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Navigating Ethical Research: A Study on Automatic Authorization in Informed Consent

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Abstract

In a survey conducted in the UK in June 2021, 61 per cent of participants admitted that they always accepted all cookies when they opened a website and it asked them to accept cookies (statista.com, 2023). Most users across the world show similar behaviour on the Internet. Does it mean most online users exercise autonomy when they consent to data tracking? If they don't, should mere authorization to allow tracking be the parameter to explain informed online consent? The Autonomous Authorisation (AA) model (Faden and Beauchamp, 1986) argues that the condition for informed consent includes 1. Understanding 2. Intentionality 3. Absence of control and 4 Authorization. In the online context, when users authorize apps and sites to track their personal data, do they understand what they are authorizing and how the data collectors may use their data? Andre et al. (2018) argues that while the AA model for online facilitates more accessible consumer choices and enhances well-being, the model's efficacy for online informed consent may undermine their sense of autonomy and could undermine the user's well-being. Weighing on the views of Andre et al. 2018, the proposed paper reviews the suitability of the AA model for online informed consent. It seeks to incorporate the ideas from other models of consent and behavioural theories to adapt the AA model to the online data collection context.

Keywords: Autonomous Authorization Model, Research Ethics, Informed Consent, Online Data Collection,

Introduction

In a survey conducted in the UK in June 2021, 61 per cent of participants admitted that they always accepted all cookies when they opened a website and it asked them to accept cookies (statista.com, 2023).[1] Most users across the world show similar behaviour on the Internet. Does it mean most online users exercise autonomy when they consent to data tracking? If they don't, should mere authorization to allow tracking to be the parameter to explain informed online consent?

1. https://www.statista.com/statistics/1273012/consent-cookies-worldwide/#:~:text=During%20a%20survey%20conducted%20in,United%20States%20(32%20percent).

Driven by the push for speed and scale, businesses often collect data at the expense of consumers' privacy concerns (Kelly and Rowland, 2000). Most Internet users have to relinquish their control over information when performing commercial transactions. Businesses argue they must be allowed to collect both non-identifying and personally-identifying information to meet consumer's needs and personalize their offerings (Stead and Gilbert, 2001). Privacy is considered an essential individual right, and by invading it without the participant's consent, we perform an intolerable act as per Rawl's Theory of Justice. All involved in collecting and storing data must understand that information gathering without consent is unethical, irrespective of any justification, like the universality of such practices, the argument about the utility of the data, or the justification that both consent seekers and participants hold equal power. Even though existing policies on consumer data collection may favour some groups, they threaten these groups and research in the long run.

Data sharing online involves a complex web of stakeholders, each with their concerns. Regulations and ethical guidelines continue to evolve to address these concerns and strike a balance between innovation and data protection. One of the beneficiaries of existing policies is Data intermediaries who rely on the buying and selling data as a revenue source. Changes in data privacy regulations or public sentiment can disrupt their business models. Users are increasingly concerned about their personal information, such as their name, address, financial details, and browsing habits, being shared without their consent.

Some activists are concerned about the implications of data sharing, especially when it involves vulnerable populations or sensitive issues. Activists may be concerned about data being used to suppress dissent or target marginalized communities. If these concerns keep increasing, marketers will have little or no access to quality and accurate data they receive for targeting their ads.

A more significant concern would be the unavailability of data for legitimate research purposes. For this ecosystem to flourish without depletion of further trust in online data collection, we must review the existing practices of online informed consent and improve it further to instil confidence in the stakeholders. We must also address the issue of consent fatigue caused by inappropriate presentation of details before consent is solicited. Consent fatigue also leads to consent desensitization as the subject feels powerless when provided with the option to provide or deny their consent (Obar, 2020).

The Dilemma of Online Consent Seeker and Provider

Unlike traditional consent seeking, the challenges of online consent seekers and providers are very different. Their dilemma remains a puzzle which researchers have tried to understand and reason with. The biggest puzzle for online informed consent seeking lies in the use of publicly available data like online reviews, social media posts, blogs, videos and other content that are available publicly but not necessarily available for research. Therefore, Auckland (2013) calls the guidelines for online trace data a moving target. The researchers are debating a few questions: 1. Can we use openly accessible data without seeking consent? 2. Is informed consent feasible for every online study? 3. How can we ensure authorization is not

forced but willingly provided? 4. How should researchers approach a situation causing distress to online communities?

Some researchers strongly oppose the practice of using openly accessible information for research without consent as they argue that when a user shares information with friends, peers, or followers, they have not consented to making their information available for analysis and publication (Eysenbach and Till, 2001, Wilson and Atkinson (2005)). This approach of collecting data without consent also creates a power imbalance between the seeker and provider (Heath et al. 1999, cited in Grinyer, 2007: 2).

On the other hand, the Scientific Affairs Advisory Group (SAAG) believes that online informed consent can be waived off if the research doesn't pose any threat or puts individual in any risk or compromises on their well-being when the research can't be carried out without such exceptions (Kraut et al., 2004). However, another agency, the Association of Internet Researchers (AoIR), differs from this view as they believe that sometimes it may not be apparent why principles of research on human subjects should be applied in research. Still, concerns may arise later (AoIR, 2012).[2]

Against this background information, we are looking into the existing models of informed consent and reviewing the suitability of the Autonomous authorization model for online informed consent.

Models of Informed Consent

An approach to informed consent studies has been to characterize the purpose of consent, for example, broad or blanket consent (ploug & Holm, 2015), presumed consent (Hofman, 2009), express consent (Win, 2005) and implied consent (Hofman, 2009).

The idea of soliciting broad or blanket consent comes from the limitation of collecting data for each separate research project dependent on the same set of data. The biological samples may sometimes be used for research unspecified during data collection.

Similarly, in the context of research, especially regarding healthcare, express consent indicates that a person agrees to participate in a study, get medical treatment, give personal information, or engage in any activity that requires explicit approval.

Sometimes, the consent giver may not be able to provide their consent being unconscious, but they may require preventive treatment. Healthcare professionals may proceed with life-saving treatment based on the notion of implied consent that the individual would approve of the treatment intended for saving their lives. Some businesses may use implied consent even when users land on their sites. They may believe that if an individual continues to use their website, they have provided implied consent to abide by the terms and conditions of the online business.

[2] http://ethics.aoir.org/index.php?title=Main_Page

The notion of presumed consent developed when healthcare professionals used organs from dead bodies. While some countries like the UK practised 'express consent' even in these situations, some others like Austria, Spain, and Belgium allowed for the use of organs from dead bodies unless the individuals had opted out of organ donation in their lifetime. In some countries, the consent of relatives may be sought in this condition, but in others, the relatives' views won't influence the decision. Countries allowing for presumed consent for organ donation have seen higher numbers of organ donation (Rodriquez-Arias, 2016).

While it was essential to understand the characteristics of consent, other studies on informed consent investigated the intrinsic nature of consent. The models that fall into this category are the disclosure model (Sim & Wright, 2000), the effectiveness consent model (Faden & Beauchamp, 1986), the AA model (Faden & Beauchamp, 1986) and the fair transaction model (Miller & Wertheimer, 2011).

The disclosure model identified five elements of consent: disclosure, comprehension, voluntariness, competence and agreement (Faden & Beauchamp, 1986). Here, disclosure is defined as the adequacy of the information shared with the participant. In this model, disclosure is defined as the comprehensiveness of information shared with the participants; another constituent comprehension relates to the participant's understanding of the details shared. The constituent competence in this model is concerned with the subject's ability to decide rationally. Absence of control is labelled as voluntariness, and the last constituent agreement can be explained as consent or decision.

Another prominent informed consent model – the effective consent model – is similar to the disclosure model in several ways. Additionally, this model offers insights into consent-seeking practices and how the behaviour of consent seekers can be governed to ensure a fair informed consent process (Faden & Beauchamp, 1986).

While the essence of the disclosure model has been retained even in the fair transaction model (Miller & Wertheimer, 2011), the constituents - disclosure, comprehension, competence, voluntariness and agreement - are proposed to be context-sensitive in this model. The model offers perspective on how consent seekers can provide information more adequately to the participants when there is a higher risk to the participants.

The autonomous authorization (AA) model, first introduced for medico-legal purposes, is being repurposed in a new domain of online subscription to goods and services, including data collection for marketing activities (Burkhardt et al., 2023). The idea of autonomy in the business context relates to protecting the right of consumers to make an informed decision. An informed decision implies that consumers are protected from coercion or manipulation. The AA model defines autonomy as a condition where the subjects have a substantial understanding, are not controlled, and have the freedom to exercise their intention.

The AA model describes substantial understanding as apprehension of all the material or important descriptions – but not all the relevant descriptions. The model explains that the importance of a description may largely be decided based on its requirement for authorization

decisions. As per Faden and Beauchamp (1986), the concept of non-control relates to the absence of external control on the decision. The third element of the AA model – intentionality – propounds an action according to a plan despite certain unwanted or undesirable Tolerated acts.

Even though the idea of the importance of autonomy has been discussed in various other studies, the notion of autonomy differed from study to study. Kant's idea of autonomy is that individuals should decide because of their reason and not due to external control, thereby being similar to the AA framework. The stakeholder theory, however, elaborates on autonomy from the agents' perspective. This paradigm recognizes the importance of agent autonomy but argues that the larger group's interests should prevail (Hasnas, 1998).

The idea of autonomy in Contractualism is contrary to Stakeholder theory, which advocates for the individual ability to abide by the terms of the agreement and have adequate freedom to stick to self-imposed constraints. Another crucial ethical framework in ethics study is Consequentialism. Even though this approach doesn't identify the idea of individual autonomy as it allows for aggression against an individual to aid others (Cummiskey, 1990), Mill (1859), whose ideas are rooted in consequentialist theory, viewed autonomy as an essential element for individual well-being.

Unlike the central ideas of individual or community orientation in Stakeholder or Contractual approaches, the AA model pertains to the presence of the critical ideas of providing autonomy by explaining the tolerated acts, too. For online informed consent seeking, it is desirable to review the procedure of consent seeking from the perspective of tolerated acts and the substantive knowledge shared with the participant.

Adoption of Autonomous Authorization Model for Online Informed Consent

Burkhardt et al. 2023 proposed that a conceptual model for online informed consent for personal data collection should be designed from the lens of Contractualism and not from stakeholder and consequentialism approaches. In online consent space, the intention to share personal information is situated in the 'tolerated space.' For example, sharing personal information in exchange for access to online goods and services is an example of tolerated acts from the AA model. Should the act of sharing personal information, in the circumstances where we are sharing this information in return for access to the goods/services, be considered an act of unwillingness?

The AA model questions the imbalance in the power of the consent requester vs the consent-provider. If we view tolerated acts as binary, we will consider all such tolerated acts as instances of unwilling consent, but if we see tolerated acts as the degree of tolerance, we can choose to consider some consents acceptable and some others as nullified. Adopting the AA model for online personal information collection will require providing subjective and objective information to the subjects. Although this is operationally challenging, sharing information of an individual's interest will uphold the ideas of the AA model.

Measures to Increase Trust in the Consent Seeker

Online informed consent requires more stringent norms to win participants' trust. By disclosing information about the background of the information seeker, we can build trust and get consent without manipulating or coercing the participants into sharing their details. For example, if the consent seeker provides their mission statement and information about their values and character, they can establish trust and succeed more with informed data collection. However, there is a fear of manipulation by shell companies as they violate user trust. This challenge can be addressed by a third-party certification regarding honesty in disclosure.

For example, McAfe.com has earned a TRUSTe (an initiative for fair information practices) trust mark by disclosing the following information about data collection practices:

1. What type of data does the company collect?
2. How is this data used?
3. Who will have access to this data?
4. The opt-out policy
5. The company allows for correcting and updating personally identifiable information.
6. The company's policy for children who visit its site.
7. The company's policy on deleting or deactivating a party's name from its database.

Even though disclosing such information increases trust in the consent seeker, the credibility of the third party is equally desirable for trust building. The third party must also declare how frequently they audit these businesses' data collection practices to improve the consent seeker's trustworthiness. In addition, an online consent seeker should conspicuously provide their phone number to convey that information is being shared with an individual, not just a business/ research organization. Sharing a number also conveys to the participant that the consent seeker is accountable for any data collection or usage wrongdoing.

In addition, marketers should refer to the USA Federal Policy for the Protection of Human Subjects, published in 2017, which clarifies how information should be solicited. The regulation suggests that a consent document should have a 'concise and focused' presentation of crucial information at the outset.

A 'concise and focused' opening statement shall help subjects understand the objective of data collection and help them decide why they should or shouldn't participate in it.
The USA Federal guidelines on consent seeking, 2017, require sharing the following eight pieces of information before seeking consent, unlike the previous guideline that advocated seeking consent before collecting personal data.

The eight items of USA Federal guidelines include:

1. an explanation of the purposes of the research, its duration, and procedures involved, and identification of any experimental procedures;
2. a description of the reasonably foreseeable risks
3. a description of any potential benefits
4. a disclosure of appropriate alternative procedures or courses of treatment as relevant
5. information about the confidentiality of records, compensation, and treatments if injury occurs

6. for research involving more than minimal risk, an explanation as to whether any compensation or medical treatments are available if injury occurs;
7. contact information;
8. a statement that participation is voluntary and that refusal to participate or decision to withdraw will involve no penalty or loss of benefits to which the subject is otherwise entitled.

These requirements may seem to create difficulty in seeking personal data and may seem discouraging for marketers. Still, implementing these trust-building measures will lend more credibility and ease of consent seeking. When such information is not provided to participants, they either overestimate the negative consequences of participation or the benefits received by the consent seeker. Either of these conditions may inflate biases against the information seeker. Conversely, online practices perceived as fair may encourage higher participation in online information consent submission.

A sense of autonomy is vital to participants in a commercial context as it is related to their well-being arising from the perception of being in control of their behaviours or choices (Andre et al., 2018). To provide a sense of control, the participants should be apprised of any waiver from the normative condition by offering disclosure of important information concisely, unlike the prevailing practice of full disclosure inundating participants with unimportant or inappropriate information. Industrial and academic researchers must remember that there are people behind the online interface, and the researchers must treat their users with care and respect, irrespective of their diverse backgrounds.

Future Directions for Online Informed Consent Studies

The present review of the status of online informed consent studies reinforced the idea that any academic or industrial research must protect individuals from any risk or harm, even if the traditional ethical guidelines are not applied to online informed consent procedures. Future studies should look into various contexts of personal data collection requiring consent. The AA model suggests looking at the online consent process through toleration as against the traditional willingness approach. Also, studies need to be further conducted to explore ways substantive understanding can be attained by operationalizing informed attitudes based on information material to the participant.

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References

1. Ackland R (2013) *Web Social Science: Concepts, Data and Tools for Social Scientists in the Digital Age*. London: SAGE.
2. André, Q., Carmon, Z., Wertenbroch, K., Crum, A., Frank, D., Goldstein, W., Huber, J., Van Boven, L., Weber, B., & Yang, H. (2018). Consumer choice and autonomy in the age of artificial intelligence and big data. *Customer Needs and Solutions*, 5(1), 28–37.
3. Burkhardt, G., Boy, F., Doneddu, D., & Hajli, N. (2023). Privacy behaviour: A model for online informed consent. *Journal of business ethics*, 186(1), 237-255.
4. Cummiskey, D. (1990). Kantian Consequentialism. Ethics, 100(3), 586–615.

5. Eysenbach G, Till J (2001) Ethical issues in qualitative research on internet communities. *British Medical Journal* 323(7321): 1103–1105.
6. Faden, R. R., & Beauchamp, T. L. (1986). A history and theory of informed consent. Oxford University Press.
7. Grinyer A (2007) The ethics of Internet usage in health and personal narratives research. *Social Research Update* 49: 1–4.
8. Hasnas, J. (1998). The normative theories of business ethics: A guide for the perplexed. Business Ethics Quarterly, 8 (1), 19–42.
9. Hodge, J. G., & Gostin, L. O. (2017). Revamping the US Federal Common Rule: Modernizing human participant research regulations. JAMA, 317(15), 1521-1522.
10. Kelly, E. P. and H. C. Rowland: 2000, _Ethical and Online Privacy Issues in Electronic Commerce, Business Horizons 43(3), 3–12.
11. Kraut R, Olson J, Banaji M, Bruckman A, Cohen J, Couper M (2004) Psychological research online: Report of Board of Scientific Affairs' Advisory Group on the Conduct of Research on the Internet. *American Psychologist* 59(2): 105–117.
12. Mill, J. S. (1859). On liberty. Broadview Press.
13. Miller, F. G., & Wertheimer, A. (2011). The fair transaction model of informed consent: An alternative to autonomous authorization. *Kennedy Institute of Ethics Journal*, 21(3), 201–218.
14. Obar, J. A. (2020). Sunlight alone is not a disinfectant: Consent and the futility of opening big data black boxes (without assistance). Big Data & Society, 7(1), 2053951720935615.
15. Ploug, T., & Holm, S. (2012). Informed consent and routinization. *Journal of Medical Ethics*, 39(4), 214–218.
16. Rodrıguez-Arias, D., & Morgan, M. (2016). "Nudging" deceased donation through an opt-out system: a libertarian approach or manipulation? *The American Journal of Bioethics*, 16(11), 25-28.
17. Sim, J., & Wright, C. (2000). Research in health care: Concepts, designs and methods. Nelson Thornes.
18. Stead, B. A. and J. Gilbert: 2001, Ethical Issues in Electronic Commerce, *Journal of Business Ethics* 34(2), 75–85.
19. Wilson B, Atkinson M (2005) Rave and straightedge, the virtual and the real: Exploring online and offline experiences in Canadian youth subcultures. *Youth & Society* 36(3): 27–311.
20. Win, K. T. (2005). A review of security of electronic health records. Health Information Management, 34(1), 13–18.

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