



Chapter 1

Belmont 2.0: Ethical Research Expectations for PII in AI, ML, and Data Mining/Scraping

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ABSTRACT

With the growth of ubiquitous digital technologies, such as artificial intelligence and machine learning, specialized training and preparation are needed to best guide social science researchers for human research protections that involve protections for data with personally identifiable information. Some human research protection (HRP) officers have called for a Belmont 2.0 that offers more aligned guidance for HRP programs and institutional review boards (IRB) to address data ethics in this new era. This chapter presents an analysis of the shifting climate of HRP data ethics, Belmont Principles, and IRB and HRP implications for artificial intelligence, machine learning, data mining/scraping, and other ubiquitous technologies.

INTRODUCTION

For human research protections (HRP), the data ethics and personally identifiable information (PII) surrounding artificial intelligence (AI), machine learning (ML), and data mining/scraping (DMS) have been widely discussed within scholarship

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and among regulatory bodies. In recent research, much has been published in the recent scholarship about the institutional review board (IRB) and human research protection program (HRPP) implications for the protections of human subject data for AI, ML, and DM. “The purpose of the IRB is to ensure the safety of human subjects involved in research, privacy, and confidentiality for human subjects identifiers, fairness and equity in research recruitment, and to ensure risks are minimized for all research involving human subjects and/or their data, and to make certain no physical or psychological harm comes to the research participants” (Throne et al., 2023, pp. 1-2). Yet, the 2020s have seen an evolving and competing momentum in the rise of individual agency for data privacy. Many regulatory bodies and other governmental groups globally have continued to issue new guidance, regulations, and restrictions for PII and data privacy for these continually evolving digital technologies and IRB and HRPP leaders have concurrently considered these in the context of HRP and PII with discussions and considerations for new policy ongoing.

In past work, the chapter authors, with others, have continued to examine the shifting climate of HRP and specific to PII data ethics within the era of emergent ubiquitous technologies and respect to the use of AI, ML, and DMS (Throne, 2022; Throne et al., 2023). In 2022 and 2023, many regulatory bodies and other governmental groups globally issued new regulations and restrictions for PII, AI/ML, DMS, and personal data privacy for these continually evolving technologies (Throne, 2022). It remains essential in this time of momentous change for IRB and HRPP leadership to remain attentive to these emergent policy events in the context of the growing use of these ubiquitous digital technologies for HRP and PII protections.

Further, the Menlo Report¹ from the U.S. Department of Homeland Security (2012) in Science and Technology provided a set of guidelines and ethical principles for communication technology research (Throne et al., 2023). Built on the Belmont Report, the Menlo Report includes the three principles of the Belmont Report: Respect for Persons, Beneficence, and Justice. It includes a fourth principle of Respect for Law and Public Interest, and some authors have noted its relevance for biomedical computational research yet limited and dated for a contemporary data ethics framework (Hosseini et al., 2022). Many have since called for the scientific community and regulatory bodies to devote more attention and scrutiny to the ethical issues that surround big data (BD) research, including AI, ML, and DMS (Doerr & Meeder, 2022; Eto, 2022; Hosseini et al., 2022). More recently, Finn and Shilton (2023) noted the Menlo Report offered a case study in governmental ethics and the trade-offs sometimes necessary to establish ethical guidance amid rapid technological change. They explained, “The processes we observed at work during in the Menlo Report can be used as a framework not only for understanding how the development of ethics governance has proceeded in the past, but also for predicting tensions within, and perhaps improving, current and future projects that seek to

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