PRIM&R
PUBLIC RESPONSIBILITY IN MEDICINE AND RESEARCH

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October 21, 2022

Joel Christie
Acting Secretary
Federal Trade Commission
600 Pennsylvania Avenue, NW
Suite CC-5610 (Annex B)
Washington, DC 20580

RE: "Commercial Surveillance ANPR, R111004"

Dear Mr. Christie,

Public Responsibility in Medicine and Research (PRIM&R) appreciates the opportunity to comment on the Federal Trade Commission (FTC) Advance Notice of Proposed Rulemaking (ANPR) on "Commercial Surveillance and Data Security," published in the *Federal Register* on August 22, 2022.

PRIM&R is a nonprofit organization dedicated to advancing the highest ethical standards in the conduct of research. Since 1974, PRIM&R has served as a professional home and trusted thought leader for the research protections community. Through educational programming, professional development opportunities, and public policy initiatives, PRIM&R seeks to ensure that all stakeholders in the research enterprise appreciate the central importance of ethics to the advancement of science.

PRIM&R strongly endorses the FTC's intent to issue trade regulation rules to ensure that, in this digital age, individual citizens are protected from largescale commercial surveillance and lax data security practices that have tremendous potential for harm. We recognize that the intent of the ANPR is to establish a federal oversight mechanism for the digital technology sector, specifically to protect consumers from harms that may result from commercial use of their personal data. However, as an organization dedicated to promoting ethically sound and scientifically valid research, in lieu of addressing the questions listed in the ANPR, we would like to share our perspective on the issue of data stewardship, broadly, at a time when digital technology is pervasive across society.

Blurring of Lines

Relevant to the current ANPR, it is imperative to recognize that the line between research and commerce is becoming increasingly blurry. For instance, many activities in which technology companies increasingly engage, such as the development and validation of technological innovations and devices, are similar to scientific activities aimed at the creation of generalizable knowledge, i.e., research. In other words, there is often little distinction between ways in which data are collected and used in research and the collection, retention, and use of consumer data by for-profit commercial entities. This blurring of lines has been further exacerbated by the entry of big technology companies into the field of biomedical and health research, via their direct-to-consumer marketing of behavioral and health apps and their currently unregulated access to data generated by users of their digital apps, platforms, and devices. Furthermore, in their efforts to develop newer and ever-more sophisticated digital applications, devices, and services, **big technology companies often engage in activities that fit the federal regulatory definition of research with human subjects.** In both cases, the data are generated by individuals and are often very similar**. However, while researchers in academic and healthcare settings are required to abide by ethical and regulatory standards that ensure scientific integrity as well as protection of the research subjects, these commercial entities fall outside the purview of the current regulatory oversight system for protecting the rights and welfare of human subjects.**

Currently there are no standards of accountability for technology companies who engage in "research" activities, nor are there guardrails to protect consumers. For example, recently *The New York Times* reported that between 2015 and 2019 LinkedIn conducted algorithmic experiments on over 20 million users from around the world, without users' explicit consent, supposedly to improve the services it provides to its members. The algorithm was informed by, and the resulting data was used to test, a longstanding sociological theory regarding interpersonal connections.[1] This study was conducted despite a public outcry about a similar study conducted by Facebook, which came to light in 2014 and involved manipulation of users' news feeds to study its impact on the users' mood and emotions.[2] Regardless of claims by LinkedIn and Facebook that they did not engage in research with human subjects, it is activities like these that have raised questions about the adequacy of the current regulatory definition of research.

[1] https://www.nytimes.com/2022/09/24/business/linkedin-social-experiments.html; https://www.upi.com/Science_News/2022/09/25/linkedin-ran-secret-experiments-20-million-users-strength-weak-social-ties/7411664131874/; https://observer.com/2022/09/tech-researchers-are-divided-over-a-linkedin-experiment-that-tested-the-networking-power-of-weak-connections/

[2] https://www.npr.org/sections/alltechconsidered/2014/06/30/326929138/facebook-manipulates-our-moods-for-science-and-commerce-a-roundup; https://www.theatlantic.com/technology/archive/2014/06/everything-we-know-about-facebooks-secret-mood-manipulation-experiment/373648/; https://www.theguardian.com/technology/2014/jun/30/facebook-emotion-study-breached-ethical-guidelines-researchers-say

Prevailing Regulatory Structures as a Model

As noted in the ANPR, digital technologies are such an integral part of life that most individuals have little, if any, control over the personal data and information about themselves that are being collected as they go about everyday life activities, such as communicating with friends and family, shopping, working, seeking entertainment, etc. Similar data are generated when scientists use the same digital technologies such as mobile phones/smartphones, health apps, wearable computing devices, social networking platforms, and digital body sensors as tools to collect research data to study myriad health and societal issues. **But unlike data collected for commercial purposes, there are mechanisms for ethical and regulatory oversight of data collected in research settings, in pursuit of knowledge to advance science and medicine.** For instance, the requirements for obtaining informed consent from prospective research subjects far exceed the terms of use, end user license agreements, and privacy notices required of commercial entities that own and operate digital platforms. As the ANPR notes, these documents are often lengthy and rife with legalese rendering them beyond the grasp of most consumers. In stark contrast, regulations for protecting the rights and welfare of research subjects require that information about the study and the risks and potential benefits of participation be provided in language that is accessible to the prospective subject ensuring that their decision regarding research participation is "informed."

Federal agencies charged with oversight of research have issued regulations and policies based on three foundational ethical principles elucidated in the Belmont Report—respect for persons, beneficence, and justice. For example, all the signatories to the Federal Policy for the Protection of Human Subjects at 45 CFR 46 Subpart A, or the Common Rule, have developed rules, policies, and procedures to contend with issues such as privacy, confidentiality, and consent. When scientific and technological advances and evolving societal norms have sometimes challenged the adequacy and appropriateness of these research regulations, the research community have had the benefit of using these ethical principles to resolve emerging dilemmas.

New Landscape

People shed vast amounts of personal information as they go about their daily lives in this digital world. Irresponsible use of such information by technology companies can have a deleterious effect on public trust in science. Given the increasing difficulty of distinguishing between the collection, sharing, and use of this information for research purposes versus commercial purposes, we believe it is time for a unified infrastructure and framework for responsible data stewardship. Ensuring a uniform approach to and standards for the protection of personal data calls for either a harmonized effort across federal agencies whose missions cover different sectors (for example, FTC oversees the technology industry, while signatories to the Common Rule regulate biomedical, behavioral, and social science research), or the creation of a new agency charged with overseeing data stewardship across the board (similar to the Consumer Financial Protection Bureau).

In conclusion, it is important to recognize that technology companies are no longer merely commercial entities focused on producing and marketing technologies, apps, and devices, but are drivers of societal change engaged in developing models of human behavior that also shape how we see the world. To this end, these technology companies strive to learn more about peoples' everyday life activities, both public and private, in ways similar to behavioral and social scientists studying human behavior. Further, there is lack of transparency about the proliferating collaborations between academic institutions and technology companies engaged in activities such as the LinkedIn and Facebook studies mentioned above. Thus, we recommend that similar to the Belmont principles for ethical research, FTC efforts to protect consumers and their data be grounded in a set of foundational principles for responsible data stewardship.

PRIM&R shares the FTC's interest in protecting consumers' rights and believes that it is imperative for the public to have more control over their personal information, in the form of data that are generated as people go about their daily lives. We thank the FTC for this opportunity to share our perspective and hope our comments will be useful to the in its ongoing deliberations on this important issue. PRIM&R stands ready to provide any further assistance or input that might be of use. Please feel free to contact me at 617.303.1872 or ehurley@primr.org.

Sincerely,

Elisa A. Hurley, PhD
Executive Director

cc: PRIM&R Public Policy Committee, PRIM&R Board of Directors