September 25, 2020

Andy Crawford (acrawford@cdt.org)
Policy Counsel
Data and Privacy Project
Center for Democracy and Technology

Alice Leiter (alice@ehi.org)
Vice President and Senior Counsel
eHealth Initiative & Foundation

RE: NAI Comments CDT – eHI Draft Health Privacy Framework

Dear Ms. Leiter and Mr. Crawford,

The Network Advertising Initiative (NAI) appreciates the opportunity to comment on the draft Proposed Consumer Privacy Framework for Health Data ("Draft Health Framework"). The NAI welcomes thoughtful perspectives and an open dialogue about opportunities to better protect sensitive consumer data, including but not limited to consumer's health information. We share the Center for Democracy and Technology's (CDT) and the eHealth Initiative's (eHI) support for uniform national consumer privacy legislation that establishes strong and clear protections around the use of sensitive health data that are not covered by the Health Information Portability and Accountability Act (HIPAA) and applies these consistently across the entire marketplace.

About the NAI

The Network Advertising Initiative (NAI) is the leading self-regulatory organization dedicated to responsible data collection and use governing third parties engaged in Tailored Advertising and Ad Delivery and Reporting (ADR)[1] in the United States. The NAI, a non-profit self-regulatory organization and trade association, was formed in 2000 and has over 100 member companies, each of which is required to adhere to the strong digital advertising best practices set forth in the NAI Code of Conduct ("Code" or "NAI Code"), which the NAI enforces through annual compliance reviews, and which implements stringent consumer privacy protections. Our Code is rooted in the widely accepted Fair Information Practice Principles (FIPPs)[2], and it applies those principles to the digital advertising

[1] Tailored Advertising is defined by the NAI Code as the "use of previously collected data about an individual, browser, or device to tailor advertising across unaffiliated web domains or applications, or on devices, based on attributes, preferences, interests, or intent linked to or inferred about, that user, browser, or device." Ad Delivery and Reporting is "separate and distinct from Tailored Advertising, and it refers to the collection or use of data about a browser or device for the purpose of delivering ads or providing advertising-related services, including, but not limited to: providing a specific advertisement based on a particular type of browser, device, time of day, or real-time precise location; statistical reporting, traffic analysis, analytics, optimization of ad placement; ad performance, reach, and frequency metrics (including frequency capping); sequencing of advertising creatives; billing; and logging the number and type of ads served on a particular day to a particular website, application or device. ADR does not include data collection and use for security and fraud prevention." *See* Network Advertising Initiative, 2020 NAI Code of Conduct § I.A, I.Q (2020), https://www.networkadvertising.org/sites/default/files/nai_code2020.pdf [hereafter 2020 NAI Code of Conduct].

[2] *See* Fed. Trade Comm'n, Privacy Online: A Report to Congress 7 (1998), https://www.ftc.gov/sites/default/files/documents/reports/ privacy-online-report-congress/priv-23a.pdf; see also Fed. Trade Comm'n, Privacy Online: Fair Information Practices in the Electronic Marketplace (2000), https://www.ftc.gov/sites/default/files/documents/reports/privacy-online-fair-information-practices-electronic-marketplace-federal-trade-commission-report/privacy2000.pdf.

ecosystem by, among other things, instituting robust notice and choice requirements and restrictions on the use and sharing of data. The Code heightens restrictions and requirements for more sensitive data types, including sensitive health information.

The NAI has been the leading self-regulatory organization with respect to the use of sensitive health information, including our long imposed and enforced restrictions on the use of Sensitive Data for Tailored Advertising, with the understanding that while targeted ads help to fund a robust and diverse Internet and provide users with relevant ads, a user's engagement with certain limited types of content may not always be appropriate for Tailored Advertising. For example, research about potential cancer treatments while at home on a personal device may not be appropriate for Tailored Advertising. Additionally, the placement of web browsers or devices into audience segments labeled with sensitive conditions to be used for ad targeting could also negatively affect a user's privacy, especially if such segments were to be misused or accessed without authorization. This practice is prohibited by the NAI Code of Conduct without a consumer's Opt-In Consent.

Summary

In addition to our support for a national privacy law that establishes uniform protections around consumer health data, the NAI also supports many of the core objectives of the Draft Health Framework. First, we strongly support the goal to shift the burden away from consumers, recognizing that there are considerable limitations to the "notice and choice" model for consumers to protect themselves from harmful uses of their health-related data. Second, we strongly support the core focus of this framework to establish a self-regulatory model based on a self-certification program to provide accountability for member companies based on a common set of standards. This is consistent with the NAI Code and Compliance program, and it could provide substantial value applied specifically to the use of consumer health data beyond marketing and advertising purposes. Third, we agree with the goals to enhance notice and transparency regarding health-related information, both for better informing consumer choice and control, and to bolster regulatory enforcement. Fourth, we also applaud your recognition of the value that de-identified data can play in protecting consumer privacy by sufficiently minimizing the risk of harmful uses of consumer data.

However, we also have significant concerns regarding the broad scope of the Draft Health Framework beyond data that is directly health-related, as well as concerns about the use limitations. We offer the following recommendations for your consideration, with the goal of enhancing the effectiveness of a truly outcomes-based approach.

I. The proposed scope of the Draft Health Framework is overly broad, encompassing virtually all data.

The broad scope of Consumer Health Information (CHI) ultimately strays from the stated objective of creating a true "purpose and outcomes approach" to CHI. Specifically, Section 4(b) defining CHI is

intentionally broad, including eight data sets "*regardless* of the purpose or outcome of the collection, disclosure or use."

i. Data that reflects racial and ethnic origin;
ii. Genetic data;
iii. Biometric data;
iv. Data that reflects reproductive health;
v. Data that reflects sexual orientation;
vi. Data that reflects disability;
vii. Data that reflects sensitive disease conditions; and
viii. Data that reflects substance abuse.

As drafted, particularly the focus on any data that "reflects" these various elements, this definition appears to pertain not only to explicit data that falls within this set, but also to "inferences" that could be derived from these data. Additionally, the commentary in conjunction with this definition states that, "[m]odern data use is complex, opaque, and instantaneous. Trying to delineate distinct data sets as worthy of coverage and others as not no longer makes sense for the people whose information is implicated." The end result would be that all data be construed as CHI because when combined with other data it infers, and therefore all data would be subject to the consent requirements and prohibitions for secondary uses. At minimum, the NAI urges you to scope the definition of CHI to be more specific than "data that reflects" in order to help companies identify information that may be sensitive and information that may not be, particularly with respect to "inferences."

While we recognize that big data analytics have created an environment where various elements of non-sensitive data could be pieced together to derive conclusions, and to take actions, that could be considered sensitive or pose harm to consumers, defining CHI broadly—essentially covering nearly all data because of the possibility of inferences—undermines the objective of moving away from notice and choice. That is, it could have the effect of extending the consumer consent requirement for collection of virtually any data, even in instances where a company that does not collect truly sensitive information, does not share the data or derive harmful conclusions, or take actions that put consumers at risk. Ultimately, this definition runs counter to the prudent objective of taking an outcomes approach, and it renders the Draft Health Framework a catch-all for virtually all consumer data, including for instance all browsing data.

Instead, the NAI recommends that this definition be narrowed to apply to specific categories of data that are widely recognized as sensitive, and to provide a set of restrictions on the use of all other data to prevent it for being applied to a defined set of health-related conclusions or outcomes, such as the prohibition on eligibility uses proposed by the Draft Health Framework. For many of the categories listed under CHI, the NAI Code of Conduct has strict requirements. The NAI Code requires Opt-In Consent for the use of "Sensitive Information" for Tailored Advertising or Ad Delivery and Reporting. "Sensitive Information" and other information requiring Opt-In Consent include: information, including inferences, about sensitive health or medical conditions such as cancer, sexually transmitted diseases, mental health-related conditions; information, including inferences, about a user's sexual orientation; information about health or medical condition (including genetic, genomic, and family medical history) based on pharmaceutical prescriptions or medical records).[3]

[3] *See* 2020 NAI Code of Conduct § I.O.

Additionally, while the NAI Code is focused on the use of data for advertising and marketing, we extended its application years ago to apply to non-advertising uses, establishing clear prohibitions against eligibility uses of data collected for advertising purposes,[4] which is largely consistent with the prohibitions contained in the Draft Health Framework. We believe clear prohibitions of unreasonable practices is an effective approach that can provide strong protections around harmful uses of data, while enabling the use of a broader category of data types.

As we proposed in the legislative framework produced by the Privacy for America Coalition,[5] the NAI recommends reliance on opt-in consent for personal information relating to the physical or mental health of an individual that was inferred for a commercial purpose based on other personal information obtained from or about the individual, where such inference relates to a health condition that reasonable individuals would consider highly sensitive, such as depression, a sexually transmitted disease, or cancer.[6] The Privacy for America framework also gives individuals the right to request access to, or deletion of, the personal information that a company maintains about them, and to learn about the types of third parties with whom personal information has been shared.

Of course, to achieve a more effective outcomes-based result, the Coalition's framework is bolstered by a prohibition on *per se* unreasonable data practices, which would be buttressed by rulemaking authority for the FTC to further identify unreasonable practices, and to enforce on a case-by-case basis for novel practices. To ensure widespread compliance and rigorous enforcement, the Coalition's framework would significantly expand federal and state oversight of data practices, including by creating a new data protection bureau at the FTC, authorizing FTC rulemaking in certain key areas, and providing civil penalty authority to both the FTC and State Attorneys General.

Recognizing that the Draft Health Framework is intended as both a model for federal framework and the basis for a self-regulatory regime, the Draft Health Framework could draw from Privacy for America's proposal to create a system for making determinations about unreasonable data practices relating to CHI.

II. An effective outcomes-based health data framework should be tailored in a way that is focused on preventing harms while enabling beneficial uses of data, rather than substantially limiting valuable uses of data that could provide benefit.

As currently written the Draft Health Framework is "use-based," whereby it seeks to limit a wide range of practices considered to be to "secondary uses." This approach, while possibly effective in its goal to prevent harms to consumers, is unambitious with respect to the goals of maximizing data-driven innovation, and it is overly restrictive to a wide range of beneficial outcomes that could be provided without posing significant privacy risks to consumers.

Specifically, the section on Permissible Collection and Use Practices of CHI (p. 12) establishes a key limitation that the data may be "used to only what is necessary to provide the product or feature the consumer has requested." The commentary related to this section also recognizes that "[t]his section is

[4] *See* 2020 NAI Code of Conduct § II.D.2 (prohibiting the use of advertising data for credit eligibility, insurance eligibility and other non-marketing eligibility purposes).
[5] For more information, see https://www.privacyforamerica.com/overview/.
[6] Sec. 3H(b) regarding unreasonable uses of data
https://www.privacyforamerica.com/overview/principles-for-privacy-legislation-dec-2019/

intended to categorically prohibit secondary uses of health data that do not fall under one of the clearly defined exceptions of the framework."

This construct is overly limiting. It fails to recognize the value of data-driven advertising and marketing that supports a robust digital content ecosystem, and a range of other potential beneficial uses beyond the primary uses of the data. Any effective consumer privacy framework must seek to limit or prevent harmful data uses, incentivize and encourage beneficial uses, and to the best extent possible, differentiate between the two. Instead, the Draft Health Framework appears to reach the conclusion that certain "secondary" use practices simply pose too much risk to be allowable, despite a lack of substantial evidence of privacy harms in the marketplace today, even if those practices also are conducted under a notice and consent model where the additional uses are clearly described and consumers have the opportunity to opt-in. While we share your goal to move away from overuse of notice and consent, but it seems more practical to provide for that as an option for tailored advertising, rather than imposing a ban on these practices.

In contrast, an approach that is outcomes-based would allow for various practices, including tailored advertising, but provide a framework whereby consumer harms are mitigated. Indeed, many users are genuinely interested in products and treatments for their health or medical conditions and may also be interested in, and benefit from, receiving Tailored Advertising for such products or treatments. Accordingly, the NAI provides those users with an opportunity to opt in to such advertising, described in a clear and conspicuous notice, through an affirmative action that manifests this intent. Neither the Draft Health Framework, nor significant case studies, provide a compelling reason to adopt a new health data framework that takes a more restrictive approach than this.

Conclusion

In considering the development of a comprehensive health data framework, we encourage you to pursue one that is adaptable to changes in technology and evolving consumer expectations around privacy and data use. Ultimately, it is not a practical endeavor to develop a new framework that does not adequately recognize the subjective nature of health data. Ultimately it is difficult to adopt any such framework that does not sufficiently weigh the potential for consumer and societal benefit, against the potential for consumer harms.

In 2017, the FTC held a workshop and performed an assessment of "informational injuries," reflecting a range of key considerations and varying perspectives to better understand consumer injury and weigh those against the beneficial uses of data.[7] These findings warrant further consideration for this initiative. It could be beneficial for consumers and businesses for a new health data framework to establish a reasonableness test that assess the uses of information, in conjunction with the type of information and the consumer harms and benefits, as well as the expectations of a reasonable consumer. This construct could be similar to—but should be more clearly defined—than the GDPR's establishment of "legitimate interest," providing for processing of personal data where consumers would expect, and that would not be deemed unreasonable. Consumers, businesses and society as a whole would benefit from this approach.

[7] FTC Informational Injury Workshop: Bureau of Economics and Bureau of Consumer Protection Staff Perspective (October 2018). https://www.ftc.gov/reports/ftc-informational-injury-workshop-be-bcp-staff-perspective

Again, we appreciate the opportunity to comment on the Draft Health Framework, and we welcome the opportunity to discuss further any of the issues we have raised in these comments, or more broadly.

Sincerely,

David LeDuc
Vice President, Public Policy