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Data Capitalism, Digital Health, and Marxism

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Abstract

When immersed in a capitalist society individuals often fail to see the ways in which they are exploited, and when these discussions do come into discourse they are often geared toward workplace labor. Less commonly do we consider the ways in which these problems arise in conjunction with free labor, mainly performed in digital spaces. While less often considered or discussed, the exploitation occurring in the digital world is real and has substantial consequences, particularly when the digital spaces involve sensitive information and data. This paper aims to address how data capitalism functions in three different digital health spaces: online patient forums and support groups, mental health apps, and direct-to-consumer DNA sequencing companies. In order to show how patients are persuaded to join and contribute to these digital spaces there will be an investigation of the rhetorical strategies utilized in marketing tactics. We will consider the economic functioning of data capitalism through a basic Marxist perspective, which criticized the capitalist mode of production and exploitation of workers, or in this case the creators of data.

Key words: Direct-to-consumer genome sequencing, rhetoric, marketing, free labor, capitalism

In the last decade a myriad of digital-based, online health communities and apps have begun to emerge at a rapid speed. Various forms of online digital health environments now exist, including patient forums that compare and connect patients with similar ailments, mental health apps, and direct-to-consumer DNA sequencing. The prevalence of these apps and sites, and our engagement with them, has been on the rise. The COVID-19 pandemic has contributed to increased promotion of these types of digital environments. While digital health has the possibility to be used in an ethical manner, we will find that the rhetorical strategies used to promote these spaces to the public is purposefully unethical and misleading–used as a way to coerce patients into using sites and apps whose true purpose is the creation of capital through selling patient data to third-party sources, not the betterment of patient health or wellbeing. This paper aims to critique the rhetorical practices used in marketing these sites and apps, as well as bringing Marxist theory into our current historical epoch by examining the nature of data and surveillance capitalism that has begun to dominate the digital realm.

Since there are a variety of different health apps and sites for patients to access depending on their needs or wants, there is a plethora of literature related to the particular types of capitalism each site or app deals with. While surveillance capitalism, data capitalism, biocapital and digital capitalism all function slightly differently, the boundaries between them are often blurred and the different forms of capitalism co-exist together. The research and literature surrounding digital health spaces often talk of these forms of capitalism together, as these different forms are so intrinsically linked. For the purposes of this paper I will primarily rely on the term data capitalism while discussing the various digital platforms.

The rhetoric of digital health

As digital health platforms become increasingly widespread, we should be interested not only in the rhetoric that is being used to invite and encourage patients to become users of a site or app, but also the ethical implications of that rhetoric. Since the accumulation of mass

amounts of data is required for the functioning of data capitalism, it is pertinent that we remain aware of what is driving people into these digital spaces. The rhetorical strategies employed are not inherently harmful in their own right--however they are unethical when considering they mask the true purpose of these digital health spaces. These sites and apps have a motive–and that motive is profit, not health and well-being. They create revenue streams by turning health data, provided by patients, into assets that can be sold to third-party sources. This results in massive amounts of capital for the platforms, and no financial compensation for those who provide the data.

Across mental health apps, genomic testing companies, and patient forum platforms, the narrative is relatively the same--if you become a member and contribute to the accumulation of data, your health and the health of others will improve. Lupton (2014), elaborates on how the language used by website developers persuades people into feeling a moral obligation to contribute to the sites and their continual stream of patient data. In the digital health world there are specialized pages geared towards patients that are suffering from a specific illness. Site developers play on the emotional need to have support during a potential medical crisis and use slogans or brand names that capitalize on the idea of being a support system–of being in it together and connecting with others who face the same medical condition. “CureTogether, CarePages and PatientsLikeMe” are all site names that imply that better health comes from the solidarity found on these pages. This contributes to the notion that by accessing these sites and sharing our medical information with others, we can ultimately create better help for everyone. One particular site has an “Openness Policy” that reads, “‘[W]e believe sharing your healthcare experiences and outcomes is good. Why? Because when patients share real-world data, collaboration on a global scale becomes possible. New treatments become possible. Most importantly, change becomes possible” (Lupton, 2014).

Geiger and Gross (2019) found that companies that collect and process genetic information, such as 23&me, use similar rhetorical strategies that appeal to emotions and the

desire for insight into intimate genetic and hereditary information. These companies increase the number of individuals who purchase genomic testing kits and send in their biological data by utilizing a variety of valorization strategies. These valorization strategies address specific aspects of human life and convince the potential buyer that these aspects of their life can be discovered or made better by the sequencing of their DNA. These companies push the notion that there is information within your DNA that can give you increased insight into your health and that your health can be improved by these discoveries. By valorizing kinship these companies also play off people's desire to know their genetic relatives or unknown information about their heritage. It also reinforces the false narrative that genetically related families are more valuable or that unlocking "your past" will fulfill some need to feel a connection to your heritage. Regardless, this accounts for a significant number of individuals who submit their DNA. A large number of recent 23&Me users fell victim to the strategy of valorizing hedonism. These companies market these kits as a fun pass-time that is bound to make for good dinner table talk. By promising customers access to interesting (albeit relatively pointless) information about your DNA, these companies drive hundreds of thousands of people to submit their DNA who are generally less concerned for their privacy because they are just doing it for good fun. (Geiger & Gross, 2019).

Since DNA sequencing companies deal with a particularly sensitive form of data and other private information, some ethical considerations surrounding the protection of our privacy have entered conversation. Roberts (2022) found that privacy policies can vary company to company, and from state to state–meaning that consumers are not equally protected. To help quell some of the anxiety surrounding the protection and management of personal DNA information, companies have implemented "opt-in" policies that provide the users with more control over how their DNA is used and shared. However, these opt-in policies use ambiguous language and merely explain that your un-identified DNA will be used for "research purposes". Out of altruism, many users agree to having their DNA used for such "research purposes",

however they are often unaware that this also allows companies to share your non-DNA data as well, including information about family members connected to you through the platform. It was also found that these companies may be asking you to provide more non-DNA data than is required to provide you with your results–since your data is what makes them a profit. Because these companies rely on the accumulation of data, they have to encourage us to give it willingly, making an investigation of their rhetorical strategies even more important. The simple, nondescript nature of the term “research”, elicits an image in a consumer’s mind of academic medical research. There are two problems with this. First, when we opt-in to providing our DNA for research, we are also consenting to our non-DNA information being shared. Once this information is in the hands of other companies, it is now controlled by their terms and conditions, not the ones you agreed to through the DNA sequencing company. Additionally, the term research does not strictly apply to medical advancement research, but also internal research which focuses on product development–this is not the type of research people imagine when they altruistically opt in to data sharing. The second problem related to the lack of return consumers face when they share this highly lucrative data (Roberts, 2022). For example, in their research into direct-to-consumer DNA sequencing, Geiger and Gross (2019) found that 23andme profited $60 million for selling the DNA profiles of Parkinson’s patients–each profile sold for $20,000. Similarly, 23andme also made over $300 million dollars in a deal with a singular pharmaceutical company.

Mental health apps are becoming more plentiful in number and are being increasingly encouraged by the media during the COVID-19 pandemic. The narrative around mental health should always be looked at with a critical eye, and the addition of the COVID 19 pandemic makes it all that more tenuous. Cosgrove et el. (2020) investigated the current discourse surrounding mental health apps, as well as their credibility and economic functioning. Media and mental health apps alike are reporting that there have been spikes in anxiety and depression among our general population. However, these reports can be harmful as they fail to address an

alternative reasoning: that people are reacting in a normal way to an extenuating circumstance. While it is true that feelings of anxiety and depression are on the rise, it is not necessarily due to abnormal brain structure or chemical imbalance, which is a fear many people are having as a reaction to this narrative. Certain apps such as Mindstrong tell people that their app will be able to detect their depression before they are ever aware of it. This kind of rhetoric convinces the potential user that there is indeed something wrong with them and this app was the key to discovering and managing their ailment. Many apps have also changed their marketing strategies to be geared more toward COVID-19, encouraging their app users that they are there to help them navigate the pandemic (Cosgrove et el., 2020).

After investigating the rhetoric of these three different digital health sites or apps we may consider that while mildly troubling, these statements seem harmless enough. This is exactly how the developers of these sites want it to seem. Data capitalism and surveillance capitalism alike only function under the stipulation that there is a constant flow of data being accumulated and analyzed. Without an increasing amount of data accumulation, data capitalism cannot function. For this reason, rhetoric used in marketing is key in getting patients to access and to continue using these sites and apps.The rhetoric is meant to be persuasive enough to convince you to be a part of the site and contribute to the accumulation of data, while also not raising any alarms to the users. The company says they have your best interest at heart, and why shouldn't you believe them? It is true that the rhetoric used here is not directly harmful when taken for face value, however when we begin to look at the underbelly of the sites--at everything that lurks beneath the smokescreen--we begin to see why this rhetoric is misleading.

Marxist understanding of data capitalism

Working from a Marxist's perspective, I argue that the kind of labor being done by patients on these sites is of an objectified or alien nature. While explaining the process by which capitalists create surplus value, Marx states "The only thing which makes him into a capitalist is

not exchange, but rather a process through which he obtains *objectified labour time,* i.e. *value,* without exchange" (Tucker, 1978, p. 248). While Marx was speaking specifically to labor done in the workplace, we are given an opportunity here to expand Marxist theory. Since Marx lived and operated in a different historical epoch, and the idea of mass amounts of free labor being performed on digital platforms will certainly not be found within his primary writings, we must make these connections ourselves. All labor completed in the digital health realm can be constituted as objectified labor, since the sites can extract value from the information that is given for free by the users of the sites. Even if the sites claim to provide a health service or information on your genomic information, they are still making a financial gain that is kept entirely from the producers of the data--the site users. It is a feature of capitalism that the wealth and power are unevenly distributed and we see this reflected in data capitalism, as it is defined as a system "in which the commoditization of our data enables an asymmetric redistribution of power that is weighted toward the actors who have access and the capability to make sense of information" (Geiger & Gross, 2019).

This creation of capital is only made possible by site users who enter into these digital spaces, either on their own volition or by means of persuasive rhetoric, and contribute to the accumulation of patient data. When we give our data, we are allowing it to be turned into a commodity. Marx states that, "To become a commodity a product must be transferred to another, whom it will serve as a use-value, by the means of exchange" (Tucker*,* 1978, p. 308). Sites are selling patient's data to third party buyers without a financial return to those who provided the information. In other words, we are providing free labor without a wage exchange. In the same way that Marx argues that the laborer is alienated from his labor, how "man's own deed becomes an alien power opposed to him, which enslaves him instead of being controlled by him" (Tucker, 1978, p.160), the users of these sites are similarly alienated from their data and the way in which it is being used. Once the data leaves our hands it is now controlled by the sites and apps to do with what they please, and leaving the patients without a fair

compensation. Support groups, genomic information or access to mental health applications are not an equal exchange for our labor, largely considering the lack of any financial compensation for the data provider.

While there is merit in these websites providing emotional support for patients that visit these sites and share their experiences, we cannot take this at face value without considering what happens out of the public eye. Lupton (2014) reports that in the past digital patient-support groups were managed by patient's themselves, or with the help of charities and non-profit organizations. However, they are now predominantly operated by companies that are in a position to benefit from the commodification of patient data with the intention of using them for commercial reasons (Lupton, 2014). Similarly, venture capitalists are aware that mental health apps are the location for potential massive earnings. For this reason, they financially contribute to these mental health apps, including Bezos Enterprises backing the app Mindstrong, which claims to be making the newest, most cutting edge mental health app. They claim that through the use of AI and mapping patient's movements on the phone that they can recognize and diagnose illnesses at an increased rate. In theory it would be groundbreaking if we could determine if someone is in the throes of a mental break. However, the research supposedly backing this "paradigm shifting technology" consisted of one small experiment that had no research posted about it. It was never peer reviewed or verified to be an accurate measure of mental state. Regardless of this, it has been advertised as such as a means of getting more digital traffic on the app (Cosgrove et el., 2020).

Since venture capitalists and web entrepreneurs' genuine interest involves how to make these sites lucrative, they fail to do the one thing they promise: benefit the patient. In the same way that Marx understands that the laborer is alienated from the commodities he produces, the site and app users are also alienated from the data they produce and the results of it. Either due to a failure to provide quality health information to the user in exchange for their data, or by unwillingness to compensate the patient financially for their contributions, the site users are

alienated from their labor and the results of that labor. What we are witnessing is a result of the United States functioning under a capitalist mode of production. The creation of the internet and our vast acceptance of digital platforms has created an environment rich with new opportunities to exploit the shift online, exploit innocent people, and create capital.

The creation of digital health communities, applications and direct-to-consumer genomic testing are a relatively new development in history. They have the opportunity to extend accessibility of healthcare and create healthy spaces for people to share and learn. However, this can only happen if the goal of these digital spaces is truly the betterment of health, not an opportunity for financial gain. Unfortunately, the nature of capitalism means that it seeps into every aspect of our lives, including ones that should remain pure of the motive of surplus value and capital accumulation. The public would like to believe that when it comes to our health, companies have our best interest in mind. Any doubts we may have are easily put to rest with the rhetoric used by these sites and apps. They deceive us into believing we are doing right by ourselves and our community by providing data, only to fail to meet their promises made to patients–choosing instead to only fulfill promises made to third-party buyers and the venture capitalists supporting them. Acknowledging the motives that drive these business models and marketing strategies is the first step in creating an awareness that allows people to break free from these digital health spaces and make educated choices about where and with whom they share their data.

References

Cosgrove, L., Karter, J. M., Morrill, Z., & McGinley, M. (2020). Psychology and Surveillance Capitalism: The Risk of Pushing Mental Health Apps During the COVID-19 Pandemic. *Journal of Humanistic Psychology*, *60*(5), 611–625. https://doi.org/10.1177/0022167820937498

This paper discusses the use and promotion of mental health apps during the COVID-19 pandemic. It investigates the ways in which various forms of data are abstracted from the users while they traffic the site and how that data is used to create a profit. The paper also considers the ethical implications of mental health apps making claims and promises about predictive diagnosis that have not been verified in replicated studies, and yet marketing it as such. **Peer Reviewed**

Geiger, S., & Gross, N. (2021). A tidal wave of inevitable data? Assetization in the consumer genomics testing industry. *Business & Society*, *60*(3), 614–649. https://doi.org/10.1177/0007650319826307

This paper investigates the rhetorical strategies in marketing strategies that encourage people to submit their DNA to direct-to-consumer DNA sequencing companies. It also provides insight into the financial motives of these companies, and how they use your data as a profit-making tool. It highlights the contradictory nature of the altruistic image the companies portray to the site users, and the business dealings that motivate their need for accumulated data. **Peer reviewed**

Lupton, D. (2014). The commodification of patient opinion: The digital patient experience economy in the age of big data. *Sociology of Health & Illness*, *36*(6), 856–869. https://doi.org/10.1111/1467-9566.12109

This paper demonstrated how rhetorical strategies and marketing tactics, such as branding, encourage online patients to contribute to the aggregation of data out of a sense of moral obligation. It explores how capitalizing on a patient's desire for camaraderie is ethically

questionable when they obstruct the fact that patient data is also being used for commercial purposes, which does nothing to provide return or benefit for the patient providing the data.

Peer reviewed

Roberts , C. (2022). *The privacy problems of direct-to-consumer genetic testing*. Consumer Reports. https://www.consumerreports.org/dna-test-kits/privacy-and-direct-to-consumer-genetic-testing-dna-test-kits-a1187212155/

This investigative study by Consumer Reports explores how the implementation of opt in policies have helped secure more privacy rights for those who partake in direct-to-consumer genetic testing. However, it also illuminates how consumers often unknowingly also grant permission for these companies to share non-DNA data, as well as the information of their family connected to their profile.

Tucker, R. C., Marx, K., & Engels, F. (1978). *The Marx-Engels reader*. Norton.

This is a collection of the primary works of Marx and Engels. The specific works included in this paper are: The Grundrisse, Capital, and The German Ideology. I pull from the basic fundamentals of Marxist ideology including the exploitation of free labor, surplus value, commodification and alienation.

Learning outcomes demonstrated

LOC #5: Critically analyze messages

LOC #7: Apply ethical communication principles and practices

LOC #9: Influence public discourse