

Biological Citizenship: The Effect of the Cross Section of Big Data and Healthcare on the Empowerment of the Citizen

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Introduction

The cross-section of Big Data and healthcare has brought forth a novel way of perceiving one's health. It also presents a turning point on how patients and citizens are classified in terms of their biological citizenship. The use of metrics that are tailored to each individual provides another layer of complexity when it comes to assessing their biological background. The integration of such data has begun to make its way into political contexts. This is primarily attributed to help define future imaginaries of medical treatment such as personalized medicine versus stratified medicine. However, this clearly demonstrates the relationship between a data-driven approach to a citizen's health and what it means to a political actor (Erikainen & Chan, 2019). Thus, I aim to provide an evaluation of how the empowerment of an individual is altered when it comes to knowing more about themselves which in turn affects how they advocate as citizens or patients – a new form of biological citizenship.

Background

Introduced in the early 2000s, the concept of biological citizenship presented a new way to collectively identify an individual on their biological traits. Adriana Petryna (2004) first introduced this term following the aftermath of the Chernobyl disaster in Ukraine. Following the explosion of the Chernobyl nuclear reactor in 1986, the negative health impact on Ukrainian citizens was assessed with a scientific and political lens (Petryna, 2004). Petryna elucidated in her studies that politics and science were constantly engaged to mutually stabilize the aftermath of such a large scale disaster that helped define post-Soviet Ukraine as well. This event brought forth the role of considering “at-risk” populations and its relationship to defining the norms of how to define different levels of citizenship. Another major treatment of the term biological citizenship was brought forth by Rose and Novas in 2005. They coin a more broader look at the

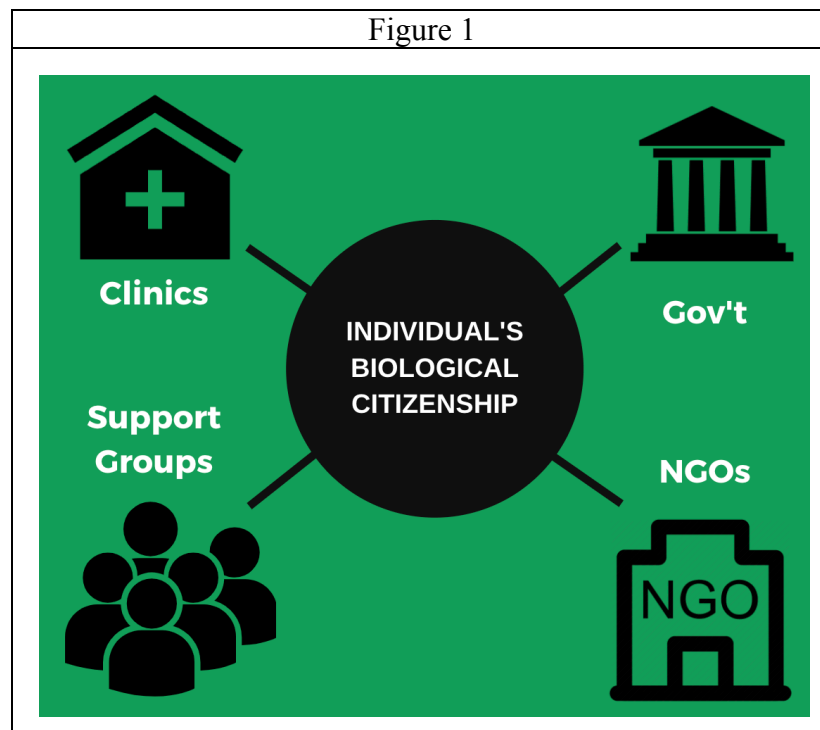
term to view how citizenship projects link conceptions of citizens to the biological background of an individual. Explicitly, they state how globally this term can come to have different meanings. For example, in post-Soviet Ukraine, biological citizenship came to be correlated to receiving financial support from political authorities. However, in the West, biological citizenship is taking the shape of a new kind of value provided to individuals, “biovalue”, to tailor the political climate as more ethical and moral (Rose & Novas, 2007) . However, it is interesting to note that biological citizenship has existed prior to its coining by Petryna under different terminology. Rabinow in 1996 and Clarke, et al. in 2003 have come up with the terms biosociality and biomedicalization respectively which come to hold similar meanings to biological citizenship. These terms however are much more broad to encompass all social processes and relationships to define political acts of organizing and advocating for access to medical knowledge or treatment (*Biological Citizenship*, n.d.).

The Biological Citizenship Network

Biological Citizenship and Data

Specific factors to consider when it comes to how biomedical data affects biological citizenship is the change in social interactions of an individual along with their classification by political and social entities. These modifications to a citizen’s lifestyle denote how their personal health data affects their standing as a citizen of a nation and what resources and rights are either offered or taken away following assessment of said data. The ideal framework to assess the aforementioned interactions is the Actor-Network Theory (ANT) as defined by Liza Potts (Potts, 2008) of creating an actor-network map with the research subject in the middle of said map (see Figure 1). By diagramming the ANT based map, it makes an ideal assessment tool to determine how additional factors affect the interactions between biological citizenship and other actors. For

the purpose of this research, the defined research subject is the biological citizenship of an individual. The interactions within the network branch to a variety of actors, including but not limited to clinics, the government (both federal and state), support groups, and even non-governmental organizations (NGOs). For this research and within the ANT based map seen in Figure 1, the interactions between an individual's biological citizenship and connected actors will be studied to determine how they change when the factor of Big Data is added into the mix.



One example that supports this framework is the study conducted via the New Zealand Organization for Rare Disorders (NZORD) in 2008 on the familial accounts of children with incurable genetic disorders. This study exemplified the growth of political activism by the parents with children exhibiting such disorders on healthcare reform policies that transcended national boundaries. This was facilitated primarily due to the affiliation and open access of public health data provided by NZORD on genetic medicine activism in New Zealand. Through

the constant journey of the parents to find treatment and cures for their children, the study showed that their social interactions began to change with a continuous engagement with healthcare workers and public genetic medicine campaigns. This led to them being regarded as “genetic political activists” by the local government in New Zealand, thus subcategorizing them within their own form of biological citizenship (Fitzgerald, 2008). This study demonstrates one of the main actors present in the ANT around biological citizenship which is non-profit organizations that focus on specific causes and provide open access data to the general public. This results in the individuals affiliated with such organizations to have an altered sense of biological citizenship to other entities including their social circles, medical professionals, and the government.

The above framework can also be seen on how government mandated programs such as the Framingham Heart Study in the United States put data behind phenotypic “risk factors” associated with heart disease which in turn affected the biological citizenship of an individual (Aarden, 2018). With over six decades of research and data on cardiovascular disease, this study provided the government with a tool to define and maintain boundaries of an at-risk population that demonstrated risk factors associated with heart conditions. The empowerment of the individuals within the aforementioned population was further altered due to study being initiated by states versus the US federal government, thus placing them deeper into a collective of communities and families rather than an overall population. The Framingham Heart Study demonstrated how through the presence of data behind those at-risk of cardiovascular disease provided the logistics of exclusion, responsibility, and resource allocation discrimination in the network surrounding the biological citizenship of the individuals that were a part of the study.

Lastly, looking at the ANT framework can help describe how determining or researching the data behind autism today is seen as a way of defining the biological citizenship standing of an individual. The biological explanation of autism demonstrates how their different social interactions has led to them be differently classified and provided additional rights when it comes to performing daily activities such as in school or the workplace, an exemplary notion of empowerment. Through the use of newer data-driven and research approaches to defining autism has led to the creation of similar boundary defined populations seen in the Framingham Heart Study above which then correlates to biological sub-citizenship based on severity of a condition. This includes a study conducted on parent decisions to participate in autism genetics research in order to define what correlation exists between their medical and personal data with the condition of their children (Singh, 2015). It was demonstrated how the willingness of a parent to participate eventually exemplified their sociopolitical interactions, simply on the notion of whether or not a parent of a child with autism was willing to further the research behind autism genetics. Another study focused on the idea of how the classification of autism itself also adds further subcategorization within the notion of neurodiversity in biological citizenship (Brownlow & O'Dell, 2013). This was exemplified through how autism is a clear distinction from neurologically typicals (NTs) which is something the study states would be furthered by new data that is added when attempting to discover the genetics behind autism. However, the concept of Big Data as a factor within the ANT framework has become further emboldened beyond the aforementioned examples with the inclusion of a new type of technology and ultimately actor in the actor-network map seen in Figure 1.

Current shift in Biological Citizenship with Wearables and Big Data

Recently, a new actor has become prevalent within the ANT surrounding biological citizenship: wearables. Such technologies have demonstrated how we are now able to capture almost everything that has happening behind the scenes within our bodies, thus both removing our ignorance but adding more data behind our everyday lives. Wearables have also further brought the concept of Big Data within the world of healthcare, introducing an additional actor to the ANT framework (*Big Data and Wearable Health Monitors*, 2019). Both wearables and Big Data have also provided tools to all the aforementioned actors present in the network (non-profit organizations, government, clinical researchers, medical facilities, individuals, social groups) to now develop a new form of an almost granular based biological citizenship.

The recent hype around wearable technology is primarily attributed to the fact that they are able to transcend the typical five senses of an individual. Through microsensors smaller than our fingernails, wearables have become both susceptible to skepticism amongst the actors present within the network around biological citizenship and also a forerunner in the discovery of non-communicable diseases in individuals. By providing a discrete way of monitoring an individual's health on an almost daily basis, wearables have also become an inclusion within Big Data in healthcare. It is said that the average person is likely to generate more than 1 million gigabytes of health-related data in their lifetime through wearables (*Big Data and Wearable Health Monitors*, 2019), which only demonstrates the significance such technology holds in our lives. Yet it also raises the question on what does this mean for the average citizen to now be fully defined, even their biological selves, with data that can be accessed by possibly anyone. This shift or alteration in citizen/individual empowerment is what leads to a new form of biological citizenship that emerges from wearable technologies.

Current wearable technology has been broken into two main sectors: devices that are entirely consumer facing such as the Fitbit, Garmin watch, Apple watch, and the Whoop band to name a few and those in the research phase that continue to become miniaturized to tell us unknown information of the human body. Wearables today are able to continuously monitor bodily conditions, functions, processes including heart rate, blood pressure, body temperature, oxygen saturation, sleeping cycles, respiration, skin conductivity, etc. Furthermore, integration within everyday devices such as watches, cellphones, belts, glasses and many more has only increased accessibility to wearables thus making it easier to see its effects on an normal individual (Lindner, 2020). With so much information on the human condition, primarily that which was unseen prior to wearables, the intersection of Big Data within healthcare has become more prominent and this eventually seeps into redefining biological citizenship different from that seen in the literature mentioned in the previous section. The data provided by wearables has become an increasingly interesting topic of research in the fields of privacy and ethics, where it raises the question on how moral or ethical are wearables. Thus, it is important to view how any wearable is able to modify the underlying biological citizenship of an individual. Are such technologies empowering the ability of the citizen within a sociopolitical setting, or does it diminish their power by providing even more personalized biological data to actors part of the biological citizenship ANT? One study into the Fitbit provides an in-depth analysis into this concern and what this may mean for future wearable technologies.

The Fitbit is a foundational tracking wearable that monitors the fitness and physical health of the intended user via the number of steps walked, calories burned, floors climbed, and even sleep monitoring in premium models. This data is stored by the tracking device and then can be uploaded to a Dashboard to view it more in depth – thus creating the Fitbit platform.

While the Fitbit has become overshadowed by other wearables, namely the Apple watch, it still demonstrated what such a technology can do to an individual's lifestyle. Primarily geared towards consumers in the realm of personal fitness and health, the data from the Fitbit has provided an easy medium of empowerment to an individual to access their own health information. This has allowed them to know more about themselves without having to go through a medical professional or government-based programs that collect health data. It has presented a pedagogic aspect of governmentality in self-tracking which assumes the ability of the individual to now advocate for themselves. This is primarily due to the inclusion of the individual or citizen themselves as part of the group of experts that tend to dominate the network around biological citizenship. Thus, the wearable itself is a source of empowerment where its data subjectivity allows the ideal individual or citizen to become an expert in their own body data production. The data, however, is subject to the diffraction of expertise where in the hands of multiple of the aforementioned actors and new ones, such as the platform of the wearable itself, they are able to track the information as well. Thus, they are made susceptible to the power such data may hold which entails a future in which it can be used both against and for the citizen for either empowerment or further subdivision as a biological citizen (Fotopoulou & O'Riordan, 2017) as seen in the literature discussed above on genetic activism and the Framingham Heart Study. Similar ideology can be seen across more recent wearables, where due to the growth in both sensor technology and data science has only increased the power associated with the data being collected. One prime example today is the Apple watch, with studies constantly being developed on the capability of the heart condition monitoring provided by the device as a tool to not just save lives but also for cardiologists to study the daily lifestyle of at-risk patients. Furthermore, many of the effects associated with wearables and the data collected has only been

further elucidated by smartphones and applications, where it is easier to share data to actors associated in the biological citizenship network and an individual's own social network. This fundamentally drives changes with the sociopolitical landscape of a citizen where their interactions can now revolve around a mobile application.

Future Wearable Technology vs. the Biological Citizenship Network

Thus the above framework and research on current wearables and their effect on biological citizenship can be applied to determine the effect personalized data can have on the social and political standing of a citizen or individual. Coupled with studies done outside this realm helps further build the ANT framework around biological citizenship to include players such as the government, non-profit organizations, and even research-based institutions. This entails then studying the different actors, both political and social, that may influence the biological citizenship of an individual based on the assessment of data on their health. Such data is not limited to only categorizing ailments of the biological self but also the constant monitoring of our health. This can include the daily medication we take, how much food we eat thus our nutrition levels, and even the way we move. Data on our motion has become more and more critical as new health and fitness technologies have entered the market assessing how much we move or exercise on a daily basis. Thus, by monitoring every part of our motion provides an even more in depth analysis on how we move fundamentally which gives access to a whole new way to categorize individuals both socially and politically.

Similar to the Fitbit, a wearable focused on capturing the motion of an individual provides the capability for constant monitoring of something as fundamental as movement. While the wearable itself and its emphasis on making motion data more accessible provides a sense of empowerment to an individual, it has the issue around the data being collected. Like the

Fitbit platform, a novel platform will develop around a more accessible motion capture wearable, but unlike the data collected from the Fitbit more actors become involved in the world of motion. This includes not only one's clinical or medical professional, but also companies that rely heavily on movement data including entertainment companies, city/infrastructure developers, and even recruiters for athletics or rehab programs. With an increased network size, the biological citizenship of the individual becomes more complex with new categories besides the aforementioned at-risk populations. This now includes those who may be ignorant of their own movement, or commodification of prime individuals who move better than most, and even potential control by those in the world of fitness who can now monitor an individual's compliance on an almost daily basis.

It can be seen how wearable technology through its evolution and the data they collect have become increasingly important to understand on its impact within biological citizenship. Depending on what data the wearable provides of our individual selves, it can drastically change the ability of such devices to empower us to advocate as citizens to the actors present in our own biological citizenship network, especially with political actors affiliated with studying the human condition or pushing the boundaries of biomedical research.

Discussion

Overall, it can be seen how the inclusion of biomedical data affects the biological citizenship of an individual. This relationship can either empower or degrade an individual's access to specific citizen rights depending on their biological standing. In this following thesis, precedent of specific cases where biological citizenship has changed based on the health or medical data utilized to assess a citizen was explored. This included studying a wide range of actors, from the individual to government mandated research programs to wearable technologies.

The ANT framework presented in previous research was applied to the current technical research on how a motion capture wearable redefines the actor-network interactions around biological citizenship.

The work presented in the following thesis further demonstrates the way people have begun to understand themselves in new ways, and how this leads to changes in the way they prioritize efficiency to their daily lives to empowerment as a citizen. Through wearable technology, a new lens has been added to biological citizenship, where the information collected from them represents two different approaches to the politicization of biological data. First, a bottom up approach of individuals to now become experts and advocate for one's own condition. Second, a top down approach where the aforementioned actors in the thesis give citizens specialized/personalized treatment or attention through the datafication of one's biological self. These approaches were both discussed in this thesis and within the notion of a motion capture wearable, where each approach changes the way individuals are empowered which in turn redefines the concept of biological citizenship. No more is data on personal health or the biological-self limited to a small network of players, since wearables have expanded the whole game.

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