Policy for Achieving Ethical Precision Medicine

Current practices in healthcare involve providing therapeutic interventions to patients based on strategies that have previously worked for most patients. While this standardized approach to healthcare has delivered consistent results in the past, a problem identified with this method is the lack of individualized care. To reconcile this issue, precision medicine (PM) is an innovative approach to healthcare that accounts patients’ genetic, environmental, and lifestyle factors into their treatment and prevention strategies. With precision medicine, there is no longer a “one size fits all” mentality in healthcare. However, the rise of precision medicine also leads to ethical concerns in general as well as implications on the decision-making process. Some of these ethical problems include data issues, a lack of transparency, autonomy, non-maleficence, and justice.

Policy Statement: To accomplish ethical precision medicine, healthcare organizations and researchers will have stronger data processes, promote transparency, and encourage accountability. In the new data process, researchers control who has access to data, adhere to “privacy and data protection regulations” at each stage of a research study, and endorse posthumous medical data donation (PMDD). To promote transparency healthcare professionals and more specifically genetic counselors will disclose sensitive information to patients along with establishing the patients’ preferences for what type of information (e.g. incidental findings) they want to know or whether they waive their right to know. Additionally, healthcare professionals and researchers who disclose or are connected to data breaches will be held accountable for their actions or inactions. Members of the Institutional Review Board (IRB) will also be responsible for consistently updating themselves with new processes related to precision medicine research. Furthermore, healthcare professionals and researchers will take Project Implicit’s Implicit Association Test and subsequently work towards rectifying any inherent biases they may have.

Purpose: The purpose of this policy is to provide solutions to the ethical concerns regarding precision medicine

1. To protect patients’ genetic data and personal health information (PHI)
2. To preserve the physician-patient relationship through open communication between both parties
3. To instill trust in the healthcare system and the research study process
4. To ensure that patients are receiving the proper care they need without fear of discrimination