<u>Term Project – Outline and First Post</u>

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Data Analysis:

Data analysis involves examining data sets to find meaningful insights and support decision-making through various statistical, mathematical, and computational techniques. This process includes inspecting, cleaning, transforming, and modeling the data to draw conclusions and discover useful information. Data analysis involves a various level, such as gathering data, preparing it for analysis, studying the data, constructing statistical models, and interpreting the findings. The objective is to recognize trends, connections, similarities, and dependencies among the data to attain further insight into the underlying subject matter or to make accurate predictions and informed choices. However, there are different ways to analyze data, such as using descriptive and inferential statistics, data visualization, machine learning algorithms, and data mining techniques. The main aim of data analysis is to extract meaningful insights, discover concealed patterns, resolve issues, and facilitate decision-making in fields like business, healthcare, finance, marketing, and research.

Although, talking about the data analysis' steps in dept and more simplistic manner. At first, we have to get the datasets. Later, we have to process the data organize it in proper order and

sequence. After the data is organized, we need to go through and clean it as it may contain duplicates and other uncleaned things, so it requires cleaning of errors, evaluating quality of data, removing of the duplicates and breaking down of the information into different columns. As a fruitful result, our data is all ready to be explored and mined. As analyst go through the data and explores it and mines it. After doing so, he will use some mathematical formula to get the model prepared as data modelling may use the correlation and some other such things. However, in the field of data analysis, its not that simple to just have the data gathered and work on it and so on, but there are also some issues from the ethical and legal point of views.

Background of Issue of few case:

However according to the article, 'Ripe for public debate: Legal and ethical issues around deidentified data', PHIPA Decision 175 had a significant investigation that aimed to address the sale of de-identified health data under the Personal Health Information Protection Act. This investigation was initiated based on concerns raised in a news article published in the Toronto Star. The decision identified three major takeaways, including the need for transparency in data practices and high-quality de-identification processes, the requirement for explicit inclusion of data sale intentions in public notices for accountability, and custodians' security obligations to protect personal health information. The decision also emphasizes the importance of privacy and security controls to ensure data anonymity. Additionally, it highlights ETHI's recommendations on transparency, prohibition of re-identification, and privacy law reform. The article calls for more public discussion, transparency, and accountability to protect individuals and promote trust in the healthcare system regarding the sale and disclosure of de-identified

health data. Therefore, looking to the legal and ethical point of issues of this case let's dig into it.

Reference: Information and Privacy Commissioner of Ontario. (n.d.). Ripe for public debate: Legal and ethical issues around de-identified data. Retrieved from https://www.ipc.on.ca/ripe-for-public-debate-legal-and-ethical-issues-around-de-identified-data/

Ethical Issues:

Along with the growing technology we face many kinds of issue one of them is ethical issue. So, according to our case study article let us see what are the ethical issues of it.

Ethical Issue 1:

What ethical considerations arise from the sale or disclosure of de-identified personal health information without clear and meaningful transparency? How does the lack of transparency regarding the use of de-identified data impact individuals' rights and autonomy?

The use of de-identified data in research and other health-related activities provides a vital source of information for advancing healthcare outcomes. However, the lack of transparency regarding the use of this data poses significant ethical concerns. One of the primary concerns is the infringement on individuals' rights and autonomy. Without transparency, individuals are unable to make informed decisions about how their data is used, which deprives them of control over their personal information. Furthermore, the

use of de-identified data can lead to potential harms such as stigmatization, discrimination, and unfair distribution of services or benefits. Another significant ethical concern is the erosion of public trust in the healthcare system and research institutions. When individuals are unaware of how their data is being used or who has access to it, their confidence in the system is undermined. This lack of trust can impede progress in healthcare and research, as individuals may be hesitant to participate in studies or share their health information. To address these concerns, clear and meaningful transparency is essential. Individuals have a fundamental right to know how their data is being used, and healthcare and research institutions have a responsibility to provide this information in a clear and accessible manner. By upholding ethical principles and fostering trust through transparency, we can ensure the responsible and effective use of de-identified personal health information.

Ethical Issue 2:

What ethical considerations should be taken into account when making inferences from deidentified personal health information, considering the potential impacts on individuals and communities in terms of stigmatization, discrimination, and unfair distribution of services or benefits?

Legal Issues:

Legal Issue 1:

What are the legal requirements regarding the use and handling of de-identified personal health information, particularly in terms of obtaining explicit consent and ensuring transparency through public notice? How can the failure to meet these requirements potentially lead to legal violations and what are the implications for the proper use of de-identified health data?

Legal Issue 2:

What are the legal requirements and obligations imposed on health information custodians regarding the security of de-identified personal health information, and how can they ensure compliance to prevent breaches and maintain the integrity of the de-identification process?

Solutions & Conclusion: