Data Science and Machine Learning at Scale Ethics Module

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Learning Objectives

1. Recall facts

- a. Students should come to the lecture with a baseline knowledge in order to contribute to meaningful discussion
- b. Students should be able to recall and reference facts from the case study.
- c. Assessment
 - i. Students will be given the reading before class. At the start of class a quick 5-question quiz will be used to assess whether the students read and get their mindset refreshed on the case study.

2. Explain the case study from multiple perspectives

- a. Students should be able to identify the various parties in the case study and discuss the decisions made by each party.
- b. Students can explain the thought process behind the decisions made by the parties.
- c. Assessment
 - i. Split students into small groups and assign each group a party from the case study. Have the students analyze the case study from that party's perspective. Each group will present their conclusions. Grading for this portion will be based on student participation and the instructor can regulate participation with the "raise hand tool" within the Zoom client.

3. Infer what went wrong

- a. After developing a baseline understanding of the facts at hand and a working knowledge of the actions made by each player in the case study, students should be able to make inferences about what went wrong.
- b. Students should be able to articulate one or more points of contention in the case study where a player's actions could have changed the outcome.
- c. Assessment
 - i. After working in small groups to determine possible tipping points in the story, students will participate in a discussion with the entire class to present their groups findings. Grading for this portion will be based on student participation and the instructor can regulate participation with the "raise hand tool" within the Zoom client.

4. Generate alternative actions

- a. Given an individual or party in a scenario, generate a set of alternative decisions or steps that could have been taken to achieve an alternative result.
- b. Consider how those alternatives may be unsuccessful.
- c. Assessment

i. As a class, students will work together while being guided by the instructor to generate alternative decisions ro steps that could have been taken that would alter the outcome. Grading for this portion will be based on student participation and the instructor can regulate participation with the "raise hand tool" within the Zoom client.

5. Apply learning to a new scenario and produce plan of action

- a. Apply all previously developed knowledge and vocabulary to assess a new situation
- b. Understand the similarities and differences between the scenarios.
- c. Generate possible steps, decisions, or solutions that could be utilized to prevent negative outcomes.
- d. Assessment
 - i. Students will be provided with a new scenario. They will apply previous skills to present an appropriate series of steps that should be taken.

6. Execute plan of action

- a. Apply all previous knowledge to take action with respect to the new scenario presented
- b. Develop professional writing and communication skills
- c. Assessment:
 - i. Students will write an email as if they were writing to their boss discussing the issues presented in the new scenario. The email should be persuasive and respectfully acknowledge various concerns the student has.

Justification of Design

We created this module with the intention of providing an interactive and engaging class that challenged students to deal with situations that have ethical issues embedded, but as common in life, do not have clear black and white boundaries. The learning objectives and module structure were chosen to allow students to develop their ethical reasoning step by step growing their own confidence in handling the issues as the module progresses. We want students to walk away with some basic tools and actions that they can utilize when they enter their future jobs.

The module has a significant amount of class and peer to peer discussion. The purpose of this was to allow students to learn from their classmates and to engage with different perspectives. We wanted the module to be engaging and generate discussion around various ethical topics. This was also an underlying factor as to why the particular case study centered on commercial genetic testing companies was selected. There were numerous issues and potential issues with regards to these companies. Moreover, there is not a clear bad actor involved. We anticipate different opinions on how the various issues presented should be resolved, and in fact selected the pre-reading text to encourage this by ensuring both positive and negative takes on the subjects were presented.

We want students to analyze the case study carefully, but more than that, we want them to be able to expand beyond the specific case study presented. That is why for the final two learning objectives, we present a new scenario for students to address. This is to assess whether the students can extend their learning to different situations and acts as a proxy for their ability to potentially apply this learning in a future job situation. To drive this home, we have students complete a final assignment that both assesses their learning from the module and provides them an opportunity to practice critical professional skills. They are tasked with writing an email to their boss explaining and likely respectfully disagreeing with their imaginary company's direction.

We hope that this module will help students develop critical thinking skills and give them an opportunity to consider ethical quandaries.

Instructions for Use

To use this module we first recommend reviewing all the provided materials including the case study readings. We have provided all of the resources necessary to effectively run the class, though we hope that this base material is just a starting point and that this module can be adapted to meet the needs of the particular class.

The expectation is that students will read the provided case study material prior to class and a majority of the class will be spent discussing the case study and developing the students' capacities for understanding and discussing challenging ethical issues.

We provide a short five question quiz that can be used as a basic assessment tool to ensure students completed the reading and are prepared for class. After that, we anticipate the remainder of the class to be a discussion in either small groups or as a full class. For this we provide a variety of questions that can be chosen based on the specific topics that the instructor wants to focus on. We built the set up for up to three breakout group sessions with questions for each group to answer. We envision that the questions would be provided for each group on a Google Document or Slides that they can fill out with their group members thus ensuring active participation from all groups. Students can then present their ideas or use the small group discussions as a base for further conversation with the whole class. Examples of response expectations are provided in this packet as well.

Towards the end of the class, students will switch from the case study and readings to a new scenario. This is to provide an opportunity for students to apply their learning to a different situation. The discussion can be conducted as a class or in small groups. One of the potential breakout room question sets is with respect to the new scenario. The scenario can also be changed if needed. The final assignment that can be either completed in class or as an outside assignment is a professional email to an imaginary boss with regards to the scenario the students face. We provide additional guidance and a rubric for grading.

Class Outline

- 1. Reading assessment quiz
 - a. Prior to class students will be required to read the assigned papers. At the start of class students will take a short 5 question quiz. The quiz questions are straightforward and based solely on the reading, so if students are prepared for class, they should not have any issue with answering the questions. The quiz questions are enumerated in the activity materials below.
 - b. Time: 5 minutes
 - c. Learning Objective: 1
- 2. Open discussion led by the instructor
 - a. After the quiz, the instructor will engage with the students on the reading to talk about what stood out to them and to begin to steer the direction of the conversation.
 - b. Key Topics to discuss
 - i. Summarize the case study
 - ii. Identify major issues
 - 1. Privacy, security, safety
 - iii. Consider positives and negatives
 - iv. Identify major parties involved
 - 1. Users and Customers
 - 2. Law enforcement
 - 3. FDA
 - 4. 23andMe + other similar companies (GEDMatch)
 - 5. Pharmaceutical Companies and Insurance Companies
 - 6. Nonprofits/Research Groups (working on eliminating target diseases)
 - c. Time: 15 minutes
 - d. Learning Objective: 1, 2
- 3. Small group discussion
 - a. Students will move to their first breakout group where they will discuss the case study from the perspective of a specific party in the case study. Each small group will be assigned a specific party to discuss. Question prompts provided in Activity Materials
 - b. Students will return with filled out answers to the prompt questions
 - c. Time: 10 minutes
 - d. Learning Objective: 2
- 4. Present ideas and discuss
 - a. Students present the key points from their small group and discuss major takeaways with the class

- b. Time: 5 minutes
- c. Learning Objective: 2
- 5. Class or Small group discussion (optional breakout room 2)
 - a. Students try to infer what went wrong and generate alternative steps or actions that could have been taken.
 - b. Key Topics to discuss
 - i. Tipping points
 - ii. Incentive structure
 - iii. Is there an issue that is the most pressing?
 - iv. What motivates a group to change direction
 - v. Can actions be taken to reduce the problems in the case study?
 - vi. Will those actions always receive support?
 - c. If breakout group used
 - i. Time: 10 minutes in small group, 10 minutes presenting and discussing results with class
 - d. Time: 20 minutes
 - e. Learning Objective: 3, 4
- 6. Present a new scenario
 - a. As a class review a new scenario and discuss the key points.
 - b. Time: 5 minutes
 - c. Learning Objective: 5
- 7. Small group discussion
 - a. Students apply their learning on the case study to the new scenario. In an abbreviated manner, they will progress through the learning objectives.
 - i. Start with identifying the basic facts and parties
 - ii. Assess the decisions or potential decisions of each party and determine their motives and perspective
 - iii. Generate some steps or actions that can be taken and consider the consequences of failing to do so
 - b. Time: 15 minutes
 - c. Learning Objective: 5
- 8. Assignment: Write an Email
 - a. This is designed to be done outside of class, but could be done in replacement of the final breakout group.
 - b. Students come up with a recommended course of action for the written scenario and suggest a way forward for BioNano
 - c. Students write an email to the CEO of BioNano expressing their concerns in a professional and respectful manner while still providing compelling reasoning for your recommended course of action.
 - d. Expected outcome

- i. Email is well written and free of grammatical or spelling errors.
- ii. Email is respectful and appropriate given the recipient
- iii. Email has a compelling argument and is supported by data
- iv. Student demonstrates a strong understanding of the module content
- e. Learning Objective: 5, 6

Activity Materials

Quiz

- 1. Question 1
 - a. Q: 23AndMe has never had any issue complying to FDA directives.
 - b. A:
 - i. True
 - ii. False
- 2. Question 2:
 - a. Q: When GEDMatch was breached, what peculiar operations did hackers attempt to perform on the system?
 - b. A:
 - i. Steal payment information used to pay for the service
 - ii. Change user settings to opt them into giving data to law enforcement
 - iii. Shut down the service with a DDOS and demand a ransom
- 3. Question 3:
 - a. Q: A majority of the money 23andMe makes comes from selling genetic data to the government, pharmaceutical companies, and research organizations.
 - b. A:
 - i. True
 - ii. False
- 4. Question 4:
 - a. Q: A US Court has never used a genomic data bank site to convict someone of a crime.
 - b. A:
 - i. True
 - ii. False
- 5. Question 5:
 - a. Q: What are some of the advantages 23andMe can pass to researchers studying various aspects of the human genome.
 - b. A:
 - i. Fast access to large amounts of aggregate and anonymized genome data.
 - ii. Ability to quickly conduct real time surveys on individuals that have certain genetic markers.
 - iii. Significantly reduced cost as compared to the cost to conduct traditional research studies in this area
 - iv. All of the above

Breakout Room/Small Group Questions

Below are the set up prompts for the breakout rooms/small group discussions. We intend these to be put into a slide deck or Google document that students can access with a prompt/slide for each small group. The expectation is that they respond to the questions in the slide or Google document.

Break Room Round 1

There are many groups with a stake in the 23AndMe Business and other similar companies. For this first break out room you will analyze the ethicality from the standpoint of the <insert group>.

- What argument can be made in support of your group and their involvement in this case study?
- What argument can be made against your group and their involvement in this case study?

Break Room Round 2

Now that we have made inferences about what should or should not have been done, we can put ourselves in the scenario and generate alternative actions that would have resulted in less harm.

- How would you approach this problem? Is there a way to emphasize the positive aspects of the case study and also reduce the negatives?
- Provide a few sentences about how your group brainstormed the actionable items

Break Room Round 3

Consider the new scenario presented as you answer the following questions. You may find it useful to progress through the scenario in a similar manner to our progression through the case study.

- What are some of the problems that exist with potential moves by BioNano? What are some consequences that might initially be unforeseen? Are they positive, negative, or both?
- What ethical issues are at play here? What steps could be taken to minimize one or more of them? Where in the pipeline would this need to be addressed? Come up with a few actionable items and justify them.
- How might the upper leadership of BioNano react to your actions or decisions? Are there risks involved with your actions?

BioNano Scenario

The new provided scenario for the students to consider and answer questions about.

- You are the lead Software Engineer at BioNano, a startup that makes nanochips for bodily function monitoring.
- BioNano nanochips were originally designed for use in hospitals where patients in the ICU and specifically those who could not directly communicate with the doctors could receive more focused analysis.
- BioNano maintains all of the data collected on patients on a secure server. It is currently only used for internal evaluation, but they constantly receive pressure to share anonymized versions of that data as well as provide nanochip implants to users with chronic health conditions that need to be monitored.
- The Head of R&D at BioNano feels that there is a huge market potential being missed in such scenarios and is pushing for lobbying to be done to overturn the rules preventing BioNano from being used outside the hospital.
- Several research firms and pharmaceutical companies have come forward to offer multi-million dollar contracts to have access to the current and potentially expanding databases.
- Since surgery is required to remove the chip, most who receive the implant in the ICU still have it in their body though it gets disabled once they leave the hospital. This body of individuals are being considered for a trial run for continued data collection. No additional individuals will be eligible to receive a nanochip implant for now.
- BioNano's restrictions:
 - Only individuals that sign an agreement to "opt-in" would be eligible for data collection and research.
 - BioNano also expressly indicates that anonymity of users will be guaranteed in all cases in order to prevent potential negative consequences for the individual. Individuals who opt to turn on their nanochip will have access to a health monitoring interface that can be used to check things like blood sugar, cholesterol levels, and vitamin intake. These would provide numerous health insights and benefits to the user.
 - BioNano is also considering a "turn on, opt out" option where users could still monitor their bodies, but not be included in the research databases.
- The CEO has asked you to design a proof of concept for condensing the data from the nanochip into a non-medical, user friendly, phone app capable of real time updates. She also wants your insight about how to properly share the data to outside companies and who BioNano should share data with.

Additional Questions

These questions can be used in addition or in replacement of the small group questions. They can also be integrated into the open classroom discussion led by the instructor. Each set of questions is tied to the learning objectives. The goal of these questions is to drive discussion and promote learning and critical thinking in the students

Recall facts

- How is what 23andMe is doing any different from what social media companies are doing when they monetize your data? Where are there differences? Which one feels worse, and why? How could consequences be more severe with one group or another?
- What ethical issues exist in the case study?
 - Were these issues present initially or did they develop overtime as 23andMe developed?
- What were some of the potential negative consequences discussed in the case study readings?

Explain the case study from multiple perspectives

- What argument can be made in support of your group and their involvement in this case study? What argument can be made against your group and their involvement in this case study?
- How does your group benefit from the situation? How is your group hurt?
- If you were acting on behalf of your group, would you change the current state of affairs?
 Why or why not?
- If you were to change the current state of affairs, what specifically is different? What is the same?

Infer what went wrong

- Was there a specific tipping point that resulted in negative ethical consequences?
- Is there more than one issue at play?
 - If so, which actors contributed to each issue? And, which actors are impacted by each issue? Are these positive impacts, negative impacts or both?
- Try to think about individual employees in 23andMe software developers, cybersecurity personnel, managers, PR, etc. Who shares the blame if any for the ethical issues or potential issues that could come from 23andMe's business model? Why?
 - What could those individuals do differently?

Generate alternative actions

- How would you approach this problem? Is there a way to emphasize the positive aspects of the case study and also reduce the negatives?
- Choose one specific ethical issue that was presented or discussed. What steps could be

taken to minimize it? Where in the pipeline would this need to be addressed? Come up with a few actionable items

- Justify why the steps/actions/alternative solutions would make a difference?
- Provide a few sentences about how you can brainstorm actionable ideas.
- Why might these actionable steps not be effective in a corporate setting? Would they be applicable in another setting (ie government or academia)?

Apply learning to a new scenario and produce plan of action - Note these questions specifically relate to the new scenario presented to the students

- What are some of the problems that exist with potential moves by BioNano? What are some consequences that might initially be unforeseen? Are they positive, negative, or both?
- Think about the different parties involved. What do they have to gain or lose? What is motivating their decisions?
- What ethical issues are at play here? What steps could be taken to minimize one or more of them? Where in the pipeline would this need to be addressed? Come up with a few actionable items and justify them.
- How might the upper leadership of BioNano react to your actions or decisions? Are there risks involved with your actions?

Execute plan of action

- How could you actually implement your plan? How do you invoke change in an organization?
- How does a plan of action change based on the job you hold? What are some challenges that exist only in certain jobs?
- What steps can you take if you receive pushback from your actions?

Email Assignment

In this assignment students will not only accomplish learning objective six: executing a plan of action, but also practice professional communication. The email assignment is a post-class exercise that extends off of the new-prompt that students are given at the end of class. Students will be asked to construct an email to their boss regarding their concerns over a new technology being invented (explained in the new prompt). In addition to the prompt students will also be given some mock data to use in their communication. This data can be used in their email to bolster their argument. Lastly, prior to the end of class, the instructor will give an overview of professional email guidelines and a vocabulary for how to talk about ethics in the workplace.

The students can complete this assignment in class or as a homework assignment. The finished email will be sent to the instructor for grading either as a document or in an email.

Prompt:

After careful consideration of the situation at BioNano, you decide to write an email to the CEO expressing your concerns about the direction the company is taking. How you develop your email and the recommendations you make is up to you, but you must provide clear guidance on how the company should move forward. Additionally, you should support your point of view with data. The email should be professional and respectful as the CEO is your boss.

Email Assignment Grading Rubric		
Criteria	Points	
Provides clear recommendations or actions that should be taken	4	
Evidence is used to support the recommendations	2	
Demonstrates an understanding of the audience	2	
Writing is concise, professional, and respectful	2	
Grammatically correct, free of typos or spelling errors	2	
Total Points	12	

Example Responses

This section provides example responses to the small group questions and the email assignment in order to provide some guidance and set a basic expectation for what the students produce.

Break Room Round 1

There are many groups with a stake in the 23AndMe Business and other similar companies. For this first break out room you will analyze the ethicality from the standpoint of pharmaceutical companies.

• What argument can be made in support of your group and their involvement in this case study?

Drugs are often expensive because of all of the robust testing that must be done to ensure their efficacy. If drug testing can be somewhat distributed using masses of digital genetic data then this potentially allows for drugs to be made cheaper and hit the market faster.

• What argument can be made against your group and their involvement in this case study?

It is unlikely that pharmaceutical companies will have lower consumer prices on their mind when utilizing massed digital genetic data to conduct pharmaceutical testing. There may only be an allure to pharmaceutical companies to use the data to simply lower the manufacturing cost.

Break Room Round 2

Now that we have made inferences about what should or should not have been done, we can put ourselves in the scenario and generate alternative actions that would have resulted in less harm.

• How would you approach this problem? Is there a way to emphasize the positive aspects of the case study and also reduce the negatives?

Problem 1 - Breaches of Information

If we are talking only 23AndMe, the company itself has not had a considerable breach which is a positive thing. The company claims that they are practicing the highest security standards in the industry. However, other similar companies have been hacked. The best approach to this problem is to be honest with the customer. It is best to explain that although 23AndMe is practicing high security standards, the risk of breaches still exists. This is in contrast to waving it off as a non-issue why consumers shouldn't be scared.

Problem 2 - Lack of Testing and No FDA Approval

23AndMe should have never gone against FDA recommendations and advertised their genetic disease prediction service. Doing so not only is illegal but undermines trust with their consumers. An argument along these lines could have been brought up by representatives of the company: If the company really wants to portray an image of "safety" and "reliability" doing more testing to prove to the FDA the product is accurate would be beneficial for the business.

Problem 3 - Law Enforcement may Override

23AndMe and other similar companies should do preliminary collaboration with law enforcement to enumerate what the data absolutely can and cannot be used for. Law enforcement should also show that they understand the answers returned from the genetic database are not always correct and that they should be used to augment a case, not solely convict.

• Provide a few sentences about how your group brainstormed the actionable items

We first we're unsure of the one overarching problem here so we separated the issues into 3 distinct problems posed by the company 23AndMe. Each group member had analyzed a separate party from the last breakout room. We were able to synergize these ideas to create alternative or pre-emptive actions that the different groups could take.

Break Room Round 3

Consider the new scenario presented as you answer the following questions. You may find it useful to progress through the scenario in a similar manner to our progression through the case study.

• What are some of the problems that exist with potential moves by BioNano? What are some consequences that might initially be unforeseen? Are they positive, negative, or both?

Initially it may seem like BioNano and the pharmaceutical and other medical companies only have good intentions. However, there are a lot of unanswered questions. For example, BioNano does not know for certain that it is safe to keep the devices on for extended periods of time. Additionally, when aggregated the information poses a huge security risk. When deployed at scale, the streaming data traffic will be under the crosshairs of hackers at all times.

• What ethical issues are at play here? What steps could be taken to minimize one or more of them? Where in the pipeline would this need to be addressed? Come up with a few actionable items and justify them.

The issues at play span a variety of things. The turn on, opt out option also poses issues of its own that are not alleviated with simply opting out of the medical research. If for example, the bio-data is briefly visible to someone else (unwanted), then this presents an issue. The opt in agreement allows pharmaceutical companies to improve profits without attributing monetary cost to any of the test subjects.

• How might the upper leadership of BioNano react to your actions or decisions? Are there risks involved with your actions?

There are definitely risks involved. Depending on how it is received BioNano may react positively or negatively. Navigating the business world here effectively is the key to success.

Email Response to CEO

To whom it may concern,

After careful consideration of the current direction of BioNano, I feel I must bring my concerns forward. We should not be so quick to move on the pharmaceutical contracts when we have failed to consider the second and third order effects of such a move.

While there are undoubtedly opportunities for growth for BioNano, opening our data without thoroughly vetting those we provide it to could result in misuse. Moreover, when we open our databases for other companies to access, we potentially open the doors to bad actors willing to attack our systems for profit. The idea of sharing our data for the good of the world so various groups can develop cutting edge technologies and medicine. However, I personally find it exceedingly concerning that we are in talks to close these sharing agreements, but to my knowledge there has not been any discussion with regards to vetting these companies. More concerning, there has been no effort to reach out to individuals whose data we are about to share.

My second major concern deals with the data itself. While BioNano did not have control over individual hospital decisions regarding who needed the implant during their ICU visit, we can control further testing prior to any kind of major role out. We simply do not have enough women to sufficiently make any claims about BioNano's safety. This is especially true with pregnant women. We do not know how pregnancy impacts the nanochip's effectiveness, nor do we have enough subjects to deem such a chip as safe for women who are or may become pregnant.

I hope you will give these concerns some consideration. BioNano is on the precipitate of major change, but if we are not cognizant of how we take the next few steps, we could stumble into a windstorm of negative publicity due to overlooked ethical issues.

I would be happy to elaborate and discuss my views in person, and am available all day tomorrow at your convenience.

Very Respectfully, A concerned engineer