 kilometers from the factory, they stopped at a nearby hotel to ask for ice, which they poured into the bag. “They wanted to save Jesper’s hand, just in case they could reattach it,” Louise explained. “But the arm was too mangled.” The hand was later disposed of.

When Jesper’s sister arrived at the hospital, Louise’s shock started to wear off, and reality began to sink in. She mimicked a shaking in her body. Louise’s descriptions were vivid, visceral. I could almost hear Jesper’s initial relative calm making way to howls of pain, could almost see Louise’s tunnel vision to

get to the factory, then the shaking, the slow burn of shock giving way to the acuteness of the trauma.

“The kids were scared. They didn’t want to come to visit Jesper at the hospital. But I made them,” Louise recalled. “Joel (Louise’s then-five-year-old son; Jesper’s stepson), he cried so much. He kept saying, ‘He will never grow his arm back. He will never grow it back.’”

THE NEXT PICTURE was dated July 12. The 17th. The 21st. The 24th. They were selfies, taken by Jesper. With each image, the skin of his residual limb gradually appeared less mangled and jagged; it began to grow together. But what captivated me more was the progression of the look on Jesper’s face. The corners of his eyes started to turn slightly upward. His cheeks lifted; their color returned. By the last image, I detected something close to a smile.

ONCE JESPER WAS DISCHARGED from the hospital, a mere week after the accident, the first thing he said to Louise was, “I’m going into the (grocery) store.”

Everyone knows everyone in Louise and Jesper’s town of several hundred residents. Before long, the store owner came up to Jesper, witnessed for the first time in his postamputation body outside the hospital. The owner embraced Jesper, saying, “How brave you are, to come into the store.” The ensuing weeks and months were difficult for Jesper, as he continued to go out into the community with one arm. People would point and stare but wouldn’t dare ask what happened. “Joel was so embarrassed. He didn’t want anyone to see,” Louise recalled.

She paused and looked straight at me, her eyes wide.

“That all changed, when he got the robot arm.”

THE ROBOT ARM was the reason we were all sitting in the lab in the first place, watching Jesper’s neuromuscular signals dance on the computer screen. The robot arm was also how I came to know Jesper and Louise. Until this moment of Louise sharing the story of Jesper’s amputation with me, exactly two years to the day of us first meeting, it was the only arm we talked about. We first met at a university hospital in a Swedish city in January 2018. Then, an air of doubt still lingered as to whether or not Jesper would become a patient-subject in the neuromusculoskeletal prosthesis clinical trial, the trial my field-work chronicled.

I visited Jesper in the hospital on several occasions. First, before he was about to go under general anesthesia for osseointegration—the implantation of a titanium rod into his humerus bone, to enable bone-anchoring of the prosthesis. Again, after the rod was implanted in his skeleton. Months later, after bureaucratic conflicts between the lab and clinic were smoothed out and he was finally let into the clinical trial, I visited Jesper in the hospital again, before and after the electrodes were implanted in his muscles and nerves. All of these surgeries were part of the process of preparing his body for his “robot arm.” The months (and years) following were devoted to adapting to the arm, learning to use it intuitively, and not without setbacks.

Over those two years, I made multiple visits to Jesper and Louise’s home. We sat together at their kitchen table eating tacos and watching Jesper perform his at-home training exercises with a virtual limb, using a therapeutic program developed by the same team that designed the robot arm. I slept in the *husvagn* (mobile home) in the yard behind their house (which Jesper jokingly called my “apartment”). Once, during a several-month period in which Jesper temporarily could not use his prosthesis due to compromised control signals, I stood in the kitchen with Jesper as he prepared mushroom gravy with one arm. Louise was chasing her three-year-old grandson, who was running busily from room to room flipping light switches on and off. “It is difficult,” Jesper said to me, “Not having the other arm, even just to hold something in place while I cut or open it.” It was the closest Jesper had come to airing any form of complaint during the time I knew him. Otherwise, he was always at work, even with one arm, building something. “When I’m working, it doesn’t hurt,” he explained, referring to his otherwise relentless phantom limb pain.

Just inside the front door, hanging over the coat rack to the left, was a sign Jesper made himself. It read: “*Ingenting är omöjligt, några bara tar längre tid*” (“Nothing is impossible, some things just take a longer time”). I heard Jesper voice versions of this slogan with regard to his amputation, adapting to his postamputation body, learning to use a neuromusculoskeletal prosthesis, coping with unexpected setbacks from nerve surgery that left him unable to use a prosthesis for several months, and training to participate in the 2020 Cybathlon, the global Olympics for prosthetics users.

“You become patient when you lose an arm,” Jesper once told me when I asked him whether he felt frustrated after a particular engineering setback, voicing his acceptance of the inevitable fits and starts of clinical experimentation. “Everything takes a longer time, and you have to do things over.” I was struck by this confluence of becoming-patient in the affective sense and

becoming-*patient* in the more literal sense: becoming a patient-subject in a highly experimental clinical trial. I wondered how much of Jesper's patience was an adaptation to the experience of limb loss and just how much was related to becoming a subject of ongoing clinical trials, including where these two subjectivities intersected. There was something to having these words inscribed on the walls of his home, where patience and becoming-*patient* (in all of its senses) took on new meaning. It was as if the home became a particular site for this affective expression and resilience, in perhaps a different way than the formal clinical and laboratory sites of experimentation.

"Even though I already had good patience before the accident," Jesper added, interrupting my musings, and as if to remind me that the accident was not only a radical rupture, but also a continuation.

LOUISE KEPT SCROLLING. Other pictures appeared. Jesper's residual limb attached to a rubber dinosaur head, a clever grin on his face, the hint of a wink. Jesper smiling on the beach with his newly osseointegrated prosthesis, his sleeve pulled proudly up to reveal the titanium rod. A video of Jesper working in his garage with the Greifer—instead of a humanlike hand, a set of pliers that fit onto the wrist, enabling him to delicately twist wires and maneuver a soldering iron. Jesper and Louise's wedding pictures, a year after the accident, both beaming.

It was as if, with Louise's scrolling, we were zooming out: from the limb loss itself as a site of rupture and trauma; to the unpredictable and long journey of healing, uneven as the staples holding together the incision; to the implantation of titanium and electrodes to make possible the robot arm; to Jesper's weaving of the limb into his professional and personal life, made his through injections of his own flavor of humor and lightness, as well as the import of life's major events: a wedding, a child's graduation.

As she traced this arc, the later parts of the photo roll were interspersed with Louise's own photo-documentation of tests in the lab. Together, these iPhone pictures formed an archive of sorts, a record of Jesper's five-year journey with amputation, a series of devastating losses, false hopes, and eventual entry into the neuromusculoskeletal limb prosthesis clinical trial. They also marked a domestic presence in the lab, or reversibly a lab presence in the domestic realm; the phone pulled out in between tests, the self-documentation, the intermittent entry of stories from daily life by way of a photo, a reminder that these spaces were not nearly as demarcated as one might think, that the experiment was always ongoing.

THE VERY FIRST TIME I visited Jesper and Louise at home, in late 2018, Jesper picked me up at the train station. Not long into our drive to their home, 10 kilometers away from the station, Jesper pointed out the front windshield.

“Do you see that building over there, that tower, that factory?”

I nodded.

“That is where I lost my arm.”

Jesper said this nonchalantly, as if he were pointing out a particular species of bird. I imagine now it may have been similar to his tone when first calling Louise to tell her about the accident.

“I worked there just this week.”

I asked Jesper if it was difficult to go back into the building after the accident, if it took some time before he felt ready.

“*Nja.*” (A Swedish expression that means both “no” and “yes,” simultaneously.)

Jesper shrugged. “Not really.” He paused, took a breath, and added, “I actually worked today on the same machine that took my arm.”

“Really? What was that like for you?” I asked him, imagining it must have evoked some sort of traumatic reckoning.

Jesper shrugged again.

“*Det är bara en maskin.*” (“It is only a machine.”)

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Introduction

The question of where to begin, especially amid an unfolding experimental present, is a critical one. We could begin at the chronological beginning, tracing a series of scientific discoveries and technological innovations seeding the invention of the *neuromusculoskeletal prosthesis*: a frontier in the field of brain-machine interfaces, an unprecedented integration of the human nervous system and a prosthetic machine. Or even before that, with the history of *osseointegration*, the medical discovery that bone grows onto titanium, which opened the possibility of fusing prostheses directly with a person's skeleton, rather than compressing the surface of their skin tightly into a socket. Or we could begin more fundamentally, with the question of why a replacement for a lost limb in the first place, and what hopes, expectations, or normative assumptions are embedded therein.

I begin, instead, with the story of Jesper—the phone, the images, the sign above the door, Louise, the ways artifacts of domestic life enter the lab—to mark the presence of a story that exists behind, alongside, and beyond the story of medical innovation. This is not a story in which a person inherits an already made biomedical technology and folds it into the fabric of their daily lives. It is an ongoing story of science-in-the-making that emerges beyond formally recognized zones of science. This story is written by the bodies and lives of the humans through and within which these technological innovations come to be: in this case, the first patient-subjects of the neuromusculoskeletal prosthesis clinical trial.¹

This clinical trial is not only a technoscientific frontier of human-machine integration. It also constitutes the first cases in the world in which such intimately integrated prostheses are taken out of a lab setting and used freely by

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people at home, all while still being studied. While the trial began with six subjects, at the time of writing, five people in the world (all based in Sweden)—whom I call Jesper, Rasmus, Anders, Olof, and Malin in these pages—are living with these neuromusculoskeletal prostheses, just as they are subjects of ongoing experimental study, research, and development. At once both trial subjects and subjects of their own daily lives, the neuromusculoskeletal prosthesis moves with them as they navigate these shifting terrains and subjectivities. This unique conflux of highly experimental—yet simultaneously domestically lived-with—science first drew me to this work as an anthropologist. What gets framed as “the frontier” is always the everyday for somebody. What happens when the object of scientific inquiry is also lived with, a fixture of everyday life?

The Connector takes this question as its point of departure. In these pages, I expand our sense of where biomedical innovation, scientific discovery, and the “cutting edge” come from, to include the subjects, bodies, and homes of experimental science. From the vantage point of *how* technologies intimately integrate into scientific and domestic spaces, I contemplate and intervene into how knowledge-making, experimentation, embodiment, and lived experience are understood to entwine. Refracting through the lens of novel technoscientific encounters as they viscerally embed into bodies and lives allows us to illuminate and reinvigorate classic debates in anthropology and the social studies of science and technology about the body and embodiment (Csordas 1990; Lock 1993; Mol 2003), disability (Ginsburg and Rapp 2013; Kafer 2013), and scientific knowledge production (Knorr Cetina 1999; Latour and Woolgar 1979; Rabinow 1996). Drawing ethnographic connections among multiple registers of experimental science, I examine how the sense of a body gets communicated, translated, and transformed—in formal *and* informal sites of experimentation—through instruments of datafication, people’s own embodied sensory knowledge, and the labors of living intimately with a highly experimental technology. I interrogate how homes and domestic life become key, if not obfuscated, grounds of this science-in-the-making: what I theorize as a *domestic lived science*. In doing so, I enter and extend upon efforts to further unsettle staid boundaries between nature and culture (Franklin 2003; Strathern 1992), laboratory and home (Latour 1999), human and machine (Haraway 1991). This unsettling illuminates how all of these categories are relationally produced, informed by and informing scientific research agendas and evidentiary regimes, embedded in the very design of technoscientific objects themselves.

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Situating the Connector as Object and Concept

What does it mean, as Jesper said, for a machine to be “only a machine”? When does a machine become something else, something more? The prosthetic limb is arguably the first human-made machine created specifically to act as, or functionally replace, a body part. If one were to only look at the range of highly sophisticated bionic limbs on the market today, one would think the era of seamless human-machine integration had already been heralded. Over the past decade, a profusion of highly advanced terminal devices (prosthetic arms and legs) has flooded the market, an ilk born of science fiction imaginaries. Consider the “Michelangelo Hand” with seven hand gestures and an electronically actuated thumb to mimic “natural hand movements” (Ottobock 2020) or the DEKA “LUKE Arm,” inspired by Luke Skywalker, with 100 microelectrodes to “allow [an amputee] to feel again,” a technology invested in by DARPA and provided to veterans at Walter Reed (George et al. 2019). Yet the scientists and engineers at this particular biomedical engineering and neurorehabilitation lab in Sweden (which I refer to in these pages as “the lab”) noticed a fundamental *disconnect*. Despite this array of impressive technical possibilities, there remained a perpetual dearth of ways to optimally connect them with the body to exploit their full capacities. Put differently, this surge in prosthetic research and design outpaced clinically available ways to make these devices viable for patients’ bodies and daily lives. The translational component—on scales from laboratory to clinical to commercial and home use and between technology and body—remained stunted.

This disconnect was the central challenge the lab sought to address with clinical trials developing the *neuromusculoskeletal limb prosthesis*—what Jesper and Louise called the “robot arm.” Surgically attached to the patient’s bone and controlled by the patient’s neural impulses via electrodes implanted on their muscles and wrapped around their nerves, these prostheses are intuitively steered through the user’s thoughts and intentions, with the capacity to perceive sensory feedback (touch) in the body via interactions with stimuli in the surrounding environment. The lab’s experiments aimed to reimagine how the human body and prosthetic machine could connect, to achieve control and interact in a sensorially perceptive way with one’s environment. In doing so, they endeavored to create not only a device that approximates a human limb but, ultimately, one that facilitated, in their words, “activities of daily living.”

“The connector,” then, refers at first glance to the trial’s experimental object sitting at the interface of human nervous system and prosthetic limb.²

Rather than the terminal prosthetic device (the prosthetic hand) itself, the trials are responsible for the surgical procedure, the implantation of electrodes, and the coding and machine learning, housed in the connector, that translate the body's signals into both prosthetic control and felt sensation. This technological, surgical, and algorithmic enterprise utilizes the subject's nerves and muscles, exploiting the scientific fact that the body itself is also electric, its own internal wiring made legible to a machine. In electrical engineering, the subfield of many of my experimenter-interlocutors' expertise, a *connector* joins at least two systems to facilitate a flow of electricity, a circuit. My scientist-interlocutors framed this prosthetic circuitry as *bidirectional*: intuitive control from the body to the device, sensory feedback from the device to the body. In the lab, I often heard connection framed as something that could be achieved: an aspiration of sorts. "Getting a good connection" meant that one's neural signals were legible to pattern recognition, over time more reliably predicting a person's motor commands. Here, connections were also something that could be stabilized: "connected." An aspirational connection is one in which the person is said to "embody" their prosthesis, sensorially experiencing it as their own limb. But connecting with a human being troubles the neatness and stability of this bidirectional circuitry. Especially when the connection is being lived with as it is being studied.

As its title suggests, the book is organized around "the connector," a term whose doubling I use purposely to refer to both the experimental object *and* a theoretical concept that grows out of this ethnography. As a book, *The Connector* traces the process by which this assumedly closed-loop technology, connecting prosthetic limb and human body, opens up to a third system—a social world—in which the body (and person) circulates, moves, and operates (just as it is also impinged and constrained) with other bodies, affordances, and constraints. By social world, I mean not the ways "daily life" is prefigured in the clinical trial's vernacular: as an end destination of an already made technology or merely a site of use. Instead, I mean social in a way that encompasses the laboratory just as much as it does the domestic, a product of many people enlisted in experimental life, and the new forms of being together surfaced by the experiment itself.³ Drawing upon over two years (2018–20) of fieldwork chronicling these trials as they unfolded across laboratory, clinical, industry, and domestic spaces throughout Sweden, I approach this experiment ethnographically as a means to interrogate, productively destabilize, and expand "connection" in technologically mediated human-machine relations. In doing so, I argue that the experiment of embodied human-machine connection is not merely constrained to the body and technology in question. The connector is

not only a translator of electrical signals but also a conduit of myriad social relations: not least of which machine and human—but also patient-scientist, prosthesis-scientist, patient-anthropologist, anthropologist-scientist, to name a few. It also incorporates the material-electrical entanglements emerging in the environs of the home as they interact with the connector’s own coding and the phantom limb as an expression of embodiment that extends beyond the physical or material, pushing prosthetic connection onto phenomenological terrains. All these elements arrive to this meeting with their own logics, wirings, and proclivities. To connect, each must bend, to varying degrees, sometimes breaking and forming new, unexpected connections. The assumedly bidirectional connector gets opened up by the porosity of the human—not only as body but also as embodied, emplaced, and entangled subject. In this opening, scientific logics about prosthetic connection meet the critiques and expertise of the people who come to live with/among/against machines.

In insisting upon the conceptual force of the connector as an analytic, I am consciously avoiding collapsing “connection” with “relationality” even while interpreting connection as a fundamentally relational phenomenon. Indeed, as Marilyn Strathern notes, many anthropologists have historically used the two terms synonymously, although, as she argues, their distinction is critical (Strathern [2018] 2023). I maintain this distinction to stay close to the materiality of the body and machine in question, to sustain the experiment’s emic sense of connection as a site of scientific knowledge production, and to interrogate the less-recognized inputs and labors that produce, sustain, endure, and sometimes even break these connections. This approach grows out of the anthropology of science and science and technology studies’ long history of theorizing the relational and cultural underpinnings of scientific objects (Rabinow 1996), epistemic things (Rheinberger 1997), and knowledge-making (Knorr Cetina 1999; Traweek 1988). In using the term “relationality,” I am thinking both generally as an anthropologist trained in the study of human relations—in which relational thinking and doing are always already embedded in our study of social phenomena—and specifically with Strathern’s theorizations of “new kinship” formed by “new technological regimes” (Strathern 2005). Relations, Strathern compellingly theorizes, are constitutive to, rather than bracketed from, the scientific method. In science-making, relations undergird concepts such as cause and effect, as well as the data instrument of correlation (2005, 38), and are not merely “connections among things” but rather “co-implicated” with one another (2005, 40). Strathern describes “science’s relation” as a twinned yet divergent “distinction between *discovery* and *invention*, between unfolding relations already there (co-implications) and making new

relations (meaningful connections)” (2005, 11, emphasis added). If *discovery* seeks to create explicit knowledge of relations already there (“things already connected”), *invention* is a more implicit and embedded way of creating new kinds of relations.

Throughout this ethnography, I pay attention to times when my interlocutors engaged in acts of discovery (i.e., investigating how touch works at the level of the nervous system) while also actively inventing new connections (i.e., engineering an intervention to precipitate a touch experience via neurostimulation). In doing so, I am keenly interested in how discovery and invention themselves form a connection, how invention may cast light on what can—and can’t—be discovered, or even pave inroads to unexpected discoveries. Connection, then, can be thought of as a bridge between discovery and invention, a heuristic for tracing the social and interpersonal grounds of scientific experimentation, as well as their epistemic and material effects—which critically incorporates not only their bringing-together but also what happens when connections stutter or break.

The figure of the machine is not only part of the prosthetic promise: a seamless fusion of assistive technology with the human body. It is also, for many who have lost a limb, part of the dissolution: the rupture, the accident. All but one of the patient-subjects in this ethnography lost their limb(s) in traumatic accidents involving heavy machinery, as opposed to neurodegenerative, chronic, or congenital reasons. A race car; a propeller on a barge; the mouth of a tractor; an electrical wire; a glass-pellet blender; “only a machine.” While I encountered each patient several years postamputation, trauma and the accident hung like specters over this milieu—suggested but never addressed outright. In the clinical and laboratory spaces where my fieldwork initially took place, the postamputation body was taken largely outside the context of the individual’s limb loss. This was partially out of respect for the people seeking clinical care; focus was on what was ahead, as opposed to behind. Yet the losses themselves, their indelible markings, the artifacts keeping their trace, lived on—in the home, the body, the phantom limb, and family mythologies.

Louise’s retelling of Jesper’s accident, the perceptible shift in Jesper’s expression in the camera roll interspersed with pictures of tests in the lab, the sign above their front door imploring patience, all point to a meaningfully different story of connection that emerges beyond the formally recognized zones of scientific evidence. This story is closer to what philosopher Catherine Malabou (2009) calls “destructive plasticity.” Writing in the shadow of traumatic brain injury, war, and other forms of rupture, Malabou considers the intense creativity born out of accidental destruction, a space in which new possibilities to

transform (oneself) emerge, and psyches and subjectivities reveal themselves as flexible. I move to consider how people's own destructive plasticities—largely negotiated and improvised in the intimacies of everyday life—become an engine of the experiment, a creative endeavor itself occasioned by destruction. In taking connection as a site of ethnographic inquiry, I draw upon different configurations of *plasticity*: not only destructive plasticity but also neuroplasticity (Rees 2016; Rose and Abi-Rached 2013) and the plasticity of human figures in their lived unfinishedness (Biehl and Locke 2017). If neuroplasticity—a concept fundamental to the logics of the technologies this ethnography chronicles—reminds us that the brain is constantly reorganizing itself, growing new connections throughout the course of a life, then the plasticity of the human subject attunes us to the ways in which humans too “grow out of themselves” (Biehl and Locke 2017, 4, after Nietzsche 1955), forming new material and social connections over time, however volatile or tenuous. In this book, I synergize and extend these three orientations to plasticity through the heuristic of *electricity*—the medium and substance of the body and engineering undergirding the connector, but also the wirings of homes themselves—to interpret the substance of these new connections. The experiment reminds us that electricity is not solely a property of the technical but always already pulsing in our cells, synapses, and environment (Helmreich 2013). Electricity—of the human nervous system and of the machine—is integral to the plastic nature of making, breaking, and reforming these multiple connections. Taken together, plasticity and electricity help to consider how the material, symbolic, and social forces of the prosthesis, clinical trial, body, and home are always forming new connections, just as they are marked with surges and short-circuits.

As both knowledge-making project and lived experience, connection is relationally made and unmade in distinct ways from the perspective of scientific and domestic spaces. Taking the home seriously as a site of science-in-the-making allows the range and depth of these myriad relations to become more visible. In the experimental milieu I studied, the objects of experimentation were brought home to their users' homes and family lives, manipulated to varying degrees outside the laboratory's terms, and brought back to the laboratory, recursively. Furthermore, the subjects of these studies—prosthesis users—were themselves constantly recirculating among laboratory and home spaces. This transformation and fluid exchange (of bodies and devices but also ideas and improvisations) does something to the way we think about the space of science, not as impervious to the lived (and social) environments it seeks to affect, but rather entangled with them (Latour 1987; Franklin 1995). There is an ethics of taking these peripheral sites and their happenings seriously. It

carves space for figures whose stories are not always accounted for, the ingenuities often hidden from evidentiary regimes, albeit playing an important role in the making of human-machine relations and scientific knowledge alike. It also centers the generativity of everyday life as it increasingly permeates—and gets permeated by—innovations in science and technology (Downey and Dumit 1997). This constitutes what I develop in these pages as a *domestic lived science*, a theoretical and methodological orientation to centering the lived peripheries of experimental science and a contribution to theorizations on experimental-ity (Petryna 2007) in the anthropology of science and clinical trials. Domestic lived science is a way to chart and account for the material and conceptual innovations that live outside formal parameters of evidentiary regimes, yet nonetheless produce and sustain the connections undergirding them.

Grounding the Frontier

The mirage of the frontier can, taken out of context, be blinding. In its midst, certain narrative tropes and public hypes step into frame and attempt to stabilize the story of human-machine connection. The neuromusculoskeletal clinical trial's experimental endeavors inevitably conjure posthumanist (Hayles 1999) and transhumanist (Bostrom 2003) speculations about the affordances of artificial intelligence and the degree to which human and machine may fuse. News media and popular science reports of these trials' findings, as well as selective nonreporting of its challenges, all too easy whisk away into techno-optimistic imaginaries.⁴ Such narratives also traffic in a general enthusiasm for the burgeoning frontier of the neurosciences, ushered by the “Decade of the Brain,” not only within cultures of science but also, increasingly, in global processes of subjectivation, governmentality, and commercialization (Dumit 2004; Rose and Abi-Rached 2013; Vidal and Ortega 2017). Studying neuroprosthetic connection meant engaging not only with its practices but also with the imaginaries and inherited desires ensconcing it.

With this backdrop, it became quite clear I could not study human-machine prosthetic relations without contending with the figure—if not specter—of the cyborg.⁵ The hybrid human-machine cyborg—taken literally as *CYBernetiC ORGanism*—leaked readily into media representations of the neuromusculoskeletal prosthesis. Consider, for a moment, “Professor Cyberbone,” a character on a German television network series for children and teens, based upon the principal investigator of the clinical trials, a key interlocutor and character whom I call Felix in these pages. Or the alias given to a patient-subject in the same TV series: *Arminator*, a riff off *The Terminator*. Cyborgian vernacular inevi-

tably trickled into my patient-interlocutors' own narrations of their identities, as well as my scientist-interlocutors' references to the experiment. Several of my interlocutors competed in "The Cyathlon," an international competition hosted in Zurich as a showcase of emerging assistive device technologies, with events closely tethered to what are described as "everyday activities": tying shoelaces, screwing in a lightbulb, and pinning clothes to a clothesline (ETH Zurich 2024). I noticed my patient-interlocutors typically mobilized cyborgian monikers in social encounters with normatively abled others to acknowledge the neuromusculoskeletal prosthesis as something positive, fascinating, cool. Simon, brandishing his prosthesis proudly, proclaimed to his children, "I am The Hulk!" while later clarifying to me, "I'm only half Hulk, because I still have my other arm." Rasmus and Anders each referred to friends calling them "the Terminator," or "Superman," sometimes jokingly using these labels themselves. Olof, speaking to his children's class about his arm, told me, "Their friends think it's really cool . . . like a Cyborg." Names like "Robot Arm," "the Terminator," and "cybathlete" served in part as invitations into conversation and questions about the prosthesis that, as Olof described to me, was a welcome departure from the tendency of normatively abled "others" to "just stare (at the prosthesis) and not say anything." Yet beyond these social encounters, I repeatedly noticed the instances in which the arm became "just an arm," or "only a machine," once more: often in moments of breakdown and repair. Cyborgian pet names failed to encapsulate the hard work of testing, titrating, fixing, and waiting. This cyborg-prosthetic-imaginary existed apart from the humbler and more grounded aims of my scientist- and patient-interlocutors, the practical challenges of bodies and machines making a life together.

The cyborg has a long and rather fraught relationship with the disabled subject,⁶ and here its theoretical affordances begin to break down. Indeed, the cyborg has long been conjured by the prosthesis, seeded in what Lochlann Jain (1999) identified as a "prosthetic turn" in the 1990s, in which the prosthesis even replaced the cyborg as a trope in academic discourse. As an object, the prosthesis has historically sought to "complete" or "make-whole" a human body that is anatomically "other" (Betcher 2001), what anthropologists in critical disability studies have called a normative way of being in the world (Ginsburg and Rapp 2013; Wool 2015) embedded with ideals of the "able" laboring body. Critical disability studies and queer theory scholars have extensively troubled and challenged the conceptual utility of the cyborg as it grows further and further from its feminist histories.⁷ Despite Donna Haraway's intention for the cyborg to critique dichotomies of nature/culture or machine/human (Haraway 1991), the cyborg can ironically reinforce them,

“perpet(uating) distinctions between ‘normal’ and ‘abnormal’ bodies” (Kafer 2013). Cyborgian hybridity can smooth over discordances, implying fusion of human and machine where the two may fail to meet. Or, when hybridity exposes itself not as a smooth and effortless, but as a momentary condition that takes a great deal of work to sustain. An unexamined celebratory read of prosthetized people as cyborg misses the ways in which “human/machine interfaces are not always beneficial or pleasurable” (Kafer 2013, 118) not to mention broadly accessible. It also misses how rejection of a prosthesis or assistive device (Frank 2000), or alternative improvisations, can claim a radical space for nonnormative ontologies or embodiments.

In the case of emerging neuroprosthetics, a field that not only seeks to restore an amputated body but, in certain imaginaries, to transcend the body’s perceived limitations, new questions are raised about the extent to which we incorporate technological tools into our bodies and what this suggests about what a body can do (Deleuze 1990), be, or become. The cyborg no longer provides an easy answer to adequately encompass the range and depth of the labor, intimacies, and creativity that go into producing and sustaining these relations. While acknowledging the import of the cyborg in critical theory on human-machine relations, I seek in this book to write about the neuromusculoskeletal prosthesis in a way that resists a celebratory narrative of human-machine hybridity, by accounting for the *experimental labor* of prosthetic connection. Building upon Kafer’s call for a “close crip reading of the cyborg” (2013, 105), and in the vein of disability studies scholars such as Sharon Betcher (2001), who has drawn attention to the violence of using the prosthesis as a metaphor for human-technology relations, I argue a key problem with applying cyborgian narratives to prosthetization as a gloss for connection is that they erase the labor that goes into living with a connector. Rhetorics of prosthesis-as-cyborgian-enabler also constrain possibilities for theorizing frictions and breakdowns of human-machine connection not as endings or failures but as moments that make visible the relational work that sustains. I seek to recuperate what Kafer calls the “feminist task . . . to contest for other meanings of, or other relations with, technoscience” (2013, 104). Following my patient-interlocutors’ lead, I locate these other meanings in the human figure and lived life to which a prosthesis attaches: intimately, but often incompletely, and not irreversibly, integrated. Tending ethnographically to the struggles, frictions, and breakdowns inherent in building a relationship to one’s prosthesis, I insist upon analytical grounding in the plasticity of the human—focusing on the bodies and lives through which these technologies come to be and are still becoming.

Situating this ethnographic case in a broader genealogy of scientific and humanistic histories, while grounding in the labors of an ongoing science present, inoculates the tendency to fetishize its newness, as well as the convenient slide into narratives of hybridity. This tendency risks an amnesia of the fact that humans have always been living in relation to objects since first picking up a stone and reappropriating it as a tool. Or perhaps even before then, we were already using our own bodies as tools, as Marcel Mauss suggests in “Techniques of the Body”—that the body itself is man’s “first and most natural instrument” (Mauss 1935). As Malin, a patient-interlocutor, put it, “The body is a very difficult technology,” or Olof, another patient-interlocutor, explained, “*This* is a tool” (holding up his prosthetic limb) “but in the same way as *this*, too, is a tool” (waving the fingers of his biological hand). Throughout, I attend to the ways in which my patient-interlocutors actively destabilize these categories of “tool” and “instrument” with respect to the body, as the relations among these categories get unmade and redrawn, and as bodies are continually retooled.⁸

These stakes transcend this particular ethnographic context of neuroprosthetics and assistive technologies, relevant to broader scenarios of biomedical device development and, broader still, to any human-device relationship in question. Our relationships to the technological tools we use to enhance our lives are often ambivalent. Sometimes our tools don’t work, don’t work in the way that we want them to, or work upon us in unexpected ways. We sometimes reject them because, while they may make us more efficient or productive, we are left emotionally empty or socially disconnected in their wake. The same can be true of our bodies, particularly in the face of rupture or destructive plasticity. If “the machine” is a category of constant updating and uncertain ontology, I want to resist framing or writing about “the body” or “the person” in a way that suggests that they aren’t, too. As Olof put it, “Machines are pretty easy. They do what you say. But humans, you don’t know, they’ll react differently to different things. But that’s the fun part. And, we change over time!” Machines aren’t the only things that break or malfunction; unruly bodies and plastic subjectivities continually retool themselves in encounters with technologies, as the stories in these pages evince.

Writing in an Ethnographic Sensorium

This ethnography, like all ethnographies and clinical trials as well, encapsulates a particular window of time (January 2018 to March 2020), while the stories, lives, and bodies it chronicles spiral outward. The characters who appear

in these pages are pseudonymized and at times composited and split, in an effort to protect their anonymity. A work not of reportage but of ethnographic research, this book is not about particular people per se—though the people whose stories figure in these pages matter deeply. Rather, it is about what we can learn from their lived experiences: what they tell us about how science is made and how it changes.

My field site contained myriad relations and forms of entangled knowledge-making: among patient-scientist, doctor-scientist, patient-anthropologist, device-scientist, and patient-device, to name a few. The entanglements among these characters, as they engage with complicated and novel experiences of prosthetic living, are negotiated differently in each of these relational configurations. My work is concerned with untangling the relations that constitute this in-the-making, as well as the nature, however uneven, of their collaborations. Throughout this book, I resist using “collaboration” to smooth over real differences in what is at stake for my interlocutors by virtue of their different subject positions. Instead, I draw attention to these differences to show how they themselves are relationally produced.

It is essential to acknowledge I entered and exited the field at precise moments in a currently ongoing science present and was not present for every decision made. At the time of my writing, this clinical trial is still relatively upstream, particularly as these interventions are not yet clinically available. In the trial apparatus, the indeterminate, potential, and open-ended, which can only ever be known through the experience of living, exist side-by-side measurement, datafication, and materialization. I approach this paradox not as yet-to-be-closed, but as generative in its openness. I seek to ethnographically archive the recursive, tedious process of invention, implementation, and discovery as these trials are lived, insisting upon their plasticity.

This mode of ethnographic writing aims to recuperate what gets lost in translation when scientific findings are communicated in the form of a journal article or mainstream news media: the false starts, the swerves, the U-turns, all of which make up the complexities of experimental living. Including, critically, a more expanded account of the fraught labors that sustain this becoming, I draw attention to this mutability and emergence—the uncapturability of the human-machine relationship as it is being enacted, the ways it resists stabilization—in the writing to argue that ethnographic methods themselves can attend to (rather than elide) this messiness. In this sense, the book is guided by a narrative genre in which theory emerges primarily out of the ethnography (Biehl 2013). Throughout, I articulate where and how these theorizations speak to, extend, and intervene in critical debates in medical anthropology, femi-

nist science and technology studies (STS), the anthropology of clinical trials and experimentality, embodiment and sensory studies, and critical disability studies.

In this book, I am critically interested in tracing how machinic and body logics are made legible to one another by way of the experiment and how they come to speak one another's language, if imperfectly, or perhaps create a new, shared one. As an ethnographer, the challenge of documenting this became most apparent through the effort each of us (ethnographer, scientist, patient) was embroiled in: communicating and listening to descriptions of felt sensations, specifically about touch and pain. In the trial, this is done through the transformation of bodily signals—produced by nerves and muscles—into data that the machine can recognize, translate, and generate into corresponding motor and sensory commands. It also occurs in reverse, in the case of sensory feedback: the body receives and decodes electrical signals via the nerves to produce a felt sensation. I am particularly interested in how embodied sensory knowledge about touch and pain interfaces with the scientific paradigm of datafication and the mandate to produce evidence: how the body is at once both the “existential ground of culture,” as Thomas Csordas (1990) suggests, and the empirical grounds of biomedical knowledge-making. I trace what this at-onceness reveals about the multiple ways embodiment is configured and how scientific and phenomenological understandings of embodiment are sometimes at odds, tracing their divergences as they materialize in the conduct of experiments and the design of the prosthesis itself. Consistently interweaving the ethnographic with rigorous attention to the scientific knowledge-making and materializations at play, I stay close to Marilyn Strathern's optimism that “divergence allows ideas to appear alongside of and co-produced with critiques of them” (2005, 34), with a firm conviction that multiple forms of knowledge can coexist at once.

In tracing the making of this language and consistently coming face-to-face with its limits (Wittgenstein 1922), I confronted boundaries in my own disciplinary languages—namely, in the anthropology of the body and embodiment. “One of the problems inherent in an ‘anthropology of the body,’” Janelle Taylor writes, “is the tendency to presume, rather than ask, what a body is and where its significant boundaries are located” (2005, 749). Following Taylor's provocation, I continually ask, rather than presume, what a body is and where its boundaries are being redrawn in this experimental context, particularly in relation to touch and sensory feedback. Sensory experience, which often exceeds what can be expressed in words, exerts pressure on ethnography to step outside narrative exchange. In this way, the sensory makes a claim not only

on our bodies and subjectivities but also upon our methods. It reminds us of the ways in which it exceeds our tools to capture, represent, and interpret, all the while imploring us to relate with it. I write into what João Biehl and Peter Locke (2017) call the “ethnographic sensorium,” in which larger-scale material and social flows sediment affectively in bodies and lives, and bodies and lives speak back their own conceptualizations, in the midst of their formation. This particular ethnographic sensorium has the potential not only to attend to the relational dimensions of embodied sensation—like touch and pain—but also to facilitate their expression. Ethnography is a nexus of sorts, a confluence of the missing body part, the prosthesis, the patient, the clinic, the home, the laboratory. As sensation distills in relations between, among, and within bodies and devices, so too does the ethnographic, bringing to bear the complex entanglements that cannot be captured by data machines, revealing people’s own ingenuities and improvisations, telling stories that don’t often get told.

What, then, does this mean in practice? As I write about my own participation as a control subject in lab experiments, as well as my embodied experiences in the sensory worlds of patients’ home lives, I am acutely aware of the fraughtness of lending my own body in this ethnographic research, namely due to the unparalleled stakes. On multiple occasions, I was hailed by my interlocutors as someone who had not myself lost a limb, a normatively bodied person, reminding me of the limits of what I could know. Rasmus invited me into this impasse with an important question—“Why do you need your right hand, Alexandra?”—his hand momentarily touching my own as if to communicate more deeply in the language of the body beyond words, inviting my own embodied reflexivity into this work. Removing my own body from the sensory thickness of these encounters felt just as fraught as denying my corporeal presence as participant-observer. Writing about interlocutors’ bodies without acknowledging the fact of my own reifies a disembodied distance that anthropology as a discipline has tried to overcome for decades (Stoller 1997). At times, I was humbled by the challenge of acknowledging yet also writing across and into the undeniable difference in our subject positions: one’s (patient) body being the object of scientific gaze and another’s (researcher) body doing the gazing. This paradox landed me at the crux of the question anthropologist Rita Kesselring poses in her writings on why the body matters in ethnographic research: “How precisely do we attend with our bodies and attend to bodies?” (Kesselring 2015). In attending *with* my own body’s “feel for ethnographic relevance” (Hastrup 1994, 227) through experimental and domestic encounters, I attend *to* my interlocutors’ multiple expressed forms of *embodied sensory knowledge*. I take their local, embodied experiences, perceptions (Merleau-Ponty

1962), and practices (Bourdieu 1977) as integral parts of in-the-making: their creative processes of making-sense and that which escapes sense-making, how their bodies come to be sites as well as agents of emergent forms of (biomedically mediated) life (Fischer 2003).

In recounting fragments of people's stories here, those witnessed or entrusted to me, I stay close to Gilles Deleuze's reminder that "to write is certainly not to impose a form (of expression) on the matter of lived experience" (Deleuze 1998), particularly when that lived experience is not directly one's own. Stories can be told in any number of ways and, like lives, are continually being written. With this writing, I gather stories from the center and the margins of experimental life, taking seriously their analytical and theoretical purchase, their own makings.

The Body of the Book

The Connector as a text unfolds in two parts—"Producing and Sustaining a Connector" (part I) and "Living and Dwelling with a Connector" (part II). These parts, drawn from key emic concepts that circulated throughout my fieldwork, point to different zones of knowledge production about human-machine connection. Just as I resist conceiving of the lab/clinic/home spaces as arranged in a teleological arc of translational medicine, I also resist thinking of these expressions of the connector—*producing and sustaining, living and dwelling with*—as teleological, despite their numbering. Rather, they co-occur, overlapping in ways both minute and profound, even at times reconstituting one another. Chapters, composing each part, are threaded through with ethnographic vignettes occurring within and peripheral to the formal experimental apparatus, set in the laboratory, clinic, patients' homes, and, importantly, their interstitial spaces. While the first part takes place more heavily in the lab, the balance shifts as the book progresses, as domestic encounters throw the experiment's fundamental assumptions into sharp relief. Interspersed with chapters, to create breathing room for thinking and reading, are two short ethnographic interludes that vivify the analytical and theoretical concerns raised, grounded in the intensities of a single scene. Throughout the text, elements of domestic life both come to bear in the laboratory and remain obscured; some fade away only to reemerge later. Thus, the book is meant to be read like a conversation, echoing the inchoate terrains of translation—human-to-machine, machine-to-human, and human-to-human.

Part I, "Producing and Sustaining a Connector," approaches the formation and incipience of the connector as an experimental object and the different forms of

labor producing and sustaining it, from different ethnographic and historical starting points. Chapter 1 centers the informal and often-unrecognized zones of connection through the lens of *domestic lived science*, in which the home becomes a key site of science-in-the-making. I develop domestic lived science as both a theoretical orientation and a methodological approach for studying connection as a site of ethnographic inquiry, establishing the grounds from which ensuing ethnographic theorizations in this book about embodied sensory knowledge, brain science, embodiment, and engineering will grow. This includes mapping my conceptualization of “the field” as it scales multiple physical and social registers, expanding what counts as the clinical trial. In chapter 2, I examine the work of connection through the ethnographic lens of the trial’s first human subject, Rasmus. Through Rasmus, we come to apprehend how patient-subjects are both enlisted in clinical labor (Petryna 2009; Cooper and Waldby 2014) and generate new forms of *experimental labor*, in which their embodied knowledge and domestic lived science become integral engines of experimentation, knowledge production, and materialization. I show how this experimental labor is embedded in other intersecting forms of labor inherent to prosthetization, clinical trials, and the Swedish social welfare state. Chapter 3 develops a genealogy of the neuromusculoskeletal prosthesis as an experimental object, examining how the clinical trial connects and choreographs multiple fields of engineering and science. Employing the experimenters’ metaphor of prosthetic connection as a series of “bottlenecks,” I argue for the presence of a fourth bottleneck: a social-relational system, opened up by the trials’ decision to study their devices in humans moving freely between laboratory and home with their prostheses.

Part II, “Living and Dwelling with a Connector,” enters the fourth bottleneck to consider how domestic lived science is practiced through different forms of *embodied sensory knowledge* (specifically pain, touch, sensation, and embodiment) and overlapping iterations of *breakdown* (mechanical, physiological, social) within and beyond the trial’s paradigms of datafication and measurement. Chapter 4 develops a phenomenology of the phantom limb itself as a connector, a mediator of relationships among and within body, prosthesis, and environment. Examining how experimenters and patient-subjects communicate, model, and translate lived experiences of the phantom limb, I consider how the phantom figures not only as a source of pain but also as a messenger, delivering nervous system information critical to patients’ relationship-making with the neuromusculoskeletal prosthesis. Chapter 5 ethnographically examines how experimental attempts to enhance prosthetic connection by engineering prosthetic touch also work as reverse-engineering, recursively

informing basic neuroscientific understandings about human touch itself. Tracing how touch becomes constructed, abstracted, and experienced in neurostimulation experiments, I chart how multiple coinciding versions of touch get produced, troubling the boundaries between “artificial” and “natural” touch. Chapter 6 examines the consequences (and inconsequences) of these sense-making experiments from the perspective of patients using the sensory feedback system in their homes. Interpreting sense-making as meaning-making, I identify and juxtapose multiple different registers of “functionality” as understood from the perspective of patients and experimenters. Thinking with a crip technoscientific (Kafer 2013; Hamraie and Fritsch 2019) reading of prosthetic touch and grounding this in a domestic lived science, this chapter further unsettles an understanding of what touch means and why it matters. In chapter 7, I excavate the unpinpointable concept of “prosthetic embodiment,” the holy grail of the neuroprosthetic arms race, taken as a proxy for a successful human-machine connection. Examining the tools experimenters use to prove limb ownership and analyzing how the body figures in both data-making and relation-making, I enter neuroscientific literature on prosthetic embodiment into conversation with the anthropology of embodiment. Highlighting their frictions, and thinking alongside critical disability studies theorist Tobin Sieber’s complex, multiple embodiments (Siebers 2010) and transgender and cinema studies scholar Eliza Steinbock’s notion of “the shimmer” (Steinbock 2019, after Barthes [2002] 2005) to account for an ontology of bodies in flux, I develop a theorization of prosthetic embodiment(s) not as a static, fixed state but as a *flickering*, deeply contingent process that challenges efforts to freeze sensory experience in measurement. Finally, in chapter 8, I examine prosthetic *disconnect* when the prosthesis (or the experimental apparatus) breaks down. Building upon critical scholarship in STS on breakdown in infrastructures (Star 1999; Larkin 2013; Jackson 2016), I urge an analytic focus on moments of breakdown as not foreclosures but as relational openings toward connection. Breakdown is not necessarily an aberration of connection—or of science—but rather the hard, nonguaranteed work of it. In its midst exists the everyday, the bulk of experimental time, largely negotiated in the home. Daily life is not lived on the margins of the experiment; it is the very fabric of it.

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Notes

PRELUDE

- 1 All interlocutors' names have been pseudonymized to protect confidentiality.

INTRODUCTION

- 1 "Patient" is the emic term used to describe people participating in the clinical trial and thus the identifier I use here. Alternative terms include "trial participant" and "device user," but these are not used as frequently.
- 2 "The connector" is my own term for the technology that sits at the interface of the arm and the prosthesis.
- 3 As Karin Knorr Cetina writes, "In reaching its goals, research 'intervenes' (to use Hacking's terminology) not only in the natural world but also—and deeply—in the social world" (Knorr Cetina 1992, 115).
- 4 Such imaginaries are also woven into the political economy of biomedical science itself, as Mary-Jo DelVecchio Good (2001) has argued, and, as Lesley Sharp has shown in her ethnography of highly experimental transplant technologies, are inextricable from local moral thinking and hope in the face of unfixed futures (Sharp 2013, 9).
- 5 Donna Haraway's seminal figure of the cyborg (1991) has sculpted much theorization of human-machine meetings, even as it began as a metaphor, a socialist-feminist manifesto of technoscience and politics arguing against the reification of the human. In provoking "why should our bodies end at the skin?" Haraway's figure of cyborg-as-hybrid deconstructs the machine as "an *it* to be animated, worshipped, and dominated," arguing instead that "the machine is us, our processes, an aspect of our embodiment" (1991, 179). Yet Haraway's sometimes-sweeping assertions that "embodiment is . . . prosthesis" and "we are (all) cyborgs now," in emphasizing hybridity and dissolving rigid human-machine dichotomies, also risk eliding the real frictions of labor entailed by coming to live intimately with a machine.
- 6 The implicit connection between disability and device-facilitated hybridization was built into the bedrock of Haraway's manifesto (Haraway 1991; Kafer 2013, 105).

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- 7 As Alison Kafer argues, “The cyborg as a critical intervention in feminist theory is often not the cyborg that appears in disability studies” (2013, 105).
- 8 This continual retooling pushes back against, or beyond, what Mauss (1935) observed as culturally fixed techniques of the body. As culture itself changes malleably, perhaps this retooling of the body is less the substitution of one tool for another, but rather as an updating of the properties of the tool itself.

CHAPTER 1. DOMESTIC LIVED SCIENCE

Materials on domestic lived science in this chapter have been included in “Home and the Human Machine,” in *Homeplaces: The Quest for Dwelling in Critical Times*, ed. João Biehl and Federico Neiburg (Duke University Press, forthcoming).

- 1 Here I am thinking with Marilyn Strathern’s work on the opening up and closing down of the social body to relations (Strathern 1992).
- 2 I use the word “science” as opposed to “innovation” or “engineering” to account for the ways in which innovation also informs basic scientific research. This trial, in and beyond developing a prosthetic arm, also informed basic neuroscientific research about the phantom limb, human touch, and postamputation neuroplasticity.
- 3 The COVID-19 pandemic put an abrupt end to my fieldwork in March 2020, foreclosing the kind of exit from the field I had envisioned.
- 4 “The very difference between the ‘inside’ and the ‘outside,’ and the difference of scale between ‘micro’ and ‘macro’ levels, is precisely what laboratories are built to destabilize or undo,” Latour writes (1999, 143).
- 5 After my fieldwork concluded, the lab received a large grant from a Swedish foundation and became a research and clinical center, moving from the technical university to a university hospital.
- 6 It is important to note that “the clinic” refers to multiple physical clinical sites of surgery, follow-up, and rehabilitation.
- 7 My thinking about the home is influenced by literature on the anthropology of the house, which has traveled long theoretical, conceptual, and epistemological distances from its early focus on the house as a fixed container of kinship relations (Lévi-Strauss 1991; Malinowski 1913; see Collier et al. 1997; Samanani and Lenhard 2019). Here, I am thinking with anthropological theorizations of the house/home not as a fixed space (Douglas 1991) but rather as a sensorium in flux (Biehl and Locke 2017), as localizations of relational processes (Carsten and Hugh-Jones 1995), as “structures *and* anti-structures” that both reproduce and destabilize hierarchies (Marcelin 1999, 38), as local instantiations of global economic and political currents of diaspora and exchange and cultivations of ongoing ancestral relations (Piot 1999), and as ongoing “processes of house-ing” in calamitous times, as houses and people make each other (Biehl and Neiburg 2021). I consider these framings in conversation with the uniquely Swedish configurations of *hemmet* (the home) and the social welfare state’s *folkhemmet* (the people’s house).
- 8 Another example of the analytic import of language comes from the myriad Swedish ways to say “take care.” Among these (*bryr sig*, “to care,” *krya på*, “care for,” *sköt om*,