

# Mark Riley

Lesson 9, Long Paper: Case Analysis

April 21, 2020

## Project Nightingale Summary

Project Nightingale is a joint venture between Google and Ascension that began in November of 2019. Ascension is the second largest healthcare provider in the United States with 2,600 locations in 21 states and the District of Columbia. The two parties signed a Business Associate Agreement (BAA) as part of the Health Insurance Portability and Accountability Act (HIPAA). This allows Ascension to share Protected Health Information (PHI) with Google in order to help Ascension carry out its health care functions.

The existence of Project Nightingale was not widely known, even by Ascension's patients and clinicians, until a whistleblower anonymously reported the details to the Wall Street Journal. This occurred just as Google and Ascension were ready to sign their deal. The whistleblower alleges that Ascension planned to transfer as many as 50 million patients' medical records to Google to store in the Google Cloud as part of the project. The patients' medical records would not be deidentified and would include details such as names, health histories, diagnoses, medications, diagnostic imaging and lab results, and family information. Approximately 150 Google employees and 100 Ascension employees are part of the project and would have access to the records.

The whistleblower reportedly decided to bring the details of the secretive project to the public due to a number of concerns. The first was the secrecy of the plan to transfer so much PHI to a big tech company. Patients were not informed of the plans and had no option to exclude their records from the transfer. The whistleblower was also concerned about Google's handling of PHI, including the tools being used in the data transfer not being compliant with the HIPAA law

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and Google's ability to ensure that the data was being handled properly once the data transfer had begun.

In response to the whistleblower report both Google and Ascension claimed that they had, and would continue, to be HIPAA compliant and that all employees had received proper training on the handling of PHI. Ascension disclosed that the hoped-for benefits of Project Nightingale include modernization of its infrastructure, improved quality and access for vulnerable populations, and boosting patient and clinician satisfaction.

A major ethical issue for Project Nightingale is privacy. The data was transferred to Google without any effort to deidentify the records. The whistleblower alleged that he or she knew of people who would not want to reveal their weights to their own physicians and would certainly be distressed to know their data was being shared with Google. When patients receive healthcare services, they know that records of their visits are kept by the healthcare providers and may be transmitted to health insurers, pharmacies, and other healthcare providers as part of their treatment. They would also expect all parties to make efforts to ensure their healthcare data is secured and kept private. It is reasonable to say that they would not expect their health records to be transferred to big technology firms like Google without their knowledge and consent, as transpired with Project Nightingale.

## Moral Theories

### Utilitarianism

According to utilitarianism an act is right or wrong depending on its consequences.

Consequences are evaluated according to the net total happiness or unhappiness the act causes

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across all sentient beings. For Project Nightingale, there are consequences that cause unhappiness. The project reportedly transferred up to 50 million patient records to Google from Ascension without their knowledge or permission. In addition, it is reasonable to assume that at least some of the physicians and other clinicians may be unhappy as well. When their patients' medical records were transferred to Google without the knowledge or consent it can result in mistrust between the patients and their care teams, and between the clinicians and Ascension.

Project Nightingale has not yet produced any results. If the project were to eventually produce more effective ways to prevent or treat disease, then a utilitarian could argue that the unhappiness caused by the project is outweighed by the happiness created for each person, and all their loved ones, through new discoveries. This would depend on the measure of the effect of the discoveries and the number of patients that are affected. If no beneficial discoveries are made by the project, then a utilitarian would have to say that the project was bad.

There has also not yet been any report of a data breach such as hackers accessing the data or project team members inappropriately handling the data. If that were to happen then there would be additional unhappiness by patients, clinicians, and many of the project team from both Google and Ascension. This would also cause a utilitarian to say that it was wrong to undertake the project. If both beneficial new discoveries and data breaches happen, then the utilitarian has an unenviable task of solving a complex equation.

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## Deontology

Deontology holds that one must not treat other human beings merely as a means, but always as an end. When applying deontology to Project Nightingale, one would conclude that the project is disrespectful to all affected, regardless of whatever benefits may eventually be realized. First and foremost, the patients whose data was transferred without their knowledge or consent are disrespected. Secretly providing the records to Google in any form, nevertheless with full PHI, is tantamount to lying. The patients should expect privacy and security of their healthcare data, and Ascension and Google shattered those expectations through the project. Similar disrespect was shown to the physicians and other clinicians whose documentation was secretly given to Google. They trusted their employer to be transparent and respectful to its employees and patients. By carrying out Project Nightingale, especially in secret, they disrespected those charged with providing care to Ascension's patients.

Those involved as project members are presumably being paid wages and provided benefits that are competitive to similar employers. To that end they are not being treated merely as a means. But making them party to a project that has treated patients and clinicians as a means to an end is disrespectful to the project members. The whistleblower report has triggered an investigation by the Department of Health and Human Service (HHS) Office of Civil Rights. Google and Ascension have also allegedly not provided project team members with a fully HIPAA-compliant toolset. The investigation and alleged inability to remain compliant with federal regulations could create professional repercussions for those team members. In these ways they are being disrespected and treated as merely a means to an end.

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Finally, those people with authority over the project, whose decision making resulted in the project moving forward in a manner that treats so many others as a means to an end are disrespecting themselves. They undermine their own nature by not treating other participants as rational beings with their own values and goals.

## Professional Standards Analysis

When Project Nightingale is compared to the Association for Computing Machinery (ACM) Code of Ethics and Professional Conduct, there are a number of obvious conflicts.

A computing professional should contribute to society and to human well-being, acknowledging that all people are stakeholders in computing. Those responsible for Project Nightingale probably feel that they are contributing to society and human well-being by undertaking this work. However, they have not acknowledged all stakeholders, primarily the patients and clinicians by making them aware of the project and having some input into its implementation.

A computing professional should avoid harm. Project Nightingale has caused harm to those stakeholders who were involved but not informed or given the opportunity for input. The whistleblower has also alleged that there is opportunity for further harm should the data be used inappropriately or breached by hackers.

A computing professional should be honest and trustworthy. Carrying out this project in secret, only to have the details revealed by a whistleblower shows that those responsible were neither honest nor trustworthy.

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A computing professional should be fair and take action not to discriminate. Part of this principle requires that decision processes provide some avenue for redress of grievances. Due to the secrecy, the project was unable to meet this condition. This principle also requires fair participation of all people, which Project Nightingale did not uphold. There is also potential for further discrimination since the medical records were not deidentified. Unless the project team takes care to avoid it, fields containing such information as race, ethnicity, addresses, employment status, and others may enable algorithms to learn and replicate any biases in treatment that exist in the training data.

A computing professional should respect privacy. It was not respectful of the patients' and clinicians' privacy to covertly transfer tens of millions of PHI records to a tech giant like Google. This principle states that computing professionals should establish transparent policies and procedures that allow individuals to understand what data is being collected and how it is being used, to give informed consent for automatic data collection, and to review, obtain, correct inaccuracies in, and delete their personal data. Project Nightingale fails in this regard.

## Moral Conclusion

Project Nightingale has good intentions; however, it should never have been implemented in the way that it was. Based on what we know about this project, nearly all five of the principles of the code of fair information practices have been violated. This code aligns well with the general ethical principles of the ACM Code of Ethics and Professional Conduct.

The Google Cloud database of Ascension patient information was secret until revealed by the whistleblower. Patients are not able to see how their information is being used in the project. It

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is clear that data that was obtained for recordkeeping is now being used for other purposes (research) without patients' consent. Patients cannot see if there is incorrect information in their records transferred to Google and have the opportunity to correct it. Finally, Google and Ascension contend that the patient records are not being misused, however that is not the opinion of the whistleblower and it is difficult to judge who is correct.

The project should not have been secret. Physicians should have been informed about the plan so they could raise concerns and contribute their ideas to make it more successful in its goals. Getting buy-in from physicians could also help them discuss the benefits of the project to their patients. Once the physicians were informed and major concerns were addressed, then patients should have been notified about the details of the project, ideally from trusted and well-known sources, like their primary care physicians. Once patients understood how their data would be used, the data should only have been included in the project for patients who chose to opt-in.

The data transferred to Google as part of the project should have also been deidentified. There is no good reason to include people's names and other demographic information in the dataset. There are valid concerns about the ability to take various pieces of information from a record that has been deidentified and tie it back to a specific individual (reidentify), but at least that would take some effort. Because names and other details are attached it makes it beyond simple to pull up and look through the medical records of people you know, or perhaps even the records of other project team members. These demographic fields also have the potential to cause bias in the results of any algorithms that are derived from the dataset.

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If errors in the data are discovered by the Ascension physicians, there should be a method for the Project Nightingale dataset to be corrected as well. To be fair that may be the case, but the fact that the project was secret makes it unlikely.

Finally, all tools used as part of the project should be fully compliant with HIPAA and have comprehensive auditing in place. This is a feature in electronic health records where every user who accesses a patient's record has every view and change recorded in a log that is accessible to a compliance team and can be extracted for regulatory or legal purposes.

These recommendations would bring Project Nightingale in line with deontology and treat its stakeholders as ends, not merely means to an end. These changes would also bring Project Nightingale in line with ACM Code of Ethics and Professional Conduct, which would treat the Google and Ascension employees on the project as ends as well.

## Objection to Moral Conclusion

From a utilitarian point of view, the way that Ascension and Google carried out Project Nightingale may have caused more harm compared to following deontology. But in the end the companies created much more potential for good through their chosen method.

If Ascension and Google had announced their plans to their clinicians and patients ahead of time, then there would have inevitably been delays in getting started. The clinicians and their patients would have questions, and inevitably some would object to their data being included in the project. In data science, more information fed into your algorithms frequently leads to more accuracy. Whatever portion of patients or clinicians that opt out of participation would



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degrade the quality of Project Nightingale's results. In order to maximize the benefits of the project it is necessary to have as many records as possible.

It is also important to keep the records with patient identities intact. The algorithms that result from the project are developed on testing and training data where outcomes are known. Once those algorithms are put into production, the team will need to closely monitor the algorithm performance against new data. Giving the project team members PHI will allow them to efficiently follow results of their algorithms to compare against expectations and make adjustments quickly. Project team members can also closely monitor to ensure that the algorithms are not recreating bias that may exist in the data by the inclusion of fields like race, ethnicity, and location. A growing area of focus in healthcare are the social determinants of health (SDOH), which examine environmental impacts on a person's overall health. The project must include these types of data in order to further data science effectiveness with SDOH.

The data transferred to Project Nightingale may contain errors because it is real world data. In the course of treatment many different sets of eyes are on a patient's record. If there is an error that would affect care, it is highly likely it will be caught and corrected before the mistake leads to harmful consequences. Mistakes that persist in the record are typically inconsequential to patient care. Clinicians' licenses and livelihoods are on the line, as well as their patients' health, so they must be meticulous in their duties. Errors in the data that would lead to algorithms recommending inappropriate treatment would be caught in the same manner – through diligent review by the full care team.

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As far as security of the data, it is being stored on Ascension-owned virtual private space within the Google Cloud, and Google is not permitted to use the data for marketing or research purposes. There are questions if all of the project's tools are fully compliant with HIPAA, but the project team members are fully trained and held to the specifications of the regulation. All parties know that they face scrutiny with this sensitive data and could face stiff consequences for any violations.

## Response to Objection and Final Conclusions

Communicating with and getting feedback from clinicians and patients prior to implementing Project Nightingale would have very likely led to delays in starting and delivering results. That is no reason to skip this step. The stakeholders would have raised concerns and provided feedback that could have resulted in an overall stronger project. It is also likely that many patients and clinicians would opt out of participation, creating gaps in the data. Having incomplete datasets is a fact of life of data science and there are methods to address deficiencies in the data. Providing all affected a voice in the process gives them, and yourself, respect. It also keeps the project team in line with professional codes of conduct.

If the project team wants to track the results of their algorithms against new data, there are ways to do that without giving the team access to the patient's identity details. For example, a random, unique identifier could be generated and kept in the electronic health record and the Google Cloud so that those who should know patients' identity information can do the tracking. When it comes to bias from data like race, ethnicity, and addresses, it is not always possible to determine if those fields have introduced bias into an algorithm, so it is best to keep them out

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of the equation. For social determinants of health, that information typically includes information such as income, race, housing, and education. That data could be strongly correlated with bias when it comes to access to, and quality of, healthcare treatment. Any algorithm dealing with SDOH must be very cautious with its findings. Valuing the privacy of the stakeholders is to give them respect, and to abide by common codes of ethics principles.

If errors are found in Ascensions EHR system, there should be a way to correct the data within Project Nightingale. The project team should want the most accurate data possible on which to perform their analysis. Data science is a burgeoning field in healthcare and some clinicians may not be well versed enough to identify mistakes resulting from an algorithm or may place undue trust in the algorithms' accuracy. Using the most correct data possible is foundational to professional ethics and shows a greater amount of respect to the stakeholders.

HIPAA compliance is not an à la carte menu from which to choose options. The regulations exist to protect the privacy of sensitive health information. By not being fully conforming, the Project Nightingale team is being disrespectful to all parties, including the government. The Ascension patients and clinicians trusted the organization to secure and protect health records. Google employees trusted their employer to not put them in a position to violate federal regulations. Obedience to the law is also commonly part of a professional code of ethics.

The utilitarian approach taken by Ascension and Google with Project Nightingale may indeed result in a greater overall good than taking the careful steps to treat everyone affected as having intrinsic worth. But that is not a good enough reason to justify what was done. The utilitarian view looks at only the effects on Project Nightingale. The consequences of Project

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Nightingale could be felt by other organizations looking to undertake similar efforts. Patients and clinicians may be even less trustful of healthcare data science and opt-in at lower ratios because of the disrespect shown by Google and Ascension to their stakeholders. The right approach is to value all stakeholders as having intrinsic worth.