

Covid-19 And Data: An Ethical Review of Data Policies

Introduction: The Careful Consideration of Covid

As of September 14th 2020, Covid-19 has claimed the lives of over 190,000 Americans, and infected over 6.5 million people in the United States. (CDC, 2020) The usage of data systems for disease tracking, contact tracing, and data dashboards has been a powerful toolkit in the national fight against the novel virus. However, with the increased importance of data comes the requisite responsibility of maintaining ethical standards in data collection. What happens when data would save lives, but we encounter lack of consent for data use or outright refusal?

This paper will review data consent policies, and will then discuss ethical views of a specific case study where non-consent data collection issues are a central problem, particularly in regards to multiple ethical theories. Finally, it will indicate suggestions for proceeding through multiple ethical lenses, and provide context for proceeding.

The Ethics of Data And Research Consent

When thinking about Covid-19 data, we must first consider the issue of the rights of participants. To empower participants and provide them with rights with research studies, a requirement of medical research is the idea of informed consent. As the FDA (2018) describes, “informed consent means that the purpose of the research is explained to them, including what their role would be and how the trial will work”, and requires participation to be voluntary, with opt-out policies at any time.

The idea of informed consent is built into research: looking at research consent policies, Bhutta (2004) analyzed the importance of receiving consent as “Obtaining truly informed and

culturally relevant consent is fundamental to the ethical conduct of research and is of particular importance in developing countries". In a similar analysis of human research policies, Gray (1978) adds that "The requirement that human beings be involved in research only if they have given their informed consent is a key provision of the major codes of ethics for research involvements". Both Bhutta and Gray agree that without truly informed consent which is explicitly given, otherwise data collection for research should be considered unethical.

Contextualized within society, consent is even more important in democratic societies, as it relates to privacy law. Without consent, researchers are additionally breaking patients' rights of privacy. In a summary of national data policies, Richterich (2018) asserted that "In democratic societies, privacy is considered a civil right" and "The protection of personal data tends to be considered as an extension of the right to privacy..." (35) Thus, protecting data is protecting the right to privacy, a fundamental right for American citizens.

Yet at the same time, Richterich (2018) adds these privacy issues lie in the difficult balance between "common good" and citizen's right to privacy (36). With an emergency like Covid-19, we can see that these two fundamental rights are at odds with each other. As we begin to analyze the following case study, we must keep in mind the ethical promise of consent that was broken.

Case Study: Laboratory Covid

In an effort to look critically at the ethics of data collection for Covid-19, we will consider the following hypothetical case study: Erika is a new graduate student working in a university data science lab, and she discovers that much of the data set or database information

comes from COVID-19 patients who did not agree with contact tracing and whose data was gathered without consent. What should she do?

Ethical Interpretation from Ethical Theories

Each of the five ‘workable’ theories: Kantianism, act utilitarianism, rule utilitarianism, social contract theory, and virtue ethics can shed light on how we may interpret the ethics of these actions.

According to Quinn (2017), Kantianism, with its interpretation of moral good, believes in two categorical imperatives. First, that moral actions should be universalizable. Any good action should be universalizable. Kant’s second categorical imperative states that people must never be used only as a means (Quinn, 2017, 68-69). We might interpret this as a rule protecting citizens and only allowing data collection in cases where informed consent was given.

Looking at the ethics of Erika’s lab from the case study, we cannot consider their action, even in good faith, as universalizable, as they broke the ethical standard of informed consent. Thus, the data that Erika discovers her lab has collected, even though it may be intended to inform decisions that save lives, is unethical. It additionally breaks the second categorical imperative, as if the laboratory used the data, the data must be considered as using people as a means, rather than an end, breaking the ethical standard.

Kantian ethicists could plausibly conclude that the immoral collection and retaining of information that has not received consent is unethical, and should be discarded. In this case, as with regards to Richterich’s (2018) belief in the balance between public safety and privacy, Kantianist ethics likely would side with maintaining privacy, suggesting that Erika take action to stop the use of the data.

In contrast, Utilitarianism regards the consequences of an action, with its look at utility, the principle of creating or diminishing happiness (Quinn, 2017, 72). Utilitarianism can be seen as act or rule, but we will think of it in terms of being consequentialist here. In terms of happiness, if there is less downside to the action, then the act or rule is good. In the case of Covid-19 non-consent, there are negative externalities attached to the feelings of anger or fear of the data being used, the ethical contract broken, and the small possibility of data leakage from contact tracing. However, it could be seen as being outweighed by the happiness of the lives saved.

Gillon (1985) writes that one of the advantages is the simplicity of the utilitarianism ethics, writing its claimed advantage as able to overcome “the lack of a consistent and reliable decision procedure for choosing the right course of action in particular circumstances”. In the case of Erika’s data, it removes the challenge of the ethical decision if she can assert that happiness was gained through saved lives.

Though Gillion (1985) writes that there is general difficulty in analyzing happiness, they write “modern utilitarians tend to agree... in accepting that people can roughly measure at least their personal assessments of happiness and suffering analogously to the way they can measure benefits and disbenefits in monetary terms”. We could safely assume that, if the Covid-19 data were successfully used to save lives, participants’ net benefit could be seen as positive.

Social contract theory, as premised by philosophers John Locke, Thomas Hobbes, and modern figure John Rawls, speaks to the nature of a shared contract between peoples (Quinn, 2017, 81). At a base level, the social contract is an agreement among peoples in order to maintain safety and control. This manifests today in government and society as a careful mix of our rights and obligations.

In this case, we see conflicting contracts in action. The contract and obligations of the informed contract, a written document, are being breached by the medical staff. At the same time, the right to privacy is also being breached if Erika's laboratory were to use this data. The laboratory had an obligation to protect and request the consent of its participants, which it failed. With the social contract being breached, this would be an unethical practice, as would Erika's use of the data.

Virtue ethics is the belief in virtues in guiding human behavior, both in action and feeling. In an interplay between virtues- positive traits that move us closer towards happiness and vices- negative traits which move us further from being happy, ethics are based on virtuous actions (Quinn, 2017, 89- 90). We should act to do the right things to become more virtuous.

Of course, there are many difficulties in the cultivation of ethics. Kupperman (2009), in a discussion of virtue ethics, writes that people are imperfect, inconsistent, and in many vases we are following a pattern of their lives in terms of virtue ethics (245). Additionally, "Becoming morally virtuous would be for such a person, and should be for all of us, an ongoing process" Kupperman (2009) writes, on an overview of ethics.

With its analysis of exhibiting virtues, suggests that it is in Erika's interest to report the data, and that the actions of the laboratory were unethical. If Erika were to act ethically, she must try to make the ethical decision of rejecting the data, however helpful, in this case. To act ethically, Erika must act with positive virtues, and disclose the fact that the data was not collected with consent. Only by doing so can she be happy and fulfilled in her decision.

Discussion of the different systems

As discussed previously, any private research information that is collected, used, and disseminated without informed consent is unethical. Summarily, we might assert that Kantianism and Virtue Ethics may find deep fault with the breach of morality of these actions, and reject the usage of such Covid-19 data from patients. The social contract theory also saw the shared contracts of privacy broken.

The utilitarian theories, with their look at the consequences and 'end' of the actions, could suggest that the costs merit the flaunting and negative effects of their usage, the cost of the rule-breaking. If they saved lives, perhaps the rule-breaking was ethically merited. However, from the other perspectives, we are left with deep ethical concerns over the lack of ethical protection of consent and data.

Conclusion

The case study and subsequent analysis looked through the different lenses through which Erika's actions could be interpreted. Some ethical theories may justify her actions (utilitarianism), yet a majority did not (Kantian, Social Contract, Virtue Ethics). In all cases, the root of the problem was the lack of transparency. Ideally, Erika should recommend policy changes be made, which would largely satisfy future ethical dilemmas with the collected data. Ultimately, it will be up to Erika to balance which moral decision she believes is correct.

References

- Alter, G. C., & Vardigan, M. (2015). Addressing global data sharing challenges. *Journal of Empirical Research on Human Research Ethics: An International Journal*, 10(3), 317–323. JSTOR.
- Bhutta, Z. A. (2004). Beyond informed consent. *Bulletin of the World Health Organization : The International Journal of Public Health* 2004 ; 82(10) : 771-777.
<https://apps.who.int/iris/handle/10665/72782>
- CDC. (2020, March 28). *Coronavirus disease 2019 (COVID-19) in the u. S.* Centers for Disease Control and Prevention. <https://covid.cdc.gov/covid-data-tracker>
- Commissioner, O. of the. (2019, February 8). *Informed consent for clinical trials*. FDA.
<https://www.fda.gov/patients/clinical-trials-what-patients-need-know/informed-consent-clinical-trials>
- Gillon, R. (1985). Utilitarianism. *British Medical Journal (Clinical Research Edition)*, 290(6479), 1411–1413. JSTOR.
- Gorman, J. (2003). *Rights and reason: An introduction to the philosophy of rights*. McGill-Queen's University Press; JSTOR. <https://www.jstor.org/stable/j.cttq93mw>
- Gray, B. H. (1978). Complexities of informed consent. *The Annals of the American Academy of Political and Social Science*, 437, 37–48. JSTOR.
- Kupperman, J. J. (2009). Virtue in virtue ethics. *The Journal of Ethics*, 13(2/3), 243–255. JSTOR.
- O'Neill, O. (2003). Some limits of informed consent. *Journal of Medical Ethics*, 29(1), 4–7. JSTOR.
- Quinn, M. J. (2017). *Ethics for the information age* (7th edition). Pearson.

Richterich, A. (2018). Big data: Ethical debates. In *The Big Data Agenda* (Vol. 6, pp. 33–52). University of Westminster Press; JSTOR.

<https://doi.org/10.2307/j.ctv5vddsw.5>

Tene, O., & Polonetsky, J. (2013). Big data for all: Privacy and user control in the age of analytics. *Northwestern Journal of Technology and Intellectual Property*, 11(5), 239.