The Body is no Longer Human, The Body is a Commodity

By

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Abstract

This research is concerned with critiquing how big pharma, insurance companies, and the medical model uses the disabled and chronically ill body for profit. The research considers a brief analysis of big pharma through real-world examples, but also takes on an autoethnographic approach as an individual who is an active consumer of big pharma. Utilizing my own account and voice as an individual with a genetic progressive chronic illness and disability called Cystic Fibrosis becomes integral to the research and the prototype creation process. Feminist queer Crip, which is a sub section of crip Theory, and disability aesthetics, further enrich the research as the theoretical background when analyzing how the long-standing thought process of compulsive non-disabled bodiedness is harmful and can further lead to devaluing disabled and chronically ill bodies in the medical system, and thus creates access friction or lack of access to care. The results of the research and prototype creation seeks to educate on how access friction can be harmful to disabled and chronically ill bodies, which leads us to utilize speculative futures to dream about what easy access to care might look like and helps us understand why access to care is vital when we consider disabled and chronically ill bodies as valuable within the medical system.

Keywords: Crip Theory, Speculative Futures, Disability Aesthetics, Access Friction, Big Pharma

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Chapter 1: Introduction

About the Research and Research Questions

The foundation of this research is autoethnographic research as a disabled and chronically ill person. It is informed by my experience of living with the genetic progressive diseases Cystic Fibrosis. I was diagnosed at the age of five and have about 20 years of experience dealing with big pharma, private insurance companies, and the medical system/model which are systems that seek to use disabled and chronically ill bodies for profit. While using autoethnography, I also use the theoretical background of feminist queer crip theory (which is a subgenre of crip theory), disability aesthetics, and the concept of access friction. The purpose of feminist queer crip theory is to inform how my research and creation process relies heavily on queering the narrative of compulsive non-disabled bodiedness (see Ch. 2) and how this narrative harmfully bleeds into other systems like the medical model, which perpetuates access friction. The concept of disability aesthetics (see Ch. 2) also works to queer the narrative of the concept of beautiful within aesthetics, reminding us that the disability body is beautiful, valuable, and deserves to be cared for. The usage of speculative futures in this research opens a discussion about the future of access to care for disabled and chronically ill people and bodies, what that care should look like, and how everyone outside of the disabled community must understand what access to care should look like, and how access friction is failing the disabled community.

The research consists of the creation of two art-based prototypes that work in tandem with each other and utilize some design-based methodologies that directly represent the concept of access friction (see Ch. 2 and 4). The purpose of these prototypes is to be fully immersed in the capitalistic nature of big pharma, which is intended to share my feelings of frustration, anger, sadness, and shock to educate and bring forth an eye-opening critique of big pharma (see Ch. 4). The research and creation process will be summed up with a personal and activist manifesto that is framed by speculative futures, which will feature important calls to action, beliefs, and values that are centred around access to care for disabled and chronically ill people.

The research focuses on exploring the primary question: "How can I use autoethnography, feminist queer crip, disability aesthetics, and speculative futures to critique limited access of care to the disabled/chronically ill body?"

Two secondary questions follow: "What will a future of care look like for the disabled and chronically ill community if the focus of care was on the body and not for profit?" and "how could the research and creation process meaningfully interrogate viewers' and audiences' own perceptions of care and access through art?".

Motivations and Rationale

It is crucial that I state I am in no way against science, medication, pharmaceuticals and pharmaceutical companies, medical research, and the availability of big pharmaceutical companies acquiring profit *where it is necessary*. I am a firm supporter of disabled and chronically ill people receiving open and easy access to medical care should they desire it and require it. What I am against is big pharma companies making huge profit off the disabled and chronically ill bodies, charging unreasonable costs for medications which leaves the disabled person in a position of pay, die, or constantly fight your way to access of a medication that will save your life, creating an illusion of choice.

My research is concerned with stories of big pharma within North America (Canada and the United States of America). I refer to public news stories from United States of America, and I speak about my own experiences with big pharma in Ontario and the stories of other CFers within Ontario.

The language of “able-bodied” and “non-disabled” are present within my research, however, the preferred term that I use is “non-disabled” over “able-bodied”. I believe that the term “able-bodied” can exclude those that have invisible disabilities, as they might appear to be “able-bodied” by society’s standards, but they are not. Therefore, “non-disabled” and “disabled” are more straight forward and are inclusive to those who have invisible disabilities. If the term “able-bodied” is written within my research, it is because I am referencing a direct quote from a source that uses that language.

Big Pharma

According to Kristin Compton from Drugwatch, a consumer advocacy organization, big pharma can be defined as “a term used to refer to the global pharmaceutical industry. It also includes the trade group, Pharmaceutical Research and Manufacturers of America (PhRMA).” (Compton, 2023, para. 1). According to the PhRMA’s website, their mission is fueled by scientific discovery, and they strive to “conduct effective advocacy for public policies that encourage the discovery of important new medicines for patients by biopharmaceutical research companies (PhRMA About page, n.d., para. 1). One of their main goals is to drive “patient-centred progress in innovation, affordability, and access to life saving prescription medicines” (PhRMA Homepage, n.d., para. 1). Even though this trade group claims to make medications affordable, the global revenue for pharmaceuticals was over $1.42 trillion in 2021, and the pharmaceutical industry is the most powerful and rich industry in the United States of America (Compton, 2023). One of the member companies in PhRMA is the U.S. based company Pfizer, which made a total revenue from pharmaceutical products of $52.5 billion in 2017 (Compton, 2023). The medical treatments, medications, and devices manufactured by big pharma can be lifesaving and important to the lives of humans, but they can be especially important to the lives of disabled and chronically ill bodies to ensure health and quite literally the ability to live.

According to the Oxford English Dictionary, the definition of consumer is “a person who purchases goods and services for personal use”. (Oxford English Dictionary, 2023). Big pharma places the chronically ill and disabled body as a consumer, as there are many instances where some illnesses and disabilities require pharmaceutical care through the purchasing of medications and treatments. For example, in a 2019 article titled “The human cost of insulin in America” published by the BBC and written by Ritu Prasad, highlights the realities of what it is like to obtain insulin in the USA. Insulin is required for someone with diabetes because their body no longer produces it naturally, so they need artificial insulin to survive. This article features an individual named Laura Marston, who has Type 1 Diabetes, where one vial of the insulin she uses costs $275 USD without health insurance (Prasad, 2019). In 1923, the patent of insulin was sold for $1, and the goal with this was that the cost of insulin would remain low so the treatment would be easily available to those who needed it (Prasad, 2019). Unfortunately, a price increase of over 1,000% in 100 years seems reasonable in the eyes of big pharma. Diabetics require the product of insulin produced by a big pharma company, they cannot live without it and big pharma is aware of this and takes advantage of it. If they kept the price of insulin low, like it was originally intended, then big pharma would not be able to make a huge profit off of it, so therefore they elevate the price because big pharma knows that diabetics must figure out how to pay that price, either through private insurance or directly from their own pocket, as it is their only choice for survival.

I argue that big pharmaceutical companies utilize chronically ill and disabled bodies for profit, ultimately exploiting the opportunity of choice, and big pharma places the chronically ill or disabled individuals as a consumer of their products.

A 2015 article by New York Times and written by Andrew Pollack, details how the drug Daraprim, which at that time was a 62-year-old drug, went from $13.50 USD to $750 USD overnight (Pollack, 2015). Daraprim is used to treat toxoplasmosis, which is a parasite infection that can cause serious problems for babies born to those who are infected during pregnancy, and it is also used for people with compromised immune systems, like AIDS and cancer patients (Pollack, 2015). In 2015, Daraprim was acquired by Turing Pharmaceuticals, a start-up run by a former hedge fund manager by the name of Martin Shkreli, and because of the price being raised to $750 USD overnight, this caused the annual cost of the treatment to raise into the hundreds of thousands of dollars (Pollack, 2015). Shkreli claims that because this drug is so rarely used, the impact of the cost on the health system would be minuscule, so that Turing could use the profit to develop better treatment for toxoplasmosis with fewer side effects (Pollack, 2015). Daraprim was approved by the F.D.A in 1953 and was made by GlaxoSmithKline, then they sold the marketing rights to CorePharma in 2010, and in 2014 Impax Laboratories bought Core and affiliated companies for $700 million (Pollack, 2015). In 2015 Impax sold Daraprim to Turing for $55 million. Several years before this article was published, Daraprim cost about $1, but rose sharply after CorePharma acquired it, and according to IMS Health, which tracks prescriptions, the sales of the drug jumped to $6.3 million in 2011 from $667,000 in 2010, even as prescriptions held steady at around 12,700 (Pollack, 2015). Following that increase, it rose again to $9.9 million in 2014, and the prescriptions shrank to 8,821 and with Turing's price increase, it could bring sales even higher (Pollack, 2015). However, doctors like Dr. Wendy Armstrong dispute Shkreli's claims of finding better therapies stating "I certainly don't think this is one of those diseases where we have been clamoring for better therapies" as the side effects can be managed (Pollack, 2015, para. 20). This case study demonstrates that Martin Shkreli was more focused on making a profit on thousands of patients who require easy access to Daraprim, rather than researching new therapies.

Cystic Fibrosis and Trikafta

We will shift into where my own personal story places an integral part of my critique and my consumership of big pharma. I have a genetic progressive chronic illness and disability called Cystic Fibrosis (CF), which primarily affects the function of my lungs. My body does not produce something called the cystic fibrosis transmembrane conductance regulator (CFTR) protein properly, which helps maintain the balance of salt and water in my lungs (and other surfaces in the body). In simple terms, this CFTR protein helps regulate mucus up and out of the lungs, but because I do not produce this protein properly, mucus then builds up in the lungs causing repetitive lung infections that lead to lung function loss. Overall, this cuts a lot of CFer's lifespans much shorter than the average. How am I a consumer of big pharma? Through a drug called Trikafta that, when it was approved in Ontario Canada, I started taking in May of 2022.

Trikafta, created and distributed by the pharmaceutical company Vertex, is a lifesaving and life changing drug. From my own personal experience, I have regained over 30% of my lung function back, most of the damaging scarring in my lungs has disappeared, I can take full and deep breaths normally, and I am no longer in a vicious amount of chronic pain. However, this drug in the province of Ontario costs $300,000 per year and per patient (Ontario Newsroom, 2022), which ultimately puts a price tag on my life and on the health of my body. Thankfully, I do not have to pay that amount of money for a drug that saved my life due to private insurance that decides if my life is worth paying for, but other CFers unfortunately cannot say the same. However, according to a study conducted by the *Journal of Cystic Fibrosis* in 2022, the highest production cost of Trikafta was estimated at $6,723, which is over 90% lower than the list price of the drug (Guo, et al., 2022).

I understand when it comes to producing, creating, and researching drugs, it takes time and money. I recognize that research can be expensive, and without a doubt researchers and scientists must be properly and fairly paid for their efforts when creating these lifesaving drugs. However, when viewing Vertex's annual revenue reports it states that Vertex made a net product revenue in 2023 of $6.04 billion in the U.S. and $3.83 billion outside the U.S, which is a total of 9.87 billion (Vertex Pharmaceuticals, 2024).

According to Isha Bhargava from the CBC, "…(M)any families in Ontario struggle to navigate insurance coverage to afford the drug." Bhargava continues: "Trikafta can be covered by the Ontario Drug Benefit (ODB), available through the Exceptional Access Program (EAP)" (Bhargava, 2022, para. 9) and this is where the easy access is truly not so easy. If an individual with CF is 24 years if age or younger, Trikafta is eligible through OHIP+ (provincial health program) as long as the individual does not have private insurance. If an individual is between 25 and 64, they can enroll in the Trillium Drug Program if they have a high drug cost that is relative to their income, but there is a deductible and co-payment with this option (Bhargava, 2022). Kim Steele of Cystic Fibrosis Canada states that "if you do have private insurance, you're excluded from OHIP+ altogether, even if your insurance won't cover the full cost of the drug" (Bhargava, 2022, para. 11). This unfortunately puts a lot of CFers in a very tough situation of uncertainty, the options for a lifesaving treatment seem to be risk going through private insurance that might not fully cover the drug, go through OHIP+ and lose the other benefits of private insurance, or pay deductibles and co-pays. This is another prime example of big pharma, the government, and insurance companies exploiting the meaning of choice, thus creating the illusion of choice.

Scope and Limitations

The research is very autoethnographic in nature, and my own personal story fuels much of the narrative and research. Therefore, I am not the singular authoritative voice when discussing the bureaucratic and complex nature of insurance companies, big pharma, and the medical system/model. There are many unique stories and experiences of different disabled and chronically ill people, as there are many forms of medical ableism, and those stories are just as valid as any other. I encourage you to seek out those stories to continue to gain valuable insight into the medical system from various perspectives, especially from BIPOC and 2SLGBTQI+ voices.

Discussing concrete strategies and viable solutions to repair the big pharma complex, medical system/model, and insurance companies is beyond my scope as a designer and artist. By extension, this research is not a thorough and in-depth analysis of the economic monetary background and hierarchy of such systems. The research is focused on a critique of big pharma, the medical system/model, and insurance companies, as I am conducting a broad and brief background into these systems to provide context to my own experience and narrative as an individual that has had to work with these systems throughout most of my life.

The use of speculative futures through the process of social dreaming and future positive environments will appear to be very utopic in nature. I do recognize that there are legitimate problems within the concept of "utopia" because there are still negative social issues and challenges within utopian dreams. Therefore, I do not intend to portray a perfect utopic speculative future, rather I intend to use the concept of speculative futures to critique our current political and social landscape, and as a result lead us to dream "a call to action" of a better future for disabled and chronically ill people with the current social climate as a foundation.

Chapter Overview

Chapter 1 details the primary and secondary research questions, my motivation and rationale for the research, a brief overview of the research, and the scope and limitations of the research.

Chapter 2 discusses the theoretical background portion of the research. This includes a discussion on crip theory which leads into understand queer feminist theory which describes terms such as compulsive non-disabled bodiedness, the political medical model, and access friction. This chapter also discusses aesthetics in the form of the beautiful and understands how the integration of disability aesthetics under the perception of what is beautiful is vital. Lastly, this chapter will then provide context to the theoretical background with real-world and artistic examples.

Chapter 3 will cover the research methodology, like autoethnographic research, and the methods used to create and frame the physical component of the thesis research.

Chapter 4 details the creation process of the physical prototype. The iterative process of the organ vending machine, how the breathing lung model will aid the machine as a representation of capitalism created by big pharma, and lastly the importance of the personal manifesto that is conceived through art activism and speculative futures.

Chapter 5 will conclude the thesis research with an important discussion on the future of access to care which will heavily rely on speculative futures as a framework. There will also be a brief discussion of the future of my research and prototype, which details strong hopefuls for future exhibition(s).

Glossary Of Terms

Big pharma - A term used to refer to the global pharmaceutical industry. It also includes the trade group, Pharmaceutical Research and Manufacturers of America (PhRMA).

CFer - Someone who has Cystic Fibrosis

Crip – Originally a slang term for cripple, a term that is in the process of being reclaimed by disabled people as an activist tool to create space for disabled people in social justice activism.

Cystic Fibrosis (CF) - a disorder that damages your lungs, digestive tract and other organs. It's an inherited disease caused by a defective gene that can be passed from generation to generation. Cystic fibrosis affects the cells that produce mucus, sweat and digestive juices.

Cystic Fibrosis Canada – A national non-for-profit corporation and one of the world's top three charitable organizations committed to improving and lengthening the lives of people living with cystic fibrosis (CF).

Cystic fibrosis transmembrane conductance regulator (CFTR) - The CFTR protein is a particular type of protein called an ion channel. In the lung, the CFTR ion channel moves chloride ions from inside the cell to outside the cell.

Patent - a government authority or license conferring a right or title for a set period, especially the sole right to exclude others from making, using, or selling an intervention.

Chapter 2: Literature Review and Contextual Review

A Short Introduction of Speculative Futures

The concept and understanding of speculative futures will become more relevant in the discussion portion of my thesis document, and for now I wish to introduce what it is to provide more context for further later discussion. According to Anthony Dunne and Fiona Raby in their book *Speculative Everything: Design, Fiction and Social Dreaming* (2013), speculative futures is "the idea of possible futures and using them as tools to better understand the present and to discuss the kind of future people want, and of course, one's people do not want…For us futures are not a destination or something to be strived for but a medium to aid imaginative thought – to speculate with." (Dunne and Raby, 2013, pp. 2-3). Speculative futures can be described as dreams or the process of dreaming for the future involving various future scenarios "we don't know how to fix the planet and ensure our survival. We are just hopeful…it is now easier for us to imagine the end of the world than an alternative to capitalism. Yet alternatives are exactly what we need." (Dunne and Raby, 2013, pp. 1-2). Speculative futures will be used to discuss access to care, and what care should be and a look like for disabled and chronically ill people.

Crip Theory

Crip theory is a field of studies that has emerged from disability studies and queer theory (McRuer, 2006). In Robert McRuer's book *Crip Theory: Cultural Signs of Queerness and Disability* (2006) he states "…an important body of feminist and antiracist work considers how compulsory heterosexuality reinforces or naturalizes dominant ideologies of gender and race." (McRuer, 2006, p. 1). In recognizing how compulsory heterosexuality within social norms defines notions of strict gender binary and race, McRuer goes on to mention how there are connections between heterosexuality and able-bodied identity (McRuer, 2006, p. 1). Able-bodiedness presents itself as a non-identity or in other words the "natural order of things", which is comparable to how heterosexuality is presented as "natural" (McRuer, 2006). The term "crip" might appear to be harsh to those outside of the disabled community, but, as Alison Kafer states, the harshness is a large part of its appeal (Kafer, 2013) stating "This desire to make people wince suggests an urge to shake things up, to jolt people out of their everyday understandings of bodies and minds, or normalcy and deviance." (Kafer 2013, p.

15). Similarly, the word “queer” has the same effect and desire for the queer community (Kafer, 2013).

Able-bodied Heterosexuality

According to Robert McRuer, the problem with the meaning of heterosexuality can be found in older versions of the Oxford English Dictionary (OED). “In 1971, the *OED Supplement* defined *heterosexual as* “pertaining to or characterised by the normal relations of the sexes; opp. to homosexual.”” (McRuer, 2006, p.6). Consequently, this places heterosexuality as the “normal” and homosexuality to be subordinated, thus introduces heterosexual compulsion and in the process othering and placing labels of “deviant” to homosexuality (McRuer, 2006). A similar critique of normalcy has been present within the field of disability studies as well. “…Scholarly and activist work positions us to locate problems of able-bodied identity, to see the problem of the meaning of able-bodiedness…” (McRuer, 2006, p.7). There is an underlying sense of wanting to be “normal” as in “able-bodied”, and this thought process is exemplified by a 1999 article in “Enabling Disabled Scholarship” that states that the human body is a machine, with evolved functional parts like a brain for thinking or legs for walking (McRuer, 2006). McRuer argues that this article essentially is stating that you have an able body, or you do not have a body at all, which could point us to regarding a disabled body as abnormal. We can look to how older editions of the OED defines able-bodied as “having an able body, i.e. one free from physical disability, and capable of the physical exertions required of it; in bodily health; robust.”, which implies that able-bodiedness is defined as “soundness of health; ability to work; robustness” (McRuer, 2006). When we look at and compare the older definitions of heterosexual and able-bodied, we can see how to be “free” of disability and “opposite” of homosexual is conclusive to compulsory able-bodiedness and heterosexuality, when the dictionary itself echoes that ideology. Unfortunately, this belief of compulsory able-bodiedness presents itself within various systems within society, like the medical system, which is discussed in *Feminist Queer Crip* (2013) by Alison Kafer.

Crip Theory and the Medical Model

In the book *Feminist Queer Crip* (2013) by Alison Kafer, she states “I argue that decisions about the future of disability and disabled people are political decisions and should be recognized and treated as such. Rather than assume that a “good” future naturally and obviously depends upon the eradication of disability, we must recognize this perspective as coloured by histories of ableism and disability oppression.” (Kafer, 2013, p.3). In this case, I argue, that a “good” future without disabled people can be reflective of a “normal” future, which promotes compulsive non-disabled bodiedness that is previously discussed by Robert McRuer. To further illustrate this point, Kafer discusses how society tends to accept and agree with the fact that couples do not want a child with down syndrome, and those who feel otherwise are labelled as “crazy” implying that accepting disability as normal is unbalanced or sick (Kafer, 2013).

Robert McRuer argues that such sources like the dictionary have contributed to the narrative of otherness, deviant, and abnormal when discussing disability and queerness, and Alison Kafer makes mention to various models within the structure of society that further push this narrative of compulsive non-disabled bodiedness. The medical model of disability, which is closely relevant to my thesis research and prototype, “frames atypical bodies and minds as deviant, pathological, and defective, best understood and addressed in medical terms. In this framework, the proper approach to disability is to “treat” the condition and the person with the condition rather than "treating” the social processes and politics that constrict disabled people’s lives.” (Kafer, 2013, p. 5). The book *Care Work: Dreaming Disability Justice* (2018) by Leah Lakshmi Piepzna-Samarasinha speaks to something called “crip emotional intelligence”. Crip emotional intelligence is the understanding that disabled people can be learned from, that they have knowledge that is valuable, and knowledge that non-disabled people do not know (Piepzna-Samarasinha, 2018). One of the characteristics of crip emotional intelligence is “knowing that offering miracle cures is a dirty word. Is knowing that cure is not mostly the point. Is knowing that our bodies don’t need to be cured or fixed into normalcy to be valuable.” (Piepzna-Samarasinha, 2018 p. 73). Crips know that the medical model is harmful to them, they know that the medical model wishes to place the blame onto the disabled person in the form of “cure” and not the system that is failing to provide adequate care. The medical model that Kafer describes is a system that can harm the future for crips and envisions a future without crips. This is why crip emotional intelligence allows us to gather a better understanding of the medical model, thus leading us to critiquing it, or making it political so it can function to meet and centre crip needs. Kafer is not against medical care, stating that a medical model must become political "…recognizing that a medical model is political allows for important questions about health care and social justice: "How good is the care? Who has access to it? For how long? Do they have choices? Who pays for it?"" (Kafer, 2013 p. 6). I would like to argue that big pharma functions from a medical model that is not political, because when the model becomes political, it forces us to question how big pharma limits access to care by viewing bodies as a commodity or for profit. Many disabled people do not need the perspective of the political medical model, because their disability does not require cure, and they can live fulfilling lives and we must reframe our mindset into it is the system that is broken, not the disabled person. However, some disabled and chronically ill people require the medical system to live that fulfilling life, and big pharma exploits this requirement because now the system benefits from capitalism, profit, and functions to make top executives richer. This forces us to try to make the medical model political through recognizing crip emotional intelligence so disabled individuals can receive or should receive access to care easily and effectively, without fighting for it. However, when we ask such questions of "how good is the care? Who pays for it? For how long?" and those questions are met with negative responses such as "the care is not as good as it could be, the disabled person themselves is responsible, etc." and access to care is hard to receive, we are now met with something called access friction.

What is Access Friction?

According to Calling Up Justice!, which is a non-profit organization that is centred around disability activism and justice, access friction "refers to the challenges and barriers that individuals face when trying to access resources, services, or activities. These barriers arise due to various factors such as physical, sensory, or cognitive disabilities." (Calling up Justice, 2023, para. 1). However, to bring this into the context of disability "access frictions are the obstacles that disabled people face when trying to access everyday services that non-disabled people often take for granted." (Calling Up Justice, 2023, para. 1). Various examples of access friction are spoken in crip emotional intelligence, to which Piepzna-Samarasinha states "…is understanding that everything will break, everything will take longer than you think, the elevator will be broken at the BART station and Paratransit will be three hours late. And that these are not surprises. These are deliberate acts in a world that doesn't value or fund access." (Piepzna-Samarasinha, 2018, p. 73). Essentially what Piepzna-Samarasinha is trying to state is that these services, like elevators or accessible transit, are not seen as valuable because they are not as important to non-disabled people, they are not funded adequately and therefore breakdown, which causes access friction. I argue that the lack of funding or knowledge to these resources could stem from compulsory non-disabled bodiedness that is described by Robert McRuer, because being non-disabled is seen as "the norm" there is less care to fund resources for disabled people.

The medical system, the political medical model, and big pharma could serve as examples to access friction. For some disabled and chronically ill people who require the services of the medical system, it can be a very convoluted system. When crips are failed by the system, or not given adequate access, they must create community and access spaces within themselves. Piepzna-Samarasinha speaks about a Facebook group called "Sick and Disabled Queers (SDQ)" created by a genderqueer writer and organizer named Billie Rain (Piepzna-Samarasinha, 2018). The SDQ's goals was to centre sick and disabled queer people, and disabled queer people of colour that have been marginalized from traditional disability rights spaces (Piepzna-Samarasinha, 2018). The work this group did is "…fundraising for rent and medical bills and accessible vans…SDQ folks regularly mailed each other meds and extra inhalers and adaptive equipment… we crowdsourced money for folks who needed to replace stolen wheelchairs, get living expenses for rehab…etc." (Piepzna-Samarasinha, 2018, p. 61). If the medical system or big pharma functioned properly so that disabled people received access without friction, support groups like SDQ would not have to provide medical resources or crowdsource funding. Disabled and chronically ill people are somewhat backed into a corner by the medical system and big pharma to create these support groups that focus on friction-free care, so you are not forced to choose between the harm that can come from lack of proper care, or living because your needs are met.

Disability Aesthetics

When we consider crip theory and the notion of compulsive non-disabled bodiedness, up until this point it has been framed within the context of systems and models, like the medical system, models of care, and the medical model. I argue that we must also begin to understand how the notion of compulsive non-disabled bodiedness is harmful when it comes to the appearance of the disabled and chronically ill body, especially within art and design aesthetics. In the book, *Aesthetics,* by Nicolai Hartmann (originally published in 1953) speaks about beauty and the perception of beauty stating, “The word “aesthetics” tells us that the form in which the beautiful is given to us is perception” (Hartmann and Kelly, pg. 47). Further “Aesthetics presupposes things of beauty, likewise the mental acts that appreciate them, along with a peculiar way of beholding, a sense of beauty, and an inward devotedness; even more, it presupposes the much more amazing act of artistic creation…” (Hartmann and Kelly, 1953, p. 2). Hartmann then goes on to speak upon the laws of beauty, arguing that aesthetics can say what beauty is and what its kinds and levels are, along with general preconditions, but it cannot teach in the practical sense what is beautiful (Hartmann and Kelly, 1953). Therefore, if this is the case, we must present the disabled and chronically ill body as beautiful in the same aesthetical beauty as the non-disabled body. These types of aesthetics are emphasized by Tobin Siebers in his book *Disability Aesthetics* (2010).

According to Tobin Siebers “Aesthetics tracks the sensations that some bodies feel in the presence of other bodies. This notion of aesthetics, first conceived by Alexander Baumgarten, posits the human body and its affective relation to other bodies as foundational to the appearance of the beautiful” (Siebers, 2010, p. 1). Typically, the type of bodies we see on display in the appearance of the beautiful are non-disabled, “perfect” bodies, to which led Siebers to coin the concept of disability aesthetics.

> Disability aesthetics names a critical concept that seeks to emphasize the presence of disability in the tradition of aesthetic representation…disability aesthetics refuses to recognise the representation of the healthy body – and its definition of harmony, integrity, and beauty – as the sole determination of the aesthetic. Rather, disability aesthetics embraces beauty that seems by traditional standards to be broken, and yet it is not less beautiful, but more so, as a result (Siebers, 2010, pp. 2-3).

In making the disabled body beautiful, Siebers states that there are two main goals: “1. To establish disability as a critical framework that questions the presuppositions underlying definitions of aesthetics production and appreciation; 2. To elaborate disability as an aesthetic value in itself worthy of future development.” (Siebers, 2010, p. 3). Sieber’s claim is the acceptance of disability enriches and complicates the notions of aesthetic, because disability enlarges our vision of human variation and difference (Siebers, 2010). For example, Sieber’s states that “sculpture and painting cherished by the Nazis exhibit a stultifying perfection of the human figure. Favoured male statuary such as Arno Breker’s *Readiness* displays bulked up and gigantesque bodies that intimidate rather than appeal…the perfection of the bodies is the very mark of their unreality and lack of taste…they may be healthy, but they are emotionally empty” (Siebers, 2010, p. 5). The presence of disability, which should be seen as valuable, requires us to revise our traditional conceptions of aesthetic production and appreciation (Siebers, 2010).

If we reframe our aesthetic conception of art and design to include disability aesthetics, we can start to step away from our notions of compulsive non-disabled bodiedness as the only form of beautiful within art and design. Disability aesthetics can also aid us in our inspection of how disabled bodies are viewed within the medical model and big pharma in combination with crip theory. Disability aesthetics, along with crip emotional intelligence, centres the disabled body as important, worthy, and valuable in the conversation.

Contextual Review

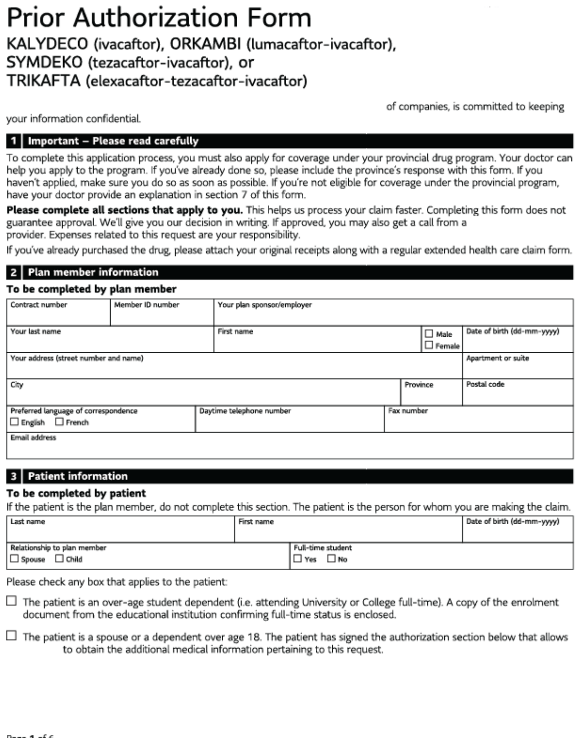
Access Friction and Disability Aesthetics

Within the medical system, in Canada, there are various forms of access friction. One great example that speaks to access friction, is parking meters at hospitals. A Cancer patient by the name of Collin Kennedy, who lives in Winnipeg, filled a parking meter with spray foam in 2016 to protest the high parking rates outside of the CancerCare Manitoba clinic (CBC News, 2016). Kennedy stated that “he did it because he is fed up with the City of Winnipeg and Impark charging sick people to park near the clinic and other treatment facilities…Kennedy estimates he’s had to pay $600 to park outside the CancerCare treatment centre since July 2015” (CBC News, 2016, paras. 3 & 12). Officials from the CancerCare centre stated that they do not have any control over parking fees and do not get any revenue from the parking meters (CBC News, 2016). So, who does the revenue go to? People who are sick and/or disabled that require the services of a treatment facility should not be tasked with paying high parking fees just so they can receive their treatment. These high fees within the parking meter create access friction because sick people have no choice but to pay them, to receive access to their treatments.

An exhibition titled *Crip Ecologies: Vulnerable Bodies in a Toxic Landscape* curated by Amanda Cachia, features work from various artists that illustrate the complex relationships with medical systems and procedures that are informed by aesthetics of pain and care. Panteha Abareshi was one of the artists whose work was shown in this exhibition, and their work could be a display of access friction and disability aesthetics. One of their exhibitions titled "*INVALID PLEASURES* (2023)" was shown at Kunsthall Trondheim. This exhibition featured various pieces that incorporated different types of medical equipment like needles, crutches, various tubing, etc. The purpose of the exhibition was to explore sexuality and sensuality within the context of disability and how the disabled body, and mind, is regarded as fetish objects (e-flux announcements, 2023). "The exhibition simultaneously explores our prejudice and celebrates variety and differences, thus suggesting that genuine equality can only emerge from what is described as disability pride" (e-flux announcements, 2023, para. 3). Therefore, Abareshi's ideology of exploring bodily differences and variety through disability pride is a representation of disability aesthetics as described by Tobin Siebers. "INVALID PLEASURES" also explores how the binary categories of "sick" and "healthy" are used to enforce the idea of how some bodies are more of value than others, and the built environment reinforces this preconceived notion by being accessible to some and inaccessible to others (e-flux announcements, 2023). Through Abareshi's artistic work we see an element of access friction through compulsive non-disabled bodiedness arise. The preconceived notions of "sick" and "healthy" which influence the built environment of "accessible" to "inaccessible", could be concluded from compulsive non-disabled bodiedness as "healthy" bodies are viewed as more valuable and therefore get to live in an accessible environment. Bodies that are "sick" and are viewed as less valuable, must deal with access friction through inaccessible environments, like the medical system.

Access Friction Objects

An example of an access friction object could be Trikafta. Trikafta is a life-saving drug for many CFers, but unfortunately receiving access is not so easy. In my own experience, there are many steps to receive access, through items like a prior authorization form from your private insurance company that must be filled out, with extensive information about your health. The six-page prior authorization form that I must fill out every year is pictured below.



Prior Authorization Form

KALYDECO (ivacaftor), ORKAMBI (lumacaftor-ivacaftor),
SYMDEKO (tezacaftor-ivacaftor), or
TRIKAFTA (elexacaftor-tezacaftor-ivacaftor)

of companies, is committed to keeping your information confidential.

1 Important – Please read carefully

To complete this application process, you must also apply for coverage under your provincial drug program. Your doctor can help you apply to the program. If you've already done so, please include the province's response with this form. If you haven't applied, make sure you do so as soon as possible. If you're not eligible for coverage under the provincial program, have your doctor provide an explanation in section 7 of this form.

Please complete all sections that apply to you. This helps us process your claim faster. Completing this form does not guarantee approval. We'll give you our decision in writing. If approved, you may also get a call from a provider. Expenses related to this request are your responsibility.

If you've already purchased the drug, please attach your original receipts along with a regular extended health care claim form.

2 Plan member information

To be completed by plan member

Contract number	Member ID number	Your plan sponsor/employer	
Your last name	First name	☐ Male ☐ Female	Date of birth (dd-mm-yyyy)
Your address (street number and name)			Apartment or suite
City		Province	Postal code
Preferred language of correspondence ☐ English ☐ French	Daytime telephone number	Fax number	
Email address			

3 Patient information

To be completed by patient

If the patient is the plan member, do not complete this section. The patient is the person for whom you are making the claim.

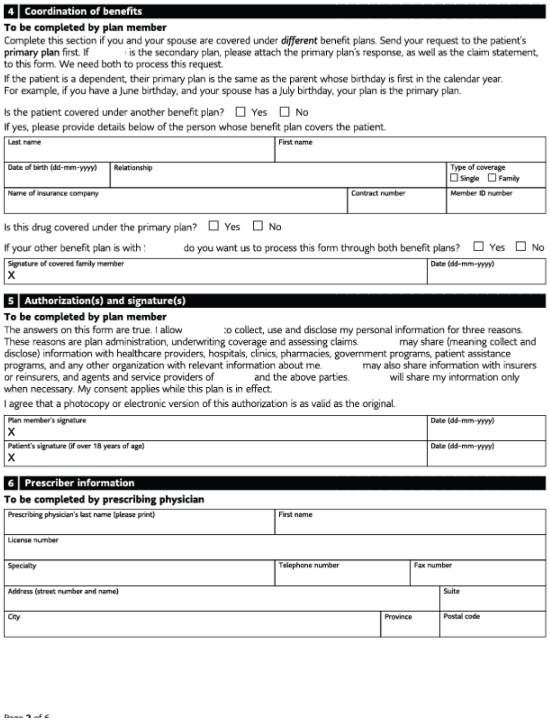
Last name	First name	Date of birth (dd-mm-yyyy)
Relationship to plan member ☐ Spouse ☐ Child	Full-time student ☐ Yes ☐ No	

Please check any box that applies to the patient:

☐ The patient is an over-age student dependent (i.e. attending University or College full-time). A copy of the enrolment document from the educational institution confirming full-time status is enclosed.

☐ The patient is a spouse or a dependent over age 18. The patient has signed the authorization section below that allows to obtain the additional medical information pertaining to this request.

Figure 1: Prior Authorization Form Page On



4 Coordination of benefits

To be completed by plan member

Complete this section if you and your spouse are covered under ***different*** benefit plans. Send your request to the patient's **primary plan** first. If is the secondary plan, please attach the primary plan's response, as well as the claim statement, to this form. We need both to process this request.

If the patient is a dependent, their primary plan is the same as the parent whose birthday is first in the calendar year. For example, if you have a June birthday, and your spouse has a July birthday, your plan is the primary plan.

Is the patient covered under another benefit plan? ☐ Yes ☐ No

If yes, please provide details below of the person whose benefit plan covers the patient.

Last name	First name	
Date of birth (dd-mm-yyyy)	Relationship	Type of coverage ☐ Single ☐ Family
Name of insurance company	Contract number	Member ID number

Is this drug covered under the primary plan? ☐ Yes ☐ No

If your other benefit plan is with do you want us to process this form through both benefit plans? ☐ Yes ☐ No

Signature of covered family member X	Date (dd-mm-yyyy)

5 Authorization(s) and signature(s)

To be completed by plan member

The answers on this form are true. I allow to collect, use and disclose my personal information for three reasons. These reasons are plan administration, underwriting coverage and assessing claims. may share (meaning collect and disclose) information with healthcare providers, hospitals, clinics, pharmacies, government programs, patient assistance programs, and any other organization with relevant information about me. may also share information with insurers or reinsurers, and agents and service providers of and the above parties. will share my information only when necessary. My consent applies while this plan is in effect.

I agree that a photocopy or electronic version of this authorization is as valid as the original.

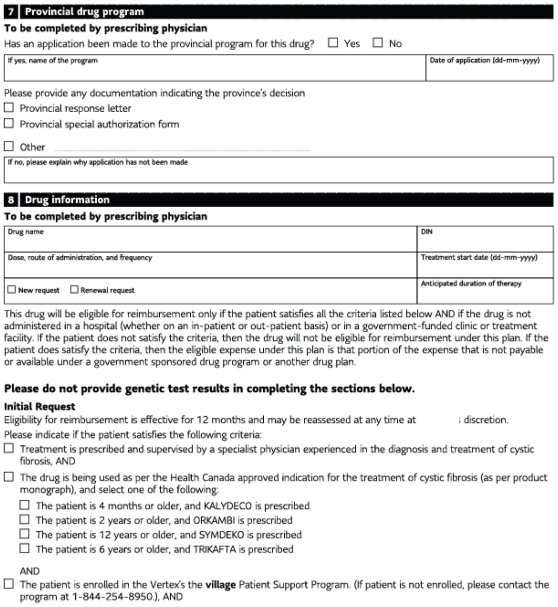
Plan member's signature X	Date (dd-mm-yyyy)
Patient's signature (if over 18 years of age) X	Date (dd-mm-yyyy)

6 Prescriber information

To be completed by prescribing physician

Prescribing physician's last name (please print)	First name	
License number		
Specialty	Telephone number	Fax number
Address (street number and name)		Suite
City	Province	Postal code

Figure 2: Prior Authorization Form Page Two



7 | Provincial drug program

To be completed by prescribing physician

Has an application been made to the provincial program for this drug? ☐ Yes ☐ No

If yes, name of the program	Date of application (dd-mm-yyyy)

Please provide any documentation indicating the province's decision

☐ Provincial response letter
☐ Provincial special authorization form
☐ Other ____________________

If no, please explain why application has not been made

8 | Drug information

To be completed by prescribing physician

Drug name	DIN
Dose, route of administration, and frequency	Treatment start date (dd-mm-yyyy)
☐ New request ☐ Renewal request	Anticipated duration of therapy

This drug will be eligible for reimbursement only if the patient satisfies all the criteria listed below AND if the drug is not administered in a hospital (whether on an in-patient or out-patient basis) or in a government-funded clinic or treatment facility. If the patient does not satisfy the criteria, then the drug will not be eligible for reimbursement under this plan. If the patient does satisfy the criteria, then the eligible expense under this plan is that portion of the expense that is not payable or available under a government sponsored drug program or another drug plan.

Please do not provide genetic test results in completing the sections below.

Initial Request

Eligibility for reimbursement is effective for 12 months and may be reassessed at any time at ; discretion.

Please indicate if the patient satisfies the following criteria:

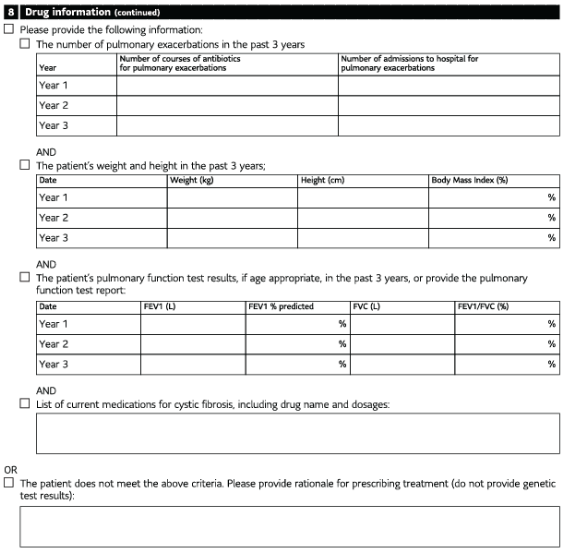
☐ Treatment is prescribed and supervised by a specialist physician experienced in the diagnosis and treatment of cystic fibrosis, AND

☐ The drug is being used as per the Health Canada approved indication for the treatment of cystic fibrosis (as per product monograph), and select one of the following:
  ☐ The patient is 4 months or older, and KALYDECO is prescribed
  ☐ The patient is 2 years or older, and ORKAMBI is prescribed
  ☐ The patient is 12 years or older, and SYMDEKO is prescribed
  ☐ The patient is 6 years or older, and TRIKAFTA is prescribed

AND

☐ The patient is enrolled in the Vertex's the **village** Patient Support Program. (If patient is not enrolled, please contact the program at 1-844-254-8950.), AND

Figure 3: Prior Authorization Form Page Three



8 | Drug information (continued)

☐ Please provide the following information:
  ☐ The number of pulmonary exacerbations in the past 3 years

Year	Number of courses of antibiotics for pulmonary exacerbations	Number of admissions to hospital for pulmonary exacerbations
Year 1		
Year 2		
Year 3		

AND

☐ The patient's weight and height in the past 3 years;

Date	Weight (kg)	Height (cm)	Body Mass Index (%)
Year 1			%
Year 2			%
Year 3			%

AND

☐ The patient's pulmonary function test results, if age appropriate, in the past 3 years, or provide the pulmonary function test report:

Date	FEV1 (L)	FEV1 % predicted	FVC (L)	FEV1/FVC (%)
Year 1		%		%
Year 2		%		%
Year 3		%		%

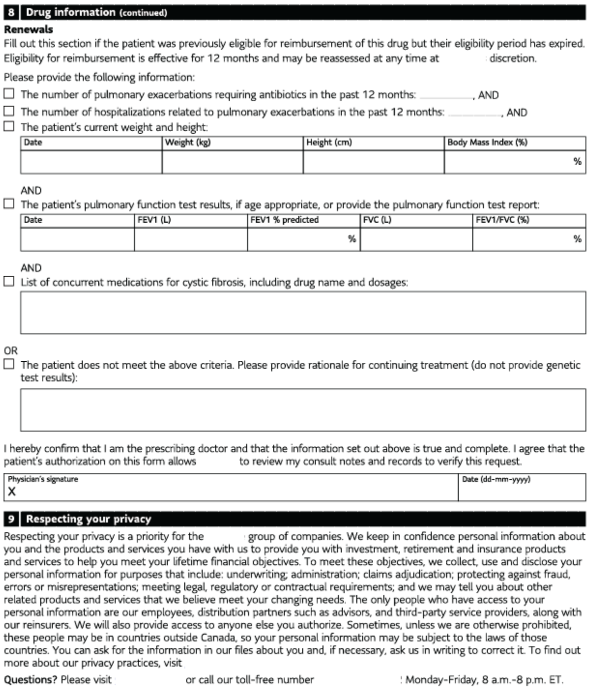
AND

☐ List of current medications for cystic fibrosis, including drug name and dosages:

OR

☐ The patient does not meet the above criteria. Please provide rationale for prescribing treatment (do not provide genetic test results):

Figure 4: Prior Authorization Form Page Four



8 Drug information (continued)

Renewals

Fill out this section if the patient was previously eligible for reimbursement of this drug but their eligibility period has expired. Eligibility for reimbursement is effective for 12 months and may be reassessed at any time at discretion.

Please provide the following information:

☐ The number of pulmonary exacerbations requiring antibiotics in the past 12 months: ________, AND

☐ The number of hospitalizations related to pulmonary exacerbations in the past 12 months: ________, AND

☐ The patient's current weight and height:

Date	Weight (kg)	Height (cm)	Body Mass Index (%)
			%

AND

☐ The patient's pulmonary function test results, if age appropriate, or provide the pulmonary function test report:

Date	FEV1 (L)	FEV1 % predicted	FVC (L)	FEV1/FVC (%)
		%		%

AND

☐ List of concurrent medications for cystic fibrosis, including drug name and dosages:

OR

☐ The patient does not meet the above criteria. Please provide rationale for continuing treatment (do not provide genetic test results):

I hereby confirm that I am the prescribing doctor and that the information set out above is true and complete. I agree that the patient's authorization on this form allows to review my consult notes and records to verify this request.

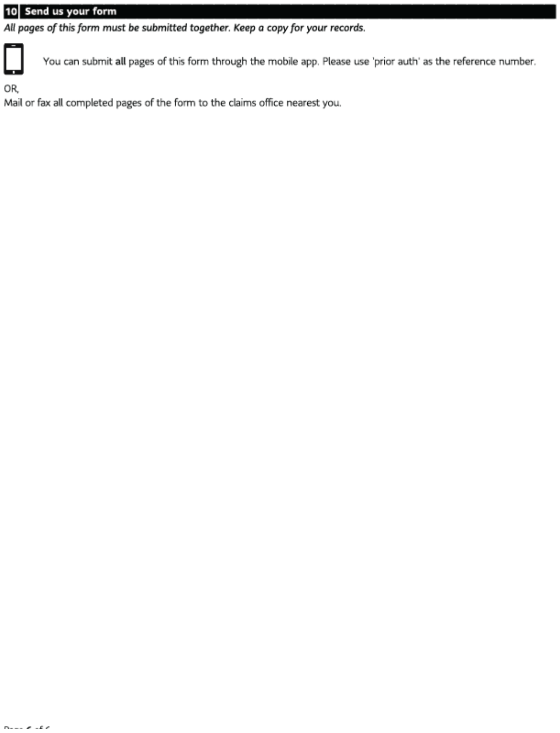
Physician's signature	Date (dd-mm-yyyy)
X	

9 Respecting your privacy

Respecting your privacy is a priority for the group of companies. We keep in confidence personal information about you and the products and services you have with us to provide you with investment, retirement and insurance products and services to help you meet your lifetime financial objectives. To meet these objectives, we collect, use and disclose your personal information for purposes that include: underwriting; administration; claims adjudication; protecting against fraud, errors or misrepresentations; meeting legal, regulatory or contractual requirements; and we may tell you about other related products and services that we believe meet your changing needs. The only people who have access to your personal information are our employees, distribution partners such as advisors, and third-party service providers, along with our reinsurers. We will also provide access to anyone else you authorize. Sometimes, unless we are otherwise prohibited, these people may be in countries outside Canada, so your personal information may be subject to the laws of those countries. You can ask for the information in our files about you and, if necessary, ask us in writing to correct it. To find out more about our privacy practices, visit

Questions? Please visit or call our toll-free number : Monday-Friday, 8 a.m.-8 p.m. ET.

Figure 5: Prior Authorization Form Page Five



10 Send us your form

All pages of this form must be submitted together. Keep a copy for your records.

📱 You can submit **all** pages of this form through the mobile app. Please use 'prior auth' as the reference number.

OR,

Mail or fax all completed pages of the form to the claims office nearest you.

Figure 6: Prior Authorization Form Page Six

Once this form is filled out, there is no guarantee that they will cover you. Below, is a user flow of the process I must go through every year to receive access to Trikafta.

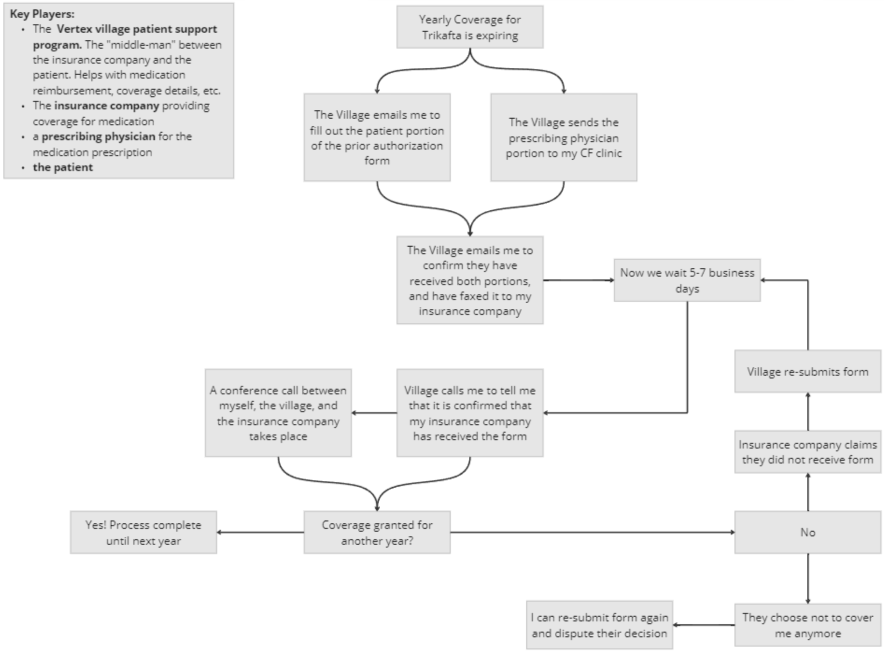


Figure 7: Access to Trikafta User Flow

The above user flow can sometimes take up to a month to hear an answer as to whether my insurance company will cover me again for a full year. The company will take anywhere from 5-7 business days to review the prior authorization form, but in my experience sometimes it can take 10-14 business days. In the meantime, my Trikafta prescription is running out, and there is the risk that there will be a gap in coverage which could be detrimental to my health and quality of life.

In conclusion, all these steps create a great deal of access friction, therefore making Trikafta the access friction object.

Chapter 3: Methodologies and Methods

Speculative Design as a Making Methodology

According to Anthony Dunne and Fiona Raby in their book *Speculative Everything: Design, Fiction and Social Dreaming,* “When people think of design, most believe it is about problem solving…design’s inherent optimism leaves no alternative but it is becoming clear that many of the challenges we face today are unfixable and that the only way to overcome them is by changing our values…design’s inbuilt optimism can greatly complicate things … as a form of denial that the problems we face are more serious than they appear” (Dunne and Raby, 2023, p. 2). To imagine these various scenarios for our future, we can use speculative design “…there are other possibilities for design as a means of speculating how things could be-speculative design…design speculations can act as a catalyst for collectively redefining our relationship to reality” (Dunne and Raby 2013, p. 2).

My physical creation prototypes are approached through an art-based lens and I am using speculative design to form the future-based “what if” scenarios these art-based prototypes exist within, positive or negative. Speculative design and futures also play a vital role in my manifesto, when I speculate what access to care for the disabled community should look like, or what it can look like.

Autoethnography

A lot of my research and prototype making is conducted and driven by autoethnography. According to Carolyn Ellis, Tony E. Adams, and Arthur P. Bochner “autoethnography is an approach to research and writing that seeks to describe and systematically analyze (graphy) personal experience (auto) in order to understand cultural experience (ethno)” (Ellis, et. al., 2010, p. 1). My own experiences and personal story drive the narrative of the discussed cultural experience of my thesis, which is being a disabled and chronically ill person that must be a consumer of the medical system and big pharma. Further, the authors state “As a method, autoethnography combines characteristics of autobiography, and author retroactively and selectively writes about past experiences. Usually, the author does not live through these experiences solely to make them part of a published document; rather, these experiences are assembled using hindsight.” (Ellis, et. al., 2010, p. 3). Therefore, I will use my prior and current experiences in combination with my theoretical research to create this thesis work.

Methods

Mind Mapping

Mind mapping was “developed as an effective method for generating ideas by association. In order to create a mind map, you usually start in the middle of the page with the central theme/main idea and from that point you work outward…” (The University of Adelaide, 2014, p. 1). For my mind map, I have chosen to conduct it through Miro. This mind map has allowed me to visualize and plan my thesis research content, but most importantly it has detailed how my thesis research has grown, evolved and began to shift into autoethnographic research.

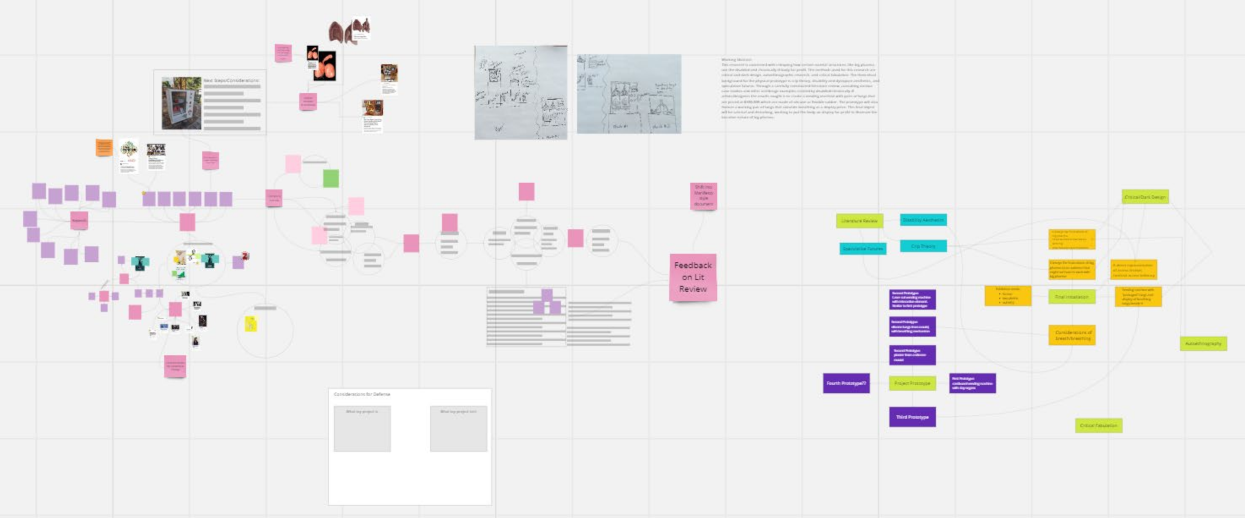


Figure 8: Entire Mind Map on Miro

There are various sections in my mind map that speak to my autoethnographic research, or detail how I began to shift my research into an autoethnographic framework. When I began to research where I was going to focus my thesis research, I had initially intended it to heavily utilize the concept of the posthuman, and at this point the research was not driven by my own story as a disabled and chronically ill person. However, that completely changed when I decided to pick up the book *The Posthuman* by Rosi Braidotti (2013 see Appendix D).

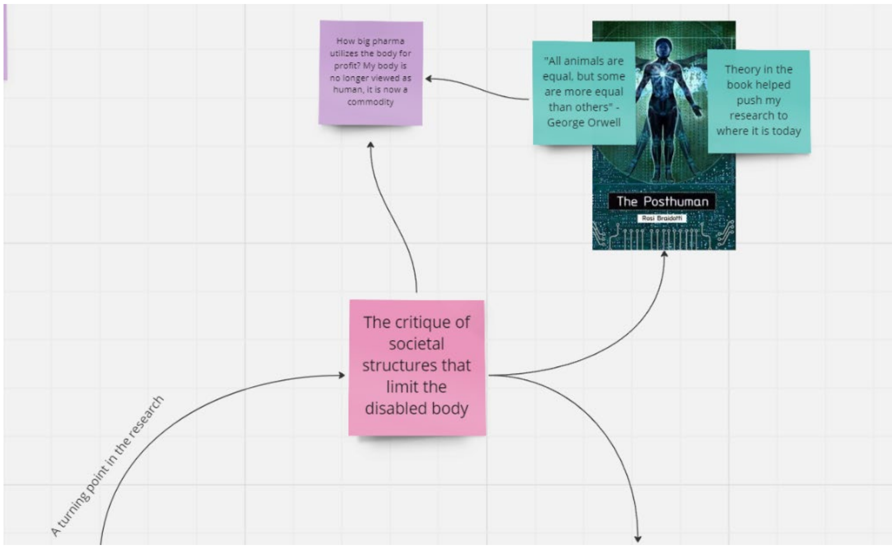
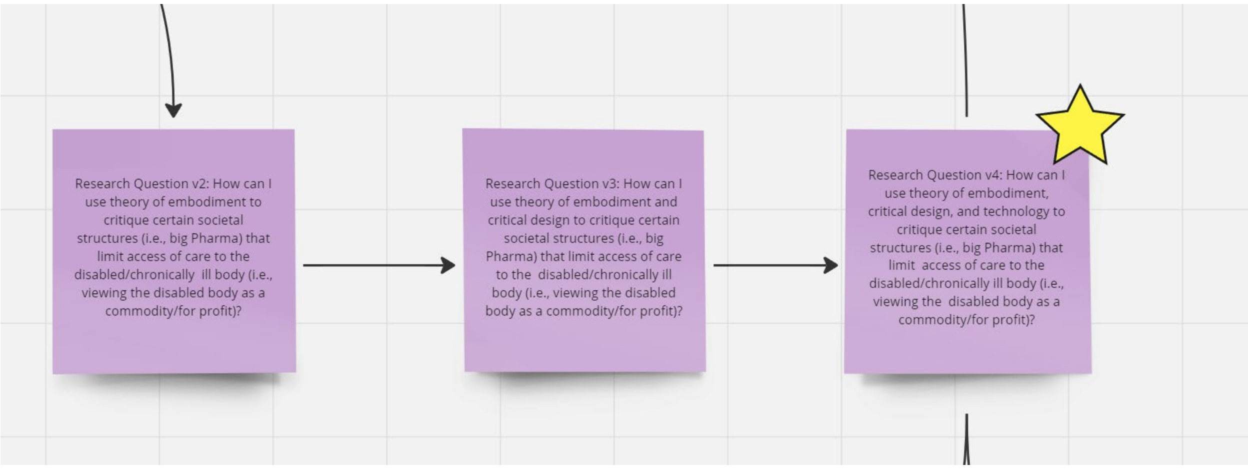


Figure 9: The Posthuman by Rosi Braidotti

Braidotti's research pushed me into thinking about equality amongst bodies, and because I already knew that I wanted to focus my thesis on disabilities, I started considering big pharma, and my experience as a consumer of big pharma.



Research Question v2: How can I use theory of embodiment to critique certain societal structures (i.e., big Pharma) that limit access of care to the disabled/chronically ill body (i.e., viewing the disabled body as a commodity/for profit)?

Research Question v3: How can I use theory of embodiment and critical design to critique certain societal structures (i.e., big Pharma) that limit access of care to the disabled/chronically ill body (i.e., viewing the disabled body as a commodity/for profit)?

Research Question v4: How can I use theory of embodiment, critical design, and technology to critique certain societal structures (i.e., big Pharma) that limit access of care to the disabled/chronically ill body (i.e., viewing the disabled body as a commodity/for profit)?

Figure 10: Research Question Considerations

At this stage, this is where I began to define some research questions, that built off Braidotti's research. At this stage, I started to narrow in my research to focus on how big pharma utilizes the body for profit.

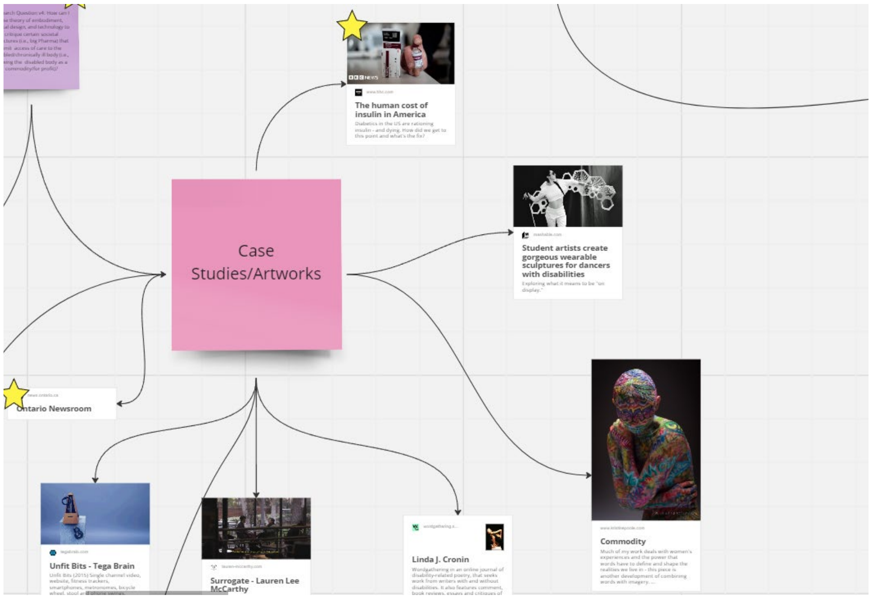


Figure 11: Brainstorming Case Studies

In this point in the research I started looking for various case studies that would fall in line with my main concepts and chosen area of study. This research was still broad and not specifically defined yet, but my own experiences in the form of case studies are relevant, for example the "Ontario Newsroom" article is discussing the price of Trikafta in the province of Ontario.

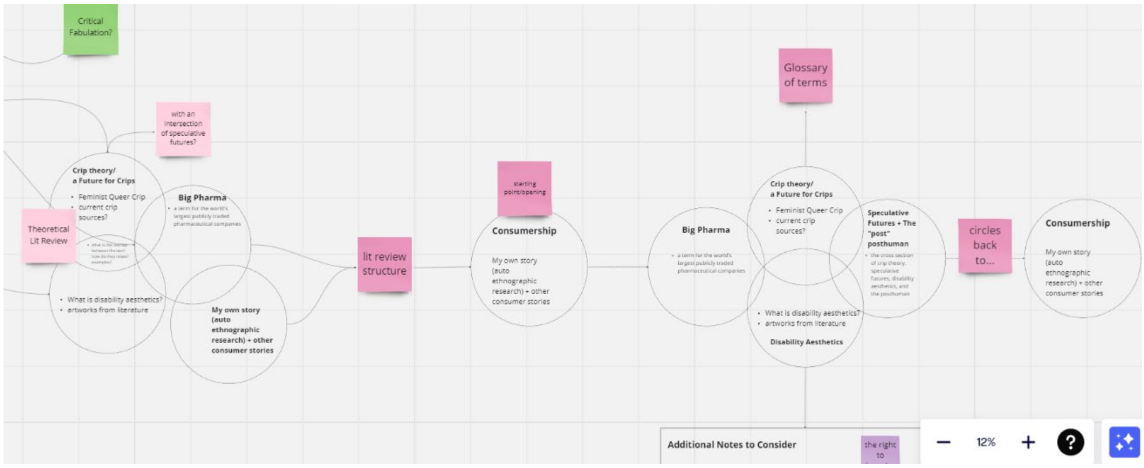


Figure 12: The Initial Structure for the Literature Review

This part of my mind map presents the initial structure of my literature review. At this point in the research, a lot of my own story began to supply the narrative of consumership within big pharma as a disabled and chronically ill person.

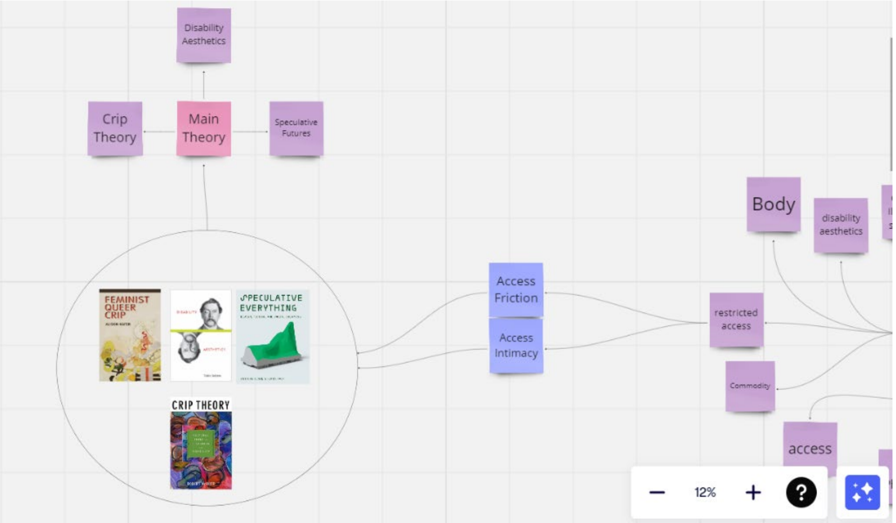


Figure 13: Main Theory used in Thesis Research

This section shows the final main sources I chose to use for the theoretical background of my thesis within my literature review, which is crip theory (feminist queer crip), disability aesthetics, and speculative futures. These sources then aid my discussion for access friction and access intimacy, which follows by example of my own experience dealing with access friction.

The creation of this mind map started in June of 2023, to organize my thoughts and ideas specifically for my thesis research. At that time, the research was still very broad, and I did not have a specific scope or research questions. To be able to lay out all my thoughts, different case studies, keywords, organize the theoretical content, the ability to explore multiple versions of my research questions, various inspiration images, highlight important turning points in the research, and detail different bits of feedback I received helped me narrow in my research to a specific narrative; an autoethnographic approach to access friction within big pharma. I was able to do this by taking all the bits and pieces listed above and start to string them together and make coherent research content.

The mind map helped me see and make connections and decide which research would be viable to move forward with and continue studying, and which research was not worth continuing. It has also been a very useful tool to look back on and see how my research has evolved and is continuing to evolve, it tells an interesting ten-month long story. Without the mind map I would have not been able to get to the point of where I am today in my journey.

Chapter 4: “The Body is no Longer Human, The Body is a Commodity” Creation Process

This chapter details the three physical creations or prototypes that were made to aid the research. All three pieces are very autoethnographic, with small pieces of my story contained within each piece. The first two pieces, the Organ Vending Machine, and the Breathable Lung Model detail the access friction that is created by big pharma and insurance companies, further, the breathable lung model represents how big pharma makes a vital function, like breathing, profitable which also aids access friction. The third prototype, the manifesto, focuses on access to care which contains a very speculative narrative about the future of care.

All three prototypes utilize speculative design to critique big pharma, and bring light to how big pharma uses the chronically ill and disabled body for profit instead of a focus on care/caring for the disabled body as human. As stated before, all three prototypes are also very autoethnographic, but my prototype also wishes to uplift the stories of other disabled and chronically ill people and their struggles with big pharma to create a collective voice.

Organ Vending Machine

First Iteration

Figure 14: First Iteration of Vending Machine

Figure 15: Clay Organs

The first iteration of the organ vending machine was a cardboard maquette of the proposed final iteration. This maquette is approximately 34 cm tall and 25 cm wide and is made from several pieces of cardboard. The three organs (stomach, heart, and lungs) are made from oven bake clay, with price tags labeling the price of each organ. I used this tutorial as a starting point for building my machine https://www.youtube.com/watch?v=NLyzoSRX7Sc. The "glass" for the front of the machine was a clear plastic tablecloth, that was cut to fit inside the door.

The first iteration of the machine was not functional, as the buttons on the machine and the coils did not work. This was done on purpose for two reasons, the first being that this was a visual piece to represent what the final version may look like, and the second reason was because I wanted the machine to start to emulate access friction.

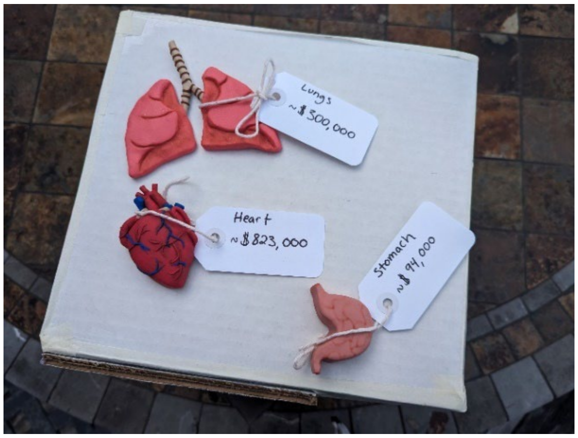


Figure 16: Clay Organs

For this iteration, I chose to sculpt a pair of lungs, a stomach, and a heart. The lungs were priced at $300,000 which is the price of the drug Trikafta. The stomach is priced at $94,000 and the heart is priced at $823,000 and these prices were decided at random. The rationale for choosing a stomach and heart were because at the time of creating this machine, I did not have the intention of focusing on my own story and narrative as a chronically ill person, so I wanted to represent other organs in the machine.

Second Iteration

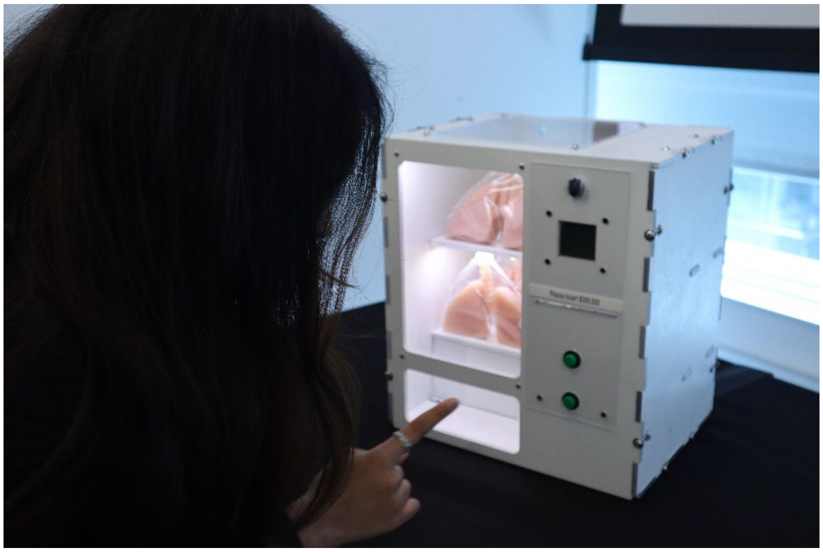


Figure 17: Final Iteration of the Vending Machine

After presenting the first iteration of the organ vending machine at colloquium, which is where I presented my thesis research proposal, I decided to focus the creation process on lungs priced at $300,000. This iteration is focused in fully representing my autoethnographic research.

The lungs were created from a silicone mould that I made, from a pair of sculpted plasticine clay lungs. After creating the silicone mould, silicone was poured in to create silicone lungs and the intention is to create four pairs total wrapped in plastic to appear as a “packaged goods” and placed within the coils of the vending machine.

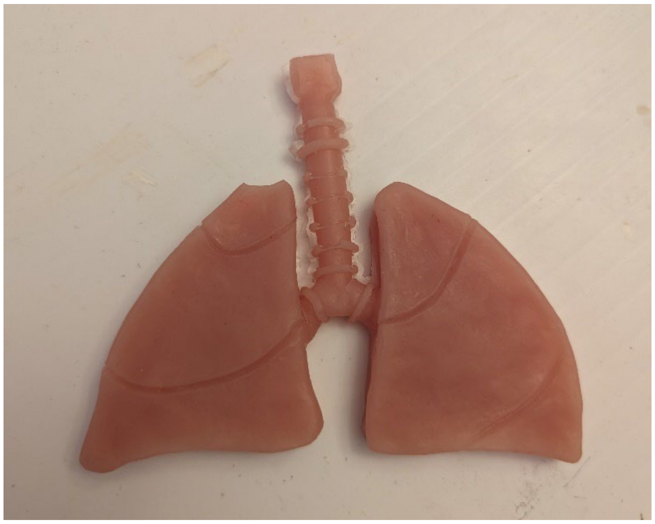


Figure 18: Silicone Lungs

The machine itself is laser cut pieces of ¼” thick birch wood that are spray painted white. I chose white because I personally think it gives the machine a “sterile” or “hospital” aesthetic, as I felt like the natural colour of the wood was too organic looking. I used this tutorial for the body of the machine and electronic components/coding: http://www.retrobuiltgames.com/the-build-page/arduino-vending-machine/, and slightly modified the design to only contain two rows of product trays, as opposed to four. The “glass” in the front of the machine are pieces of clear acrylic that were laser cut to fit on the machine.

The machine has a LCD screen and two momentary push buttons, that are interactive. Like the first iteration, the vending machine will not drop products, as they will be priced unreasonably high to create access friction. The screen will prompt the user to “please insert $300,000”, but the user will not have those funds available to them, therefore unable to complete a successful purchase. In this iteration, the user will be able to press the two buttons available, and the screen will still prompt them to insert $300,000, again not allowing the user to make a successful purchase.

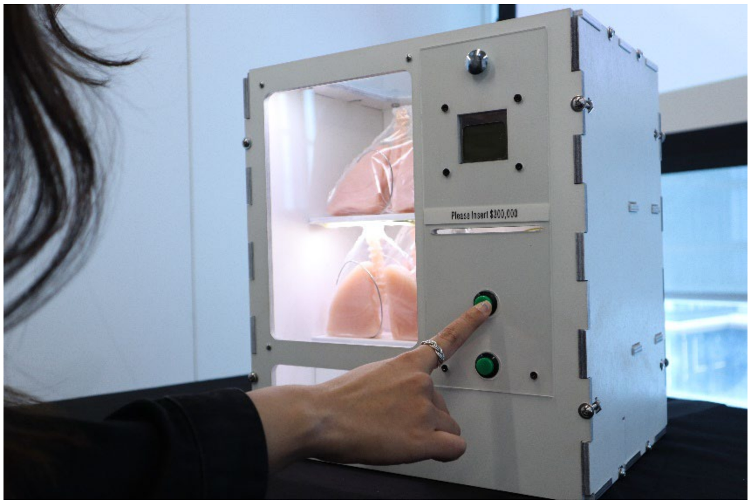


Figure 19: Vending Machine Interaction

The vending machine’s electronics (the screen and buttons) are powered by an Arduino Uno, the LED lights within the machine are powered by a 12V plug, and the coils were created by wrapping pieces of wire around the spray paint can to get the right shape, and glued to the back piece of the machine.

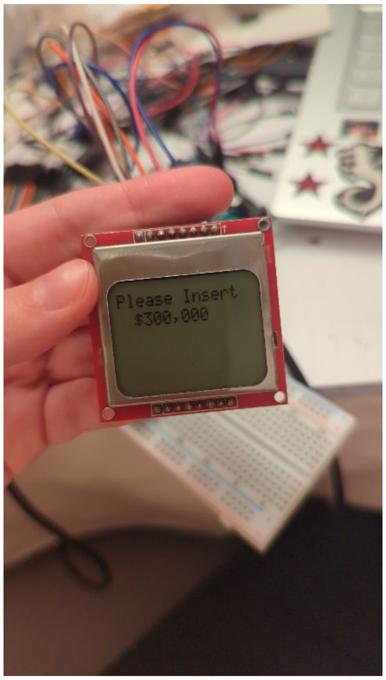


Figure 20: LCD Screen that Reads "Please Insert $300,000"

Breathable Lung Model

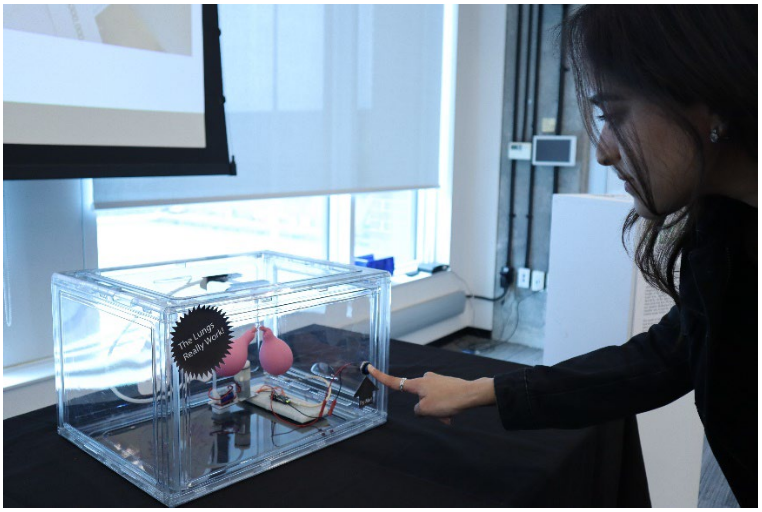


Figure 21: Breathable Lung Model

This breathable lung model is comprised of two pink balloons and tubing. The balloons are attached to a three-way valve with small elastics, that is connected to one singular tube, and the three-way valve can hold two balloons at once so the air can be pumped into both balloons simultaneously. The purpose of the lung model is to replicate the act of breathing and will be placed beside the organ vending machine in a clear display box.

Figure 22: Display Box

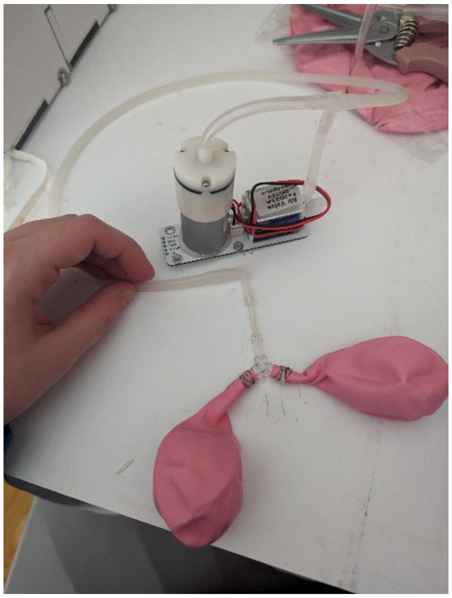


Figure 23: Air Pump

The tubing is connected to an air pump and air valve, that is connected to a breadboard and powered by an Arduino Nano. The air pump inflates the lungs for ten seconds, holds the air for 3 seconds, and then the air valve is opened to release the air and deflate the lungs. This process is repeated three times to replicate the function of lungs breathing.

Once the lung model is set up in in its display box, there is a sign that states “the lungs really work!”, to show that the lungs within the machine are “functional” when the user “purchases” a $300,000 pair. The user is prompted to start the breathing mechanism with a momentary push button that is fitted onto the front of the display box with a sign that reads “try me”. The intention of this function would be similar to a kids toy you see on a shelf in a store that prompts the user to try one of the toys mechanisms through a push button.

Manifesto

The purpose of this personal activist manifesto is to aid the visual and artistic objects of my prototype. While my prototype utilizes art as activism, its purpose to critique big pharma, the medical model, and insurance companies might not be quite obvious to one who does not understand the feelings of anger, grief, sadness, and annoyance when dealing with these systems. This manifesto is a summary of these feelings, the anger of access friction, it is to continue to queer the narrative of compulsive non-disabled bodiedness, it is a call to those who feel like they must hide their chronic illness and disability because they feel like are not worth advocating for. Lastly, it is crip speculative futures in nature, which will be discussed at length in the discussion section of my research (see Ch. 5). The call to action features my dreams of *access intimacy*; access intimacy that must be understood outside of the disabled community, a call to a future that is worth working towards.

The Crip Speculative Futures Manifesto

For the Love of Access Intimacy!

1. Crip Speculative Futures is here to queer the narrative of compulsive non-disabled bodiedness; disabled bodies are normal, valuable, and should exist within every dreamt future
2. Crip Speculative Futures refuses to accept access friction in the medical system.
3. Crip Speculative Futures centres the disabled body in discussions about care and will listen to disabled voices, involve them in decisions about their care first and foremost.
4. Crip Speculative Futures knows that cure is not always a bad thing but recognizes that it is not the answer for the disabled community. The focus should always be to care for the body that currently exists in the form that it is in. That is enough of a reason to care.
5. Crip Speculative Futures uses disability aesthetics beyond art to further queer the narrative of compulsive non-disabled bodiedness. Disabled bodies are beautiful just the way they are.
6. Crip Speculative Futures will hold big pharma accountable and prevent them from seeing the disabled and chronically ill bodies as profitable.
7. Crip Speculative Futures believes that disabled and chronically ill people should receive access to care through love, understanding, and acceptance. Care should never feel like a burden.
8. Crip Speculative Futures is a safe space for all disabled and chronically ill people. It is where we will act in access intimacy. It is for the sick, the mad, and the neurodivergent. It is for BIPOC and 2SLGBTQI+ voices. It is for those who experience medical racism and medical ableism. It is for everyone’s voice to be heard, understood, and loved.

Outcomes and Reflection

Why Art Activism?

As a chronically ill and disabled person, activism and learning to advocate for myself has been something that I learned to do and had to do my whole life, and it is a continual learning process. Because of this, I have also become very empathetic to other people's life experiences and situations, which includes other disabled people's lives as there are different types of ableism, and different types of advocacies for different disabilities. It has also taught me the importance of understanding other marginalized groups and what activism for those groups looks like, the importance of intersectionality, listening to, and up lifting the voices of others.

In my specific case, of having Cystic Fibrosis, sometimes it is very difficult to explain to someone who has never had to deal with my situation what my lived experiences are like. Truthfully, I do not expect everyone to empathize with my lived experiences, or claim to know what it feels like, because at the end of the day, it is perfectly acceptable to not know. However, I would appreciate if people without these lived experiences could understand the reason for activism and begin to empathize with folks who do not fall under the same lived experience. In my opinion, this is why I believe art activism is a very impactful and digestible way to gather a sense of empathy or understanding of various marginalized voices. I do also believe that art activism is an important tool for marginalized voices to tell their story in unique and eye-opening ways.

My prototype engages in art activism because I am engaging the audiences in new ways to the issues I am presenting. My physical creation process is a tool to invite sensory exploration, and to tell a story in engaging ways which show explicit, implicit, and tacit ways of learning what access friction is, how big pharma uses the disabled and chronically ill body for profit, and why access to care is important.

Organ Vending Machine and the Breathable Lung Model

My prototype, especially the organ vending machine, acts as a direct representation of an access friction object, to represent the frustrations I feel, and many others like me, when interacting with big pharma, the medical system, and insurance companies. When the public interacts with a functional vending machine, the intended outcome is you will receive the product you are purchasing, without friction. When vending machines do not work as intended, we experience frustration and confusion, wanting to receive the product purchased or our money back. I envision that my organ vending machine will invoke similar feelings to a dysfunctional vending machine. The user will attempt to purchase a pair of lungs, lungs that are a vital organ and are needed to perform a function, only to be met with not being able to complete a successful purchase. The price will be set very high, and the user will not have sufficient funds, thus simulating an access friction object.

The decision to create the organ vending machine to reflect my autoethnographic research came out of presenting it at colloquium. When I explained the rationale for pricing the pair of lungs at $300,000, the reaction from the audience was quite visceral. I got asked the question “why isn't your story the main narrative for the physical creation process?” and that is when I decided to move into putting my story at the forefront of my prototype, as it clearly made a large impact on my audience.

The breathable lung model is to aid the access friction that the vending machine creates. Cystic Fibrosis means that I am always conscious of my breathing, I always explain that I do not breathe involuntarily, I am always breathing in a voluntary mindset. When you start to lose a vital function, like breathing, it changes your perspective on the function itself. Before Trikafta, I could hardly breathe, and every breath was an active conscious effort and even after Trikafta, even though I can breathe much easier, my brain is permanently altered to think about every breath I take. To me, it feels like big pharma is aware of how important breathing is to someone with CF, and because breathing is not a choice, they choose to capitalize on this vital function making it very expensive through Trikafta. The breathable lung model creates this type of access friction for breathing, in the sense that to breathe properly you require to go through extra frustrating steps to receive a life-saving medication that is very expensive, which makes the very thought of breathing expensive.

Manifesto

Figure 24: The Manifesto Projection

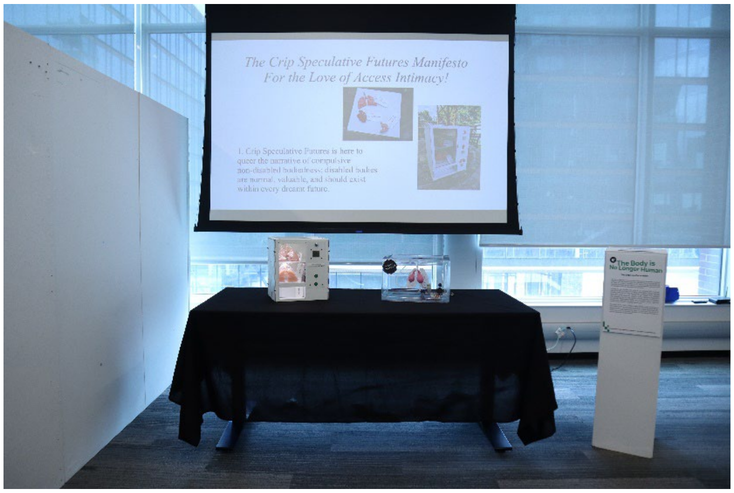
The manifesto is almost a direct contrast to the two art-based prototypes, because it speaks upon what access to care should be, what it should look like, and why easy access to care must exist for disabled and chronically ill people (this is discussed at length in Ch. 5). The manifesto itself was created by my own story, and other stories of disabled and chronically people’s fight to receive access to care, and the goal is the create a collective voice among myself and other disabled people. The structure of the manifesto is very speculative in nature and builds itself around crip speculative futures (see Ch. 5) which means that there is a good, loving future for disabled people that we must speculate with. There are a couple things I hope to achieve with this manifesto, the first is to queer the narrative, which comes from the need to dismantle compulsive non-disabled bodiedness discussed by Robert McRuer (see Ch. 2). The current narrative is that being non-disabled is the normal, or viewed as the normal which is exemplified by the OED definition of able-bodied. The manifesto seeks to queer (to shake up) that narrative by stating that is also normal to be disabled, and there is nothing wrong with being disabled. If we begin to implement this, then we can start to see disabled bodies as good, valuable bodies that deserve adequate care just like non-disabled bodies. The second purpose of the manifesto is to teach non-disabled people about access intimacy (see Ch.5), and why it needs to be a part of the future of care, or crip speculative futures. The manifesto is also a call to other disabled and chronically ill people, becoming access intimacy itself, as it seeks to create a conversation within the disabled community, a conversation of love, understanding, friendship. It is to express shared feelings of anger, failure, frustration, and a call to “we are here! Please listen to us! We deserve care!”.

Lastly, the manifesto features actionable steps to access intimacy to speculate with, it is a call to action to everyone, disabled and non-disabled, that I invite on this journey to speculate with me. If we all put in the work together, and dream of an accessible future for disabled and chronically ill people, we are one step closer to it being a reality.

The final version of the manifesto was a series of slides that displayed each of the statements. This final format gave me the opportunity to show some of my process work while creating each of the prototypes, which helped make the manifesto more visually appealing to the audience.

Link to final manifesto projection: https://youtu.be/88ue9ogOrQ0

Exhibition Results



The Crip Speculative Futures Manifesto
For the Love of Access Intimacy!

1. Crip Speculative Futures is here to queer the narrative of compulsive non-disabled bodiedness; disabled bodies are normal, valuable, and should exist within every dreamt future.

Figure 25: Final Exhibition Display

All three of these pieces were exhibited together at the Digital Futures Exhibition titled *Creative Disruptions: Re-imagining our futures (2024).* The organ vending machine and breathable lung model were displayed together on a table, and the crip speculative futures manifesto was projected behind the table. Beside the table was a plinth that displayed my didactic and artist bio card, with a QR code that brings the user to my portfolio. The manifesto is written in plain text within my portfolio together with two resources that contain additional information on access intimacy and access friction.

The Body is No Longer Human

The Body is a Commodity

This thesis research is concerned with critiquing how big pharma, insurance companies, and the medical model uses the disabled and chronically ill body for profit. The research considers a brief analysis of big pharma through real-world examples, but also takes on an autoethnographic approach as an individual who is an active consumer of big pharma.

Utilizing my own account and voice as an individual with a genetic progressive chronic illness and disability called Cystic Fibrosis becomes integral to the research and the prototype creation process. Feminist queer Crip, which is a sub section of crip Theory, and disability aesthetics, further enrich the research as the theoretical background when analyzing how the long-standing thought process of compulsive non-disabled bodiedness is harmful and can further lead to devaluing disabled and chronically ill bodies in the medical system, and thus creates access friction or lack of access to care.

The results of the research and prototype creation seeks to educate on how access friction can be harmful to disabled and chronically ill bodies, which leads us to utilize speculative futures to dream about what easy access to care might look like and helps us understand why access to care is vital when we consider disabled and chronically ill bodies as valuable within the medical system.

Figure 26: Plinth with Didactic and Artist Bio Card

In the Future Goals (see Ch. 5) section of my research, I speak about my exhibition hopefuls, and what I hoped my prototypes and exhibition would achieve. In that section, I speak upon wanting to create a space of access intimacy with my prototypes, and the opportunity to educate the audience about access friction within my own lived experiences. After having the opportunity to display these three pieces, I feel like I achieved what I set out to create. I spoke to many different people in the three days that this exhibition took place, and within that time frame, I learned many stories of people who had gone through similar experiences to myself or knew friends and family that have similar stories that involve frustration aimed towards the big pharma complex. It was a very welcoming space that allowed people to share their stories and allowed me to share my own which created access intimacy. The prototypes acted like a conduit for this access intimacy, the starting point for these conversations to take place, which resulted in a loving, intimate, and judgement free safe space.

This space was also educational, which was another one of my goals. I had many conversations with people who had never had to experience what I go through, and I had many opportunities to educate people on Cystic Fibrosis, the big pharma complex, access friction, access intimacy, and the value of including disabled people within every dreamt future.

Overall, it was a beautiful experience, an experience that inspired me to continue the work I have created because it is a valuable interjection into disability activism and justice.

Final exhibition walkthrough video: https://youtu.be/0XuH13P3jkw

Chapter 5: Crip Speculative Futures and Future Goals

What is Access Intimacy?

A large thematic element of my research and physical creation process is access friction, the importance of education surrounding access friction, and voicing my frustrations of access friction that is hopefully relatable to other individuals within the disabled and chronically ill community. In this section, I would like to discuss my own commentary on crip speculative futures and access intimacy, which was summarized in my manifesto.

Access Intimacy, according to Mia Mingus in her blog *Leaving Evidence*, who is an educator, queer, and physically disabled, defined access intimacy as “that elusive, hard to describe feeling when someone else “gets” your access needs. The kind of eerie comfort that your disabled self feels with someone on a purely access level…it could also be the way your body relaxes and opens up with someone when all your access needs are being met.” (Mingus, 2011, para. 4). Mingus goes on to explain that the deepest understanding of access intimacy typically comes from other disabled people, “…it is also the intimacy I feel with many other disabled and sick people who have an automatic understanding of access needs out of our shared lives. Together, we share a kind of access intimacy that is ground-level, with no need for explanations.” (Mingus, 2011, para. 5). It is important to not get access intimacy confused with just the action of “access” or “helping” someone, as there are instances where the “access” can invoke feelings of burden or violation (Mingus, 2011). The word “intimacy” is key here, because after you receive access or access is automatically assumed, you feel loved, happy, and joyful. (Mingus, 2011).

In my own circumstance, when I receive access to the drug Trikafta, it is not through access intimacy because the process of filing out a prior authorization form every single year leaves me feeling burdened, it puts a weight on my shoulders. What if one year my insurance decides not to cover me anymore? What if this year is the last year that I will receive coverage? What then? If my access to Trikafta was through access intimacy, then I would not experience any of these feelings. In the book *Care Work: Dreaming Disability justice* by Leah Lakshmi Piepzna-Samarasinha it also speaks access intimacy. She states, “When I think about access, I think about love…I think that crip solidarity, and solidarity between crips and non(yet) crips is a powerful act of love and I-got-your-back.” (Piepzna-Samarasinha, 2018, pg. 75). In this circumstance, Piepzna-Samarasinha is speaking to how access intimacy can translate to crip solidarity, which means almost exclusively within crip communities access is full understood, respected, and valued as critically important for disabled people’s lives. Personally, when I speak to other chronically ill and disabled people about my disabled experience, it is some of the most intimate and deeply understood conversations, conversations that are a place of love and a place where you never have to over explain yourself and your needs. Mia Mingus also speaks to crip solidarity as a form of access intimacy, stating

> We are traveling, trying to track down food. My chair can't go into this restaurant, your dog isn't allowed in…so we order in. you can't fly to the meeting, so we will come to you – all of us. They won't let you go to the bathroom because they say you're "too slow", so we will demand they do – and make them wait for you – together. Sometimes we are comrades, sometimes we are strangers, but we will stay together. We move together. (Mingus, 2010, para. 3).

Crip solidary is access intimacy because, from Mingus' statement, crips understand the burden that access friction places, from healthcare, to daily tasks, and something as simple as going to eat at a restaurant.

When recognizing adequate forms of care, we must continue to listen to and centre sick and disabled people. The Brother's Sick is a sibling artistic collaboration, Ezra and Noah Benus, that focuses on disability justice, illness, and care (Benus, 2020). At the height of the COVID-19 pandemic, the Brother's Sick curated an online gallery in April 2020 titled *An Army of the Sick Can't Be Defeated,* which consisted of 14 artists and their work. The purpose of this curated web gallery was to reconnect with others in the pandemic, it was a space to reach out and call to care for one another, and to radically give and take care (Benus, 2020). The COVID-19 pandemic gave us "visceral and inescapable realizations that our systems are failing us all…our care systems are broken and built for only the few who can afford quality care – something that many people are realizing. "(Benus, 2020, paras. 1-2). These broken systems have taught us that we must continue to centre and learn from disabled and chronically ill communities, especially from people who are marginalized by ongoing systemic racism and gender discrimination (Benus, 2020). Unfortunately, disabled and chronically ill people are seen as "disposable", as our needs are complex and cost more than "healthy" individuals, and this is exemplified by medical and insurance industry complexes. In order for disabled people to survive, we need to change these systems that function on a foundation of access friction (Benus, 2020). In this sentiment, *An Army of the Sick Can't Be Defeated* was created, a collaborative work that represents the struggle of surviving in this broken world, and disabled people supporting disabled people in the process (Benus, 2020). "Inspired by strong and deep legacies of those Sick, Queer, Mad, from Jewish communal and familial inherited trauma; from Black, Indigenous, and communities of colour's protest legacies…disability activists and artists…*An Army of the Sick Can't Be Defeated* is a call to arms to enact care and prioritize mutual aid" (Benus, 2020, para. 9). In other words, *An Army of the Sick Can't Be Defeated* is a call to access intimacy among marginalized and disabled communities and to prioritize care and crip solidarity in COVID-19, and especially post-COVID-19.

Access Intimacy in Practice

What can access intimacy look like in practice? *I wanna be with you everywhere* was a performing arts festival at the Performance Space New York in 2019, which showcased various disabled artists and performers over the course of four days (Kim, 2019). According to the organizers of the festival

> *I wanna be with you everywhere* honours disability aesthetics and disability justice…the festival celebrates the world-making and experimentation that comes from refusing both exclusion and inclusion…this gathering is propelled by a refusal of the separation that ableism imposes, starting from the belief and desire that access is a shared commitment to each other (Kim, 2019, para. 4).

All performances were accompanied by ASL (American Sign Language), real-time captioning, audio description, assisted listening and/or wearable tactile audio system called SubPac, depending on the art being presented (Kim, 2019). Further, this festival features a variety of seating options, low-stimulus environment, stim toys, and a table where you can get your transit fare reimbursed. This space cultivated calmness, a sense of trust in others to have your access needs met, and a temporary relief from the unrelenting ableism of everyday life that we cannot escape alone (Watlington, 2022). The organizers did the best that they could to remove as many forms of access friction as possible for this festival, so the participants would not feel the burden of their access not being met. There is a clear sense of access intimacy here, from all the different types of accommodations that are being considered, physical, tactile, sensory, and cognitive, to the actual performances themselves. Therefore, *I wanna be with you everywhere* showcases why implementing access intimacy is an important act of love for disabled bodies, and how everyone has the right to enjoy art equally.

My proposition for crip speculative future dreaming is through the foundation of access intimacy. Access intimacy already exists, and is proven to be something that should exist, but I feel like it is almost exclusively understood and implemented within the disabled community, when it should also be a consideration elsewhere, like big pharma and the medical system.

Crip Speculative Futures

According to Anthony Dunne and Fiona Raby in their book *Speculative Everything,* which was introduced earlier in my research (see Ch. 2)

> We believe that by speculating more, at all levels of society, and exploring alternative scenarios, reality will become more malleable and, although the future cannot be predicted, we can help set in place today factors that will increase the

> probability of more desirable futures happening. And equally, factors that may lead to undesirable futures can be spotted early on and addressed or at least limited. (Dunne and Raby, 2013, p. 6).

I propose to speculate a society of access intimacy for the community of disabled and chronically ill people. Yes, access intimacy already exists and is being implemented, but I wish to extend it to other systems within society, like big pharma and the medical system. Currently, throughout the medical system and through the works of Alison Kafer (see Ch. 2) we see a lot of burden. For example, because the medical model typically focuses on cure rather than care (Kafer, 2013), it now places a burden onto the disabled person, a burden that translates to "your body should not exist; therefore, we do not have to give you the care you need and deserve" and this results in care that is inadequate. Big pharma places this burden through high medication costs, limited access to medication, and forcing disabled and chronically ill people to pay for their choices. As I've stated before, in my own circumstance this burden is placed by the lengthy process I must go through every single year to get access to Trikafta, which is created by big pharma and then carried about by private insurance.

How can we remove this burden and begin to take the right steps towards access intimacy?

- Queer the narrative of compulsive non-disabled bodiedness. Recognize that disabled bodies are normal, valuable, and should exist within every dreamt future.
- Continue to make the medical model political, first stated by Alison Kafer (see. Ch.2) by asking questions like "Who pays for care? How good is the care? Etc.
- Centre the disabled body in discussions about care and continue to listen to disabled voices, involve them in decisions about their care first and foremost.
- Access to care and the type of care should be adequate, safe, focused on love for the disabled person's needs, and those needs should be met without a fight. "Cure" is not always a bad thing but recognizing that it is not always the answer. The focus should always be to care for the body that currently exists in the form that it is in. That is enough of a reason to care.
- By using disability aesthetics beyond art. Disability aesthetics further queers the narrative by recognizing that disabled bodies are beautiful just the way they are.
- We must hold big pharma accountable for their decisions, prevent them from seeing disabled and chronically ill bodies are profitable, and as nothing more than a commodity.
- If someone needs access to a medication or treatment, they should be given that treatment or medication easily, through access intimacy, through a deep and intimate understanding of their right to receive adequate care without burden.
- The reason someone cannot receive a medication or treatment should never be because they cannot afford it.

- The care should last for as long as the person needs it and wants it. No questions asked.

It is important to note that the actionable steps listed above come directly from my manifesto, just written out in more detail than the manifesto.

I dream to see access intimacy within big pharma and the medical system, I wish to see disabled bodies cared for, and seen as valuable bodies within these systems. I know we have a long, long way to go, and I am not sure if we will ever see access intimacy properly used within these systems, but like Dunne and Raby said, speculating is important as it will increase the probability of desirable futures becoming true (Dunne and Raby, 2013). It is important to note that, according to Piepzna-Samarasinha, “when disabled people get free, everyone gets free. More access makes everything more accessible for everybody…and once you’ve tasted that freedom space, it makes inaccessible spaces just seem very lacking…and full of hate. Why would you want to be part of that?” (Piepzna-Samarasinha, 2018, p. 78). Everybody, and this includes non-disabled people, should understand and care about access intimacy, especially within the context of big pharma and the medical system. Everybody, regardless of health, might have to rely on the care of the medical system and big pharma, care that will impact your future. I implore you to join me on the journey of crip speculative futures, a journey that will see the future of access intimacy within the systems that should properly care for us as valuable human beings.

Future Goals

Exhibition Hopefuls

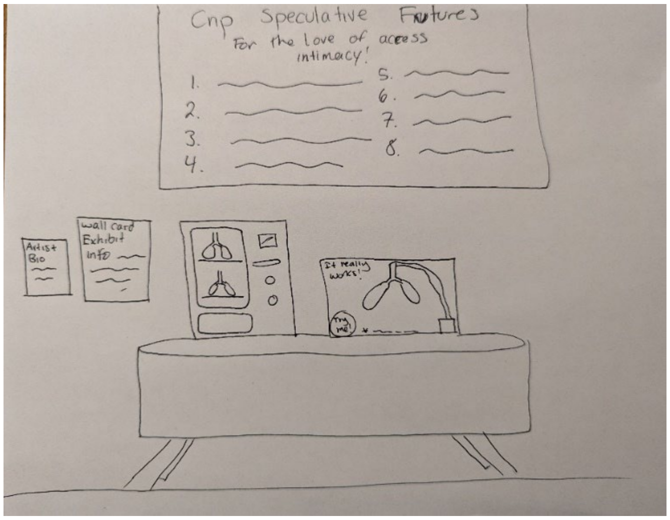


Figure 27: Exhibition Hopefuls

For the final Digital Futures exhibition in April 2024, this is what I envision my physical creation process will look like. The two art-based prototypes will be placed together on a singular table, side by side. The For the Love of Access Intimacy! manifesto will be projected behind the two pieces, to contrast them (access friction vs. access intimacy). As discussed previously, the two art-based prototypes function together to create access friction, with a, hopefully, deep understanding of how big pharma uses the body as a commodity. The hope is that people will interact with the prototype, and this interaction, through art as activism, will help the users understand access friction and the body as a commodity on a deeper more empathetic level. I hope that my prototype makes the audience deeply uncomfortable, and invokes feelings of uncertainty, anger, and frustration which are all the feelings I feel when I must deal with big pharma. I hope that the manifesto will then teach the audience what access intimacy means, why it is so important, and that is serves as a jumping off point for reflection of how access intimacy is severely lacking, and where in their own personal lives it can be implemented. I hope that the audience reflects on where they can begin to enact access intimacy, as a form of care for the people around them. For the exhibition, as a takeaway, I wish to print my manifesto on postcards that the audience can take home with them so they can be reminded of my exhibition, and the importance of access intimacy is a constant reminder through the postcard.

Lastly, I hope that other chronically ill and disabled people can relate to my exhibition and work, and I hope it is impactful for them to understand that you are never alone, as I understand your struggle on a deep empathetic level. I hope my exhibition creates an intimate open dialogue between other disabled people and myself, and a shared safe space for important conversation about access intimacy.

The Future of Access Intimacy

My biggest wish for the future of my research is for the discussion of access intimacy to continue within big pharma and the medical system, and for the care of a disabled person to always be the centre of the conversation. I wish for it to extend beyond these systems, and for it to be in the primary discussion of how to make the world a more accessible, caring place for all bodies but especially disabled and chronically ill bodies. Disabled people deserve to feel like a priority within every space, and their needs must be met and considered always. I hope my research can be used as an educational model and tool to discuss how access intimacy can be used to redesign care within educational settings, the medical system, when designing digital spaces of all varieties, when creating art, and even within fictional spaces too, like movies, games, and other mass media.

I hope to be able to continue the research I have started here, as I believe there is much work to be done. The answer(s) to my research questions are open ended, meaning that they do not necessarily have a defined answer.

- “How can I use autoethnography, feminist queer crip, disability aesthetics, and speculative futures to critique limited access of care to the disabled/chronically ill body?”
- “What will a future of care look like for the disabled and chronically ill community if the focus of care was on the body and not for profit?”
- “How could the research and creation process meaningfully interrogate viewers’ and audiences’ own perceptions of care and access through art?”

My research questions are something I wish to continue to explore, by furthering the work on my physical creation process, or look for new ways through art activism, design, and speculative futures and figure out new ways I can answer my research questions.

In conclusion, I hope this research creates space for disabled and chronically ill people to explore and discuss access intimacy as a long-term objective. I hope to create a sense of belonging within the community, and a deep sense of love for your needs and knowing that care is valid and needed. You are not a burden because you require care, and your body deserves to be loved in whichever state it is in. I hope that non-disabled people can learn the importance of the care in which disabled people need, and I hope that they can begin to expand access intimacy into many areas within their daily lives. I hope to see a prosperous future for access intimacy.

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Appendices

Appendix A: Updated and relevant OED Definitions

Heterosexuality: The state or quality of being sexually attracted to individuals of the opposite sex; heterosexual character, nature or identity.

Source: Oxford English Dictionary. (2023). Heterosexuality, *N.,* Sense 1.a. In Oxford English Dictionary. https://doi.org/10.1093/OED/7959628272.

Able-bodied: Of a person: fit and healthy; physically robust; capable of work; free from physically disability.

Source: Oxford English Dictionary. (2023). Able-bodied, *Adj.* In Oxford English Dictionary. https://doi.org/10.1093/OED/5811707569.

Unfortunately, the OED definition of able-bodied has not changed since Robert McRuer wrote the book *Crip Theory: Cultural Signs of Queerness and Disability* in 2006. Therefore, this definition still promotes compulsive non-disabled bodiedness and needs to change.

Disabled: Of a person. Having a physical or mental condition which limits activity, movement, sensation, etc. also occasionally of a part of the body.

Source: Oxford English Dictionary. (2023). Disabled, *Adj.,* sense 1.2. In Oxford English Dictionary. https://doi.org/10.1093/OED/1075079315.

Appendix B: Additional Mind Map Photos, Diagrams, and Sketches

Manifesto Brainstorm

The Crip Speculative Futures Manifesto

For the love of Access Intimacy

to queer the narrative of complusive able-bodiedness

the frustration of access friction

your body is seen as profitable

your body is seen as a commodity

the binary terms of "sick" and "healthy"

to dream of access intimacy

to dream of a future of access intimacy

easy access of medication

access to care

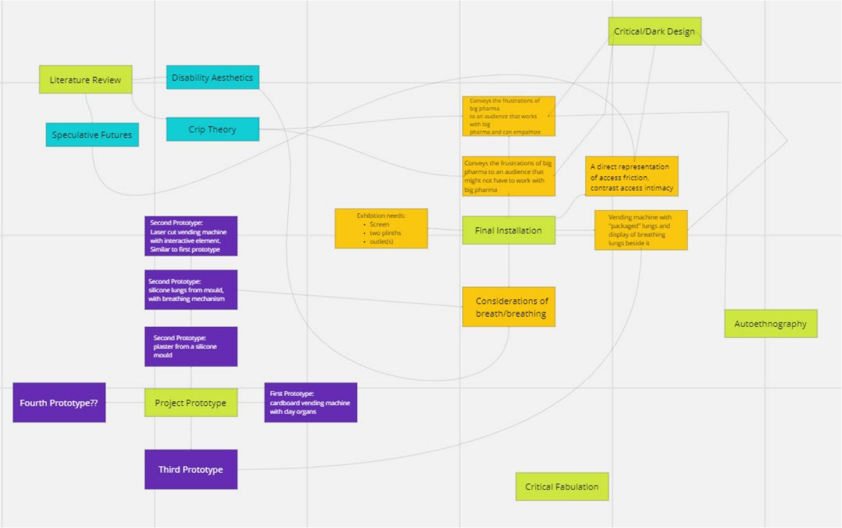
the medical model is reframed to centre the disabled body as valuable to care

No more feelings of burden

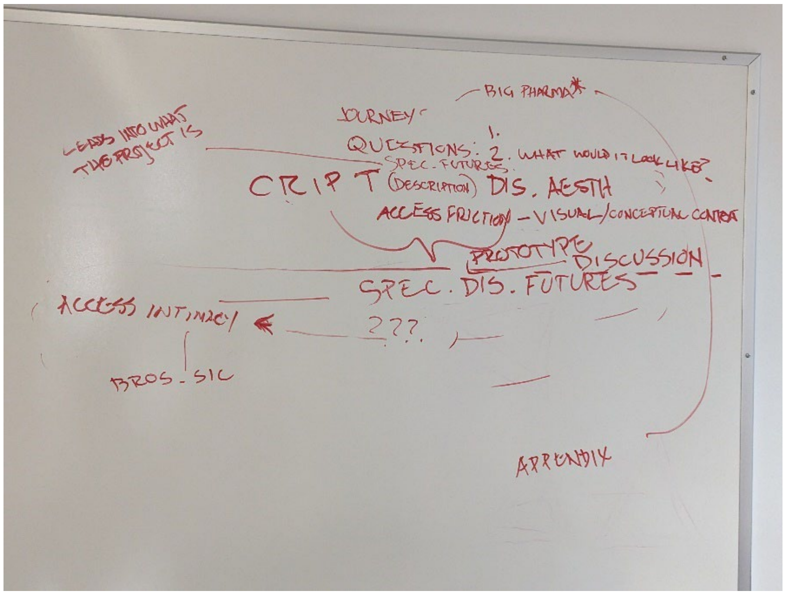
I am a human being that deserves care!

Access is always assumed, never fought for

Thesis Diagram(s)



First initial plan of document

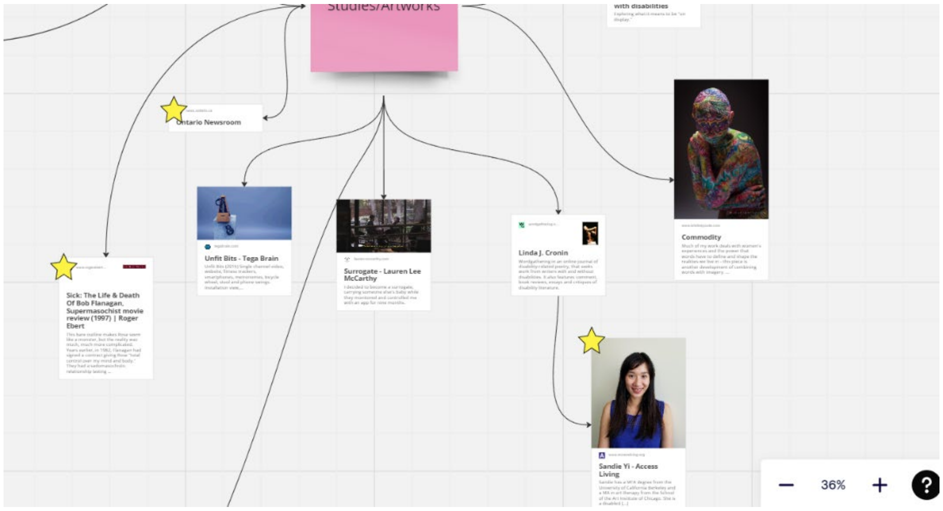


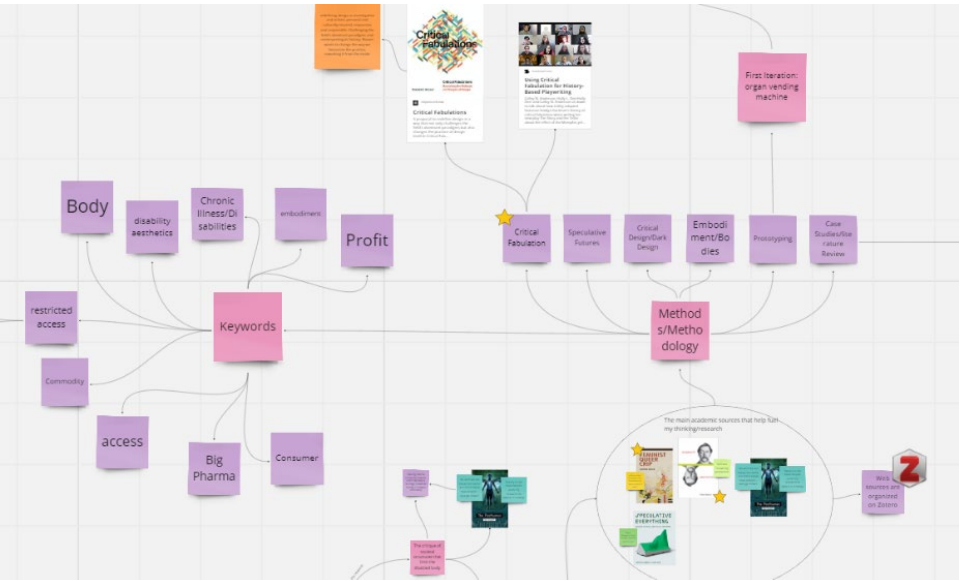
Second plan of document

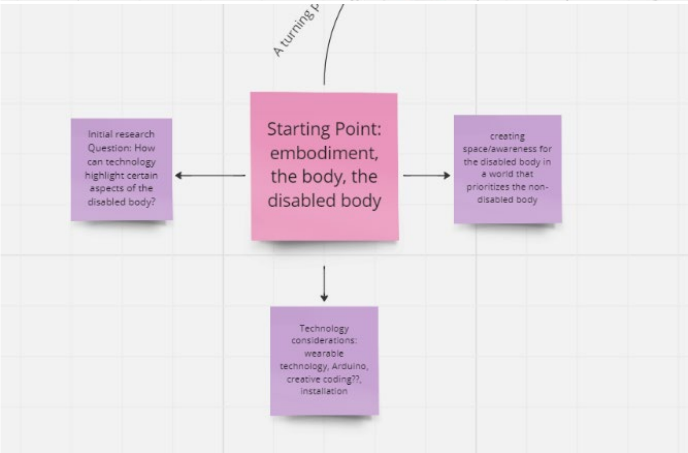
Sketches

Initial sketches for thesis exhibition plan, before I considered writing a manifesto.

Additional Mind Map Photos

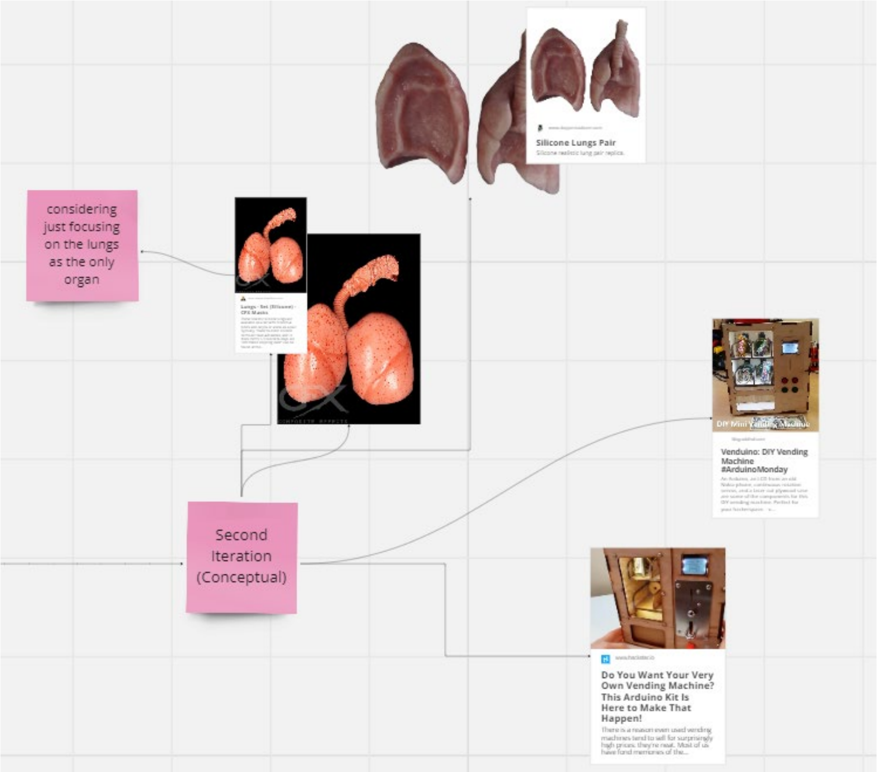






Exhibition Needs:
-3 Plinths
-Projector or screen
-outlets

Working Abstract:
This research is concerned with critiquing how certain societal structures, like big pharma, use the disabled and chronically ill body for profit. The methods used for this research are critical and dark design, autoethnographic research, and critical fabulation. The theoretical background for the physical prototype is crip theory, disability and dystopian aesthetics, and speculative futures. Through a carefully constructed literature review, consulting various case studies and other art/design examples created by disabled/chronically ill artists/designers the results sought is to create a vending machine with pairs of lungs that are priced at $300,000 which are made of silicone or flexible rubber. The prototype will also feature a working pair of lungs that simulate breathing as a display piece. This final object will be satirical and disturbing, working to put the body on display for profit to illustrate the lucrative nature of big pharma.



considering just focusing on the lungs as the only organ

Second Iteration (Conceptual)

Silicone Lungs Pair
Silicone realistic lung pair replica.

Lungs - Set (Silicone) - CFX Masks

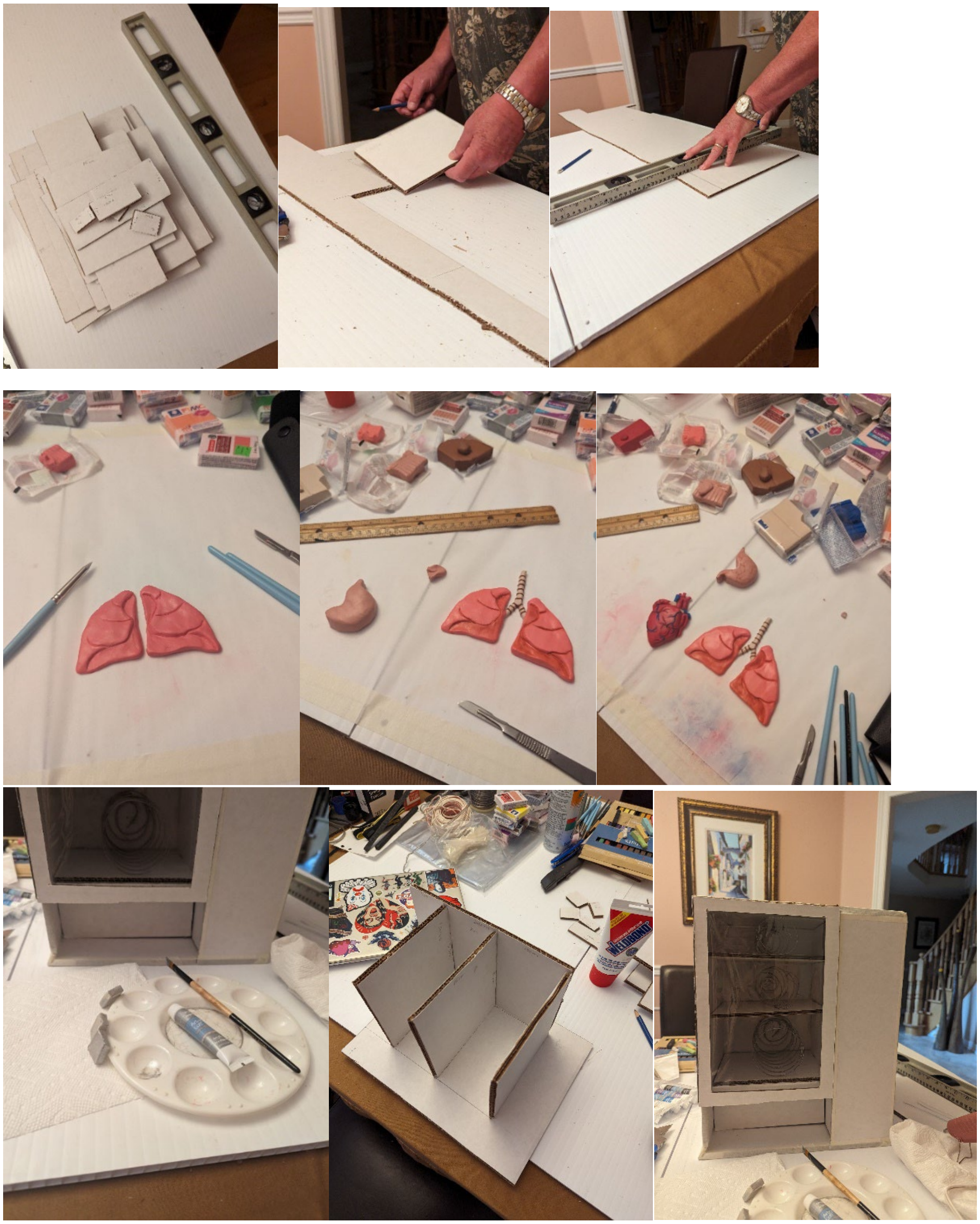
Venduino: DIY Vending Machine #ArduinoMonday

www.hackster.io

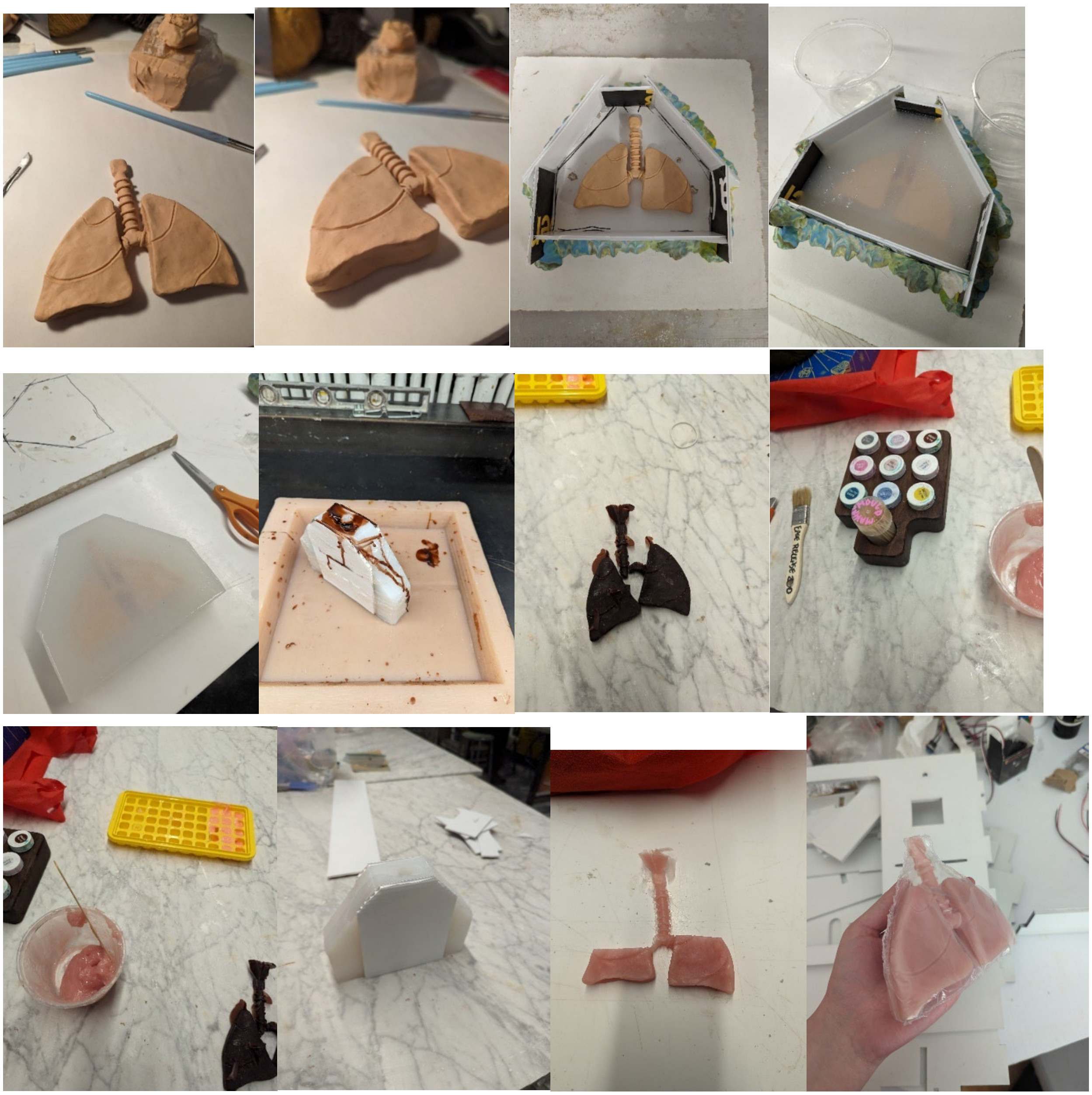
Do You Want Your Very Own Vending Machine? This Arduino Kit Is Here to Make That Happen!
There is a reason even used vending machines tend to sell for surprisingly high prices: they're neat. Most of us have fond memories of the...

Appendix C: Prototype process work

First Iteration of Vending Machine Process Photos

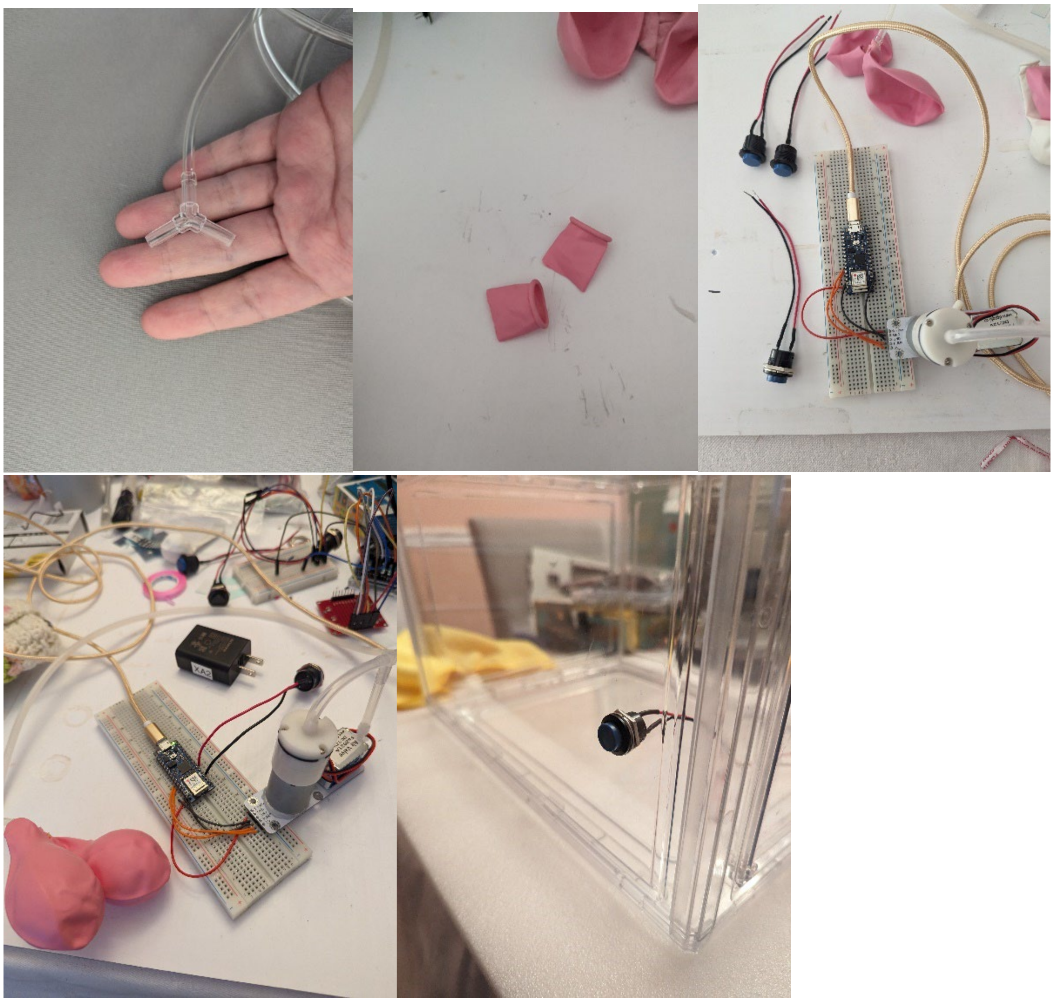


Second Iteration of Vending Machine Process Photos

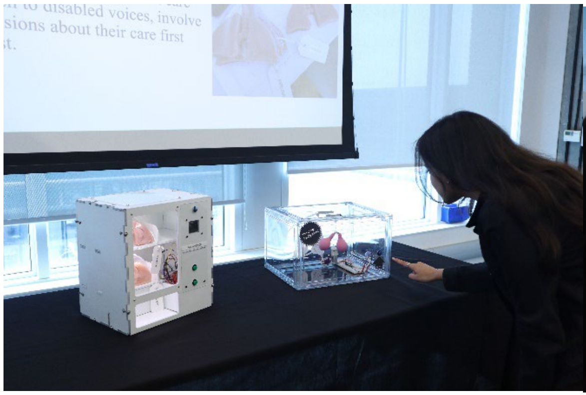



$300,000
$300,000
PAINTER'S Touch
DIGITAL (PWM~)
AREF
GND
SDA
SCL

Breathable Lung Model Process Photos



Appendix D: Additional Final Exhibition Documentation Photos




The Crip Speculative Futures Manifesto
For the Love of Access Intimacy!

1. Crip Speculative Futures is here to queer the narrative of compulsive non-disabled bodiedness; disabled bodies are normal, valuable, and should exist within every dreamt future.


The Body is No Longer Human

The Body is a Commodity

This thesis research is concerned with criticizing how big pharma, insurance companies, and the medical model uses the disabled and chronically ill body for profit. The research considers a brief analysis of big pharma through real-world examples, but also takes on an autoethnographic approach as an individual who is an active consumer of big pharma.

Utilizing my own account and voice as an individual with a genetic progressive chronic illness and disability called Cystic Fibrosis becomes integral to the research and the prototype creation process. Feminist queer Crip, which is a sub section of crip Theory, and disability aesthetics, further enrich the research as the theoretical background when analyzing how the long-standing thought process of compulsive non-disabled bodiedness is harmful and can further lead to devaluing disabled and chronically ill bodies in the medical system, and thus creates access friction or lack of access to care.

The results of the research and prototype creation seeks to educate on how access friction can be harmful to disabled and chronically ill bodies, which leads us to utilize speculative futures to dream about what easy access to care might look like and helps us understand why access to care is vital when we consider disabled and chronically ill bodies as valuable within the medical system.

SPECULATIVE FUTURES, CRIP THEORY, DISABILITY AESTHETICS, ACCESS FRICTION


Crip Speculative Futures Manifesto

Victoria Gottardi

EXHIBITOR BIO

With a background in UX/UI design and a BFA in New Media, Victoria is always looking for new ways to mix art, design, and technology to create valuable critiques and exciting forms of artistic expression. Victoria has a strong passion for accessibility within digital spaces and real-world applications, considering herself a disability and inclusivity advocate that hopes to see streamlined accessibility as a core consideration within various creation processes. Victoria wishes to integrate her affection for technology, accessible design, and art within the fields of crip theory, disability aesthetics, speculative futures/design, to create tangible, accessible, and technology driven futures.

Appendix E: Additional Inspirations

Healthcare Commercial

“Our Lives Are Not for Profit” commercial from OPSEU SEFPO.

Hyperlink to video: https://www.youtube.com/watch?v=f9ur0eKKa9c

Commercial is very dystopic in nature, and a call to save public healthcare services from privatization.

Rosi Braidotti’s Posthuman and Animal Farm

Even though Braidotti’s theory involving the posthuman is no longer a part of my research, it still serves as inspiration and helped pushed my research to where it currently is.

Quote from the book *The Posthuman* By Rosi Braidotti “Advanced capitalism and its bio-genetic technologies engender a perverse form of the posthuman. At its core there is a radical disruption of the human-animal interaction, but all living species are caught in the spinning machine of the global economy. The genetic code of living matter – “life itself” (Rose, 2007) – is the main capital. “(Braidotti, 2013, p. 7).

Another quote from the *Posthuman* “George Orwell ironically stated that “all animals are equal, but some are more equal than others” (Orwell, 1946). At the dawn of the third millennium, in a world caught in indefinite and technologically mediated warfare, such metaphorical grandeur rings rather hollow. Post-anthropocentrism rather suggests the opposite: no animal is more equal than any other, because they are all equally inscribed in a market economy of planetary exchanges that commodifies them to a comparable degree and therefore makes them equally disposable. All other distinctions are blurred.” (Braidotti, 2013, p. 71).

Source: Braidotti, R. (2013). *The Posthuman* (pp. 1-12 & pp. 55-104). Polity Press.