Sex, Lies, and Data: New Models of Informed Consent

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This paper identifies gaps within the current research ethics regime that can be complemented by intersectional feminism, queer theory, sexual education, BDSM, and critical theory. When these disciplines are applied, informed consent models can better integrate revocability, ongoing consent, and contextual consent. Future work on informed consent and research ethics should incorporate these areas to preserve the dignity of research subjects and equitably benefit all members of the research process.

## Introduction

In the summer of 2015, a company called Ashley Madison was hacked and over seven million users’ data was leaked (Lord, 2017). Data breaches like this are unfortunately common, but as Ashley Madison was specifically created to facilitate infidelity, the social fallout of the breach was more harmful than most. After the breach and subsequent fall-out, which included many individuals being publicly named and shamed after their information was found in the customer records, many users of the site ended up getting divorced, some lost their jobs, and there were multiple confirmed reports of self-harm (Baraniuk, 2015).

Several researchers saw the data breach as an opportunity to advance their research. They used the leaked data to explore different questions about user demographics, geography, and risk-taking behavior and published the results in multiple peer-reviewed articles (Billau, 2017; Vedantam, 2016). However, in order to be published, these studies first had to be approved by their university’s Institutional Review Board (IRB).

IRBs are intended to reduce the potential risks and harms in research proposals that involve human subjects (or data thereof) and are often perceived as a marker of credibility for ethical research. All IRBs use something called the Common Rule, which is a set of federal guidelines that dictate how to conduct ethical research, and there is a stipulation in it that says if data is already public, then there is little potential for risk or harm for it to be used in research. It makes no stipulations about how that data became public. In fact, IRBs have no remit to review secondary uses of data, with bio-specimen data as the sole exception. To an IRB, public data is considered low risk regardless of how that data was obtained, and regardless of how sensitive the data is, and evaluating its use is not within their scope of review. Researchers got their studies approved by their IRBs, and academics continue to use and cite Ashley Madison data in publications. As a result, many more people see the leaked data and names of the implicated humans than would have had those papers never been published.

## Nonconsensual Porn and Nonconsensual Data

There are parallels between the use of leaked data sets like the Ashley Madison hack, and the viewing of nonconsensual pornography (NCP). For the unfamiliar, NCP is "the distribution of sexually graphic images or videos of an individual without their consent in the context of an intimate relationship,” (Carter, 2021). Perpetrators of NCP sometimes upload photos or videos of their victims onto pornography websites, which allow many more people to view them. Like most platforms, these websites often use engagement metrics, like view counts, which help determine if a video is “popular”, with more popular media receiving more promotion. From a victim’s perspective, the more people who see their image or video, the worse the mental and/or emotional harm. While the original perpetrator inflicted a significant harm, that harm gets compounded every time it gets viewed or shared by other people, and by viewing it, it raises the likelihood that someone else will view it.

When researchers use data that was collected nonconsensually, unethically, or illegally, it has the potential to amplify the harm of the original data collector by pointing other people to it. Using unethical data for research is not the moral equivalent of the original hack, but there are many circumstances where it may still be considered morally wrong. The fact that the Common Rule and IRBs don’t have the mechanisms necessary to address this issue means that we need more tools to fully judge the needs and bounds of ethical research (Jordan, 2022). Fortunately, there are many disciplines and scholars that have developed theoretical tools and practices we can use to improve the ethical conduct of research. I offer several areas that have been personally productive, though there are many others that can be used.

## Intersectional Feminism, Queer Theory, Sex Education, and Critical Theory

The first area that has been helpful for developing a fuller understanding of consent is intersectional feminism. Feminism is an interdisciplinary approach to addressing oppression related to gender identity and expression. Intersectionality is a theory that when someone has more than one marginalized identity (e.g., being a Black woman), the combination of those identities produces a greater risk than the sum of their parts (Crenshaw, 2006). Intersectional feminism interrogates oppression on multiple fronts including gender, race, class, disability, and others, especially how these oppressions interact with each other. These theories have much to say about what informed consent should look like, especially when it comes to bodily autonomy and agency. An intersectional feminist approach to informed consent will ensure that participants have control over their participation in a research study, individual control over their personal data, and communal control over communal data (Sterling, 2011; Fiesler, McCann, Frye & Brubaker, 2018). Informed consent can sometimes be framed as a liability waiver for institutions. Intersectional feminism would reframe informed consent as an expression of care for the wellbeing of the person which may supersede the research goals of the researchers or the legal liability of the university.

A second helpful area is queer theory. Queer theorists critique dominant social expectations of sexual orientation and gender identity (Cohen, 1997). Informed consent can sometimes mirror hetero-patriarchal models of power by framing consent as something only certain people are qualified to give (cis, heterosexual men), while others (LGBTQ people) are disqualified, for example, the FDA’s ban on gay and bisexual men donating blood (Human Rights Campaign, 2020). Integrating queer theory and listening to the LGBTQ community can aid in analyzing how certain processes can unintentionally reify discriminatory ways of thinking, and they can help us move toward more inclusive ways of achieving informed consent (Edenfield, 2019; de Heer, Brown & Cheney, 2021).

A third area is sexual education and the BDSM community. Inclusive and evidence-based sex educators have developed models of affirmative and enthusiastic consent that are sensitive to context (Center for Sex Education, 2016). Bondage/Discipline, Dominance/Submission, Sadism, and Masochism (BDSM) are consensual sexual acts that involve a power dynamic between partners. This kind of sex has a higher potential for risk because there are elements of pain or power involved and the BDSM community has developed many practices around consent and communication to mitigate those risks such as safe words (Dunkely & Brotto, 2020). These practices include experiences ranging from in-person to remote relationships, sometimes involving people’s bodies while other times involving domination over personal documents or computers (Vogt & Goldman, 2018). Sex education and BDSM have richer, more nuanced theories and consent practices than most researchers at universities.

A fourth area is critical theory, in particular its analysis of power and push for social change. Critical theory takes many forms and is often integrated into existing disciplines as a way to challenge structural assumptions and redistribute resources and opportunities within them, such as critical legal studies, critical pedagogy, and others. A critical approach to consent would be attuned to who has power within an informed consent transaction, who doesn’t, and attempt to redress the asymmetrical dynamic. Applying a critical theory approach to informed consent can produce some unanticipated results. For example, the Panama Papers were a set of leaked documents exposing offshore financial transactions including criminal tax evasion, money laundering, and other financial crimes around the world (Fitzgibbon & Hudson, 2021). This was likely a situation where the material was obtained unlawfully and without the consent of the people whose information was publicized. Hundreds of papers and many books have been written that detail the Panama Papers and the individuals named in them. A traditional approach to informed consent would say that the Panama Papers leak was a wrongful violation of privacy. A critical consent approach would disregard claims of privacy by the victims because of the nature of the information leaked, namely a highly organized global financial system used by the rich and powerful to hide assets at the expense of the poor and powerless. Informed consent with a critical theory lens inverts traditional power dynamics, meaning that some rules about research ethics should be broken when following them would cause inequitable outcomes.

## New Models of Consent

When you look across the areas of intersectional feminism, queer theory, the LGBTQ community, sex educators, the BDSM community, and critical theory, there are commonalities that can be pulled out to help develop a better framework of consent in research. Using these as reference points, informed consent must be at least three things: revocable, ongoing, and contextual.

Revocability means that after you give your consent to something, you can change your mind at any time and for any reason. Current research practice does this somewhat. Most consent forms state that research participants can stop their participation at any time, but there are many informal and implicit forces that discourage this. Participants may feel that by changing their minds they would inconvenience or disappoint the researchers, who are in a position of authority. Some participants may be persuaded by the sunk cost fallacy that if they’ve done something long enough, they might as well finish it even if they would prefer not to. In general, research participant consent is revocable only during the data collection phase. Once that data is used to publish something, there is almost nothing that a participant can do to remove their data from the study.

Ongoing consent means that the ‘one and done’ model of most research is inadequate. In practice, it means frequent points of intentional communication gauging the interest of the participants in continuing in the research study. This does not have to devolve into performative check-ins that likely produce consent fatigue (Ranisch, 2021). The modes of ongoing consent should adapt to the environment and be naturally integrated into the requirements of the participant experience, so that providing or revoking consent is both easy and perceived as casual. In practice, this can look like introducing several points in a study where participants have to opt-in to continuing, with the expectation that if they don’t, they automatically discontinue participation. Sometimes called contextual consent or just-in-time consent, this makes leaving a study mid-way through seem less interruptive or socially uncomfortable (IF, 2022).

Contextual consent means that there isn’t a template or formula for getting consent that can be applied across all research studies. When people consent to having sex, it is for specific people, places, and times. Giving consent to have sex once does not mean that you consent to sex with that person at any time and place in the future. Contextual consent adapts to the specific conditions it is being offered in and adjusts how it is communicated. In practice, this could look like developing unique consent methods for different populations that are attentive to the cultural and rhetorical differences, even if the research protocol is otherwise the same. For some populations, the standard written forms of consent using academic language may be adequate. For other populations, offering techniques using visual, auditory, narrative, behavioral, or game-based methods might be better suited to get meaningful consent

Integrating these informed consent practices into human subject research will significantly improve the experience of participants as well as reduce the potential for unethical data collection and sharing. Academia has many justifications to ignore informed consent. Most times consent is neglected, the subsequent risks are distributed unequally among participants. The people who are put at the most risk are usually the people who are already the most vulnerable: women, children, people who are LGBTQ, non-binary, disabled, poor, people of color, and many others. Researchers have a responsibility to conduct research ethically and with respect for individual privacy needs and expectations. Using these consent practices by integrating intersectional feminism, queer theory, the LGBTQ community, sex education, BDSM, and critical theory can increase the quality of research and respect the dignity of the participants.

An admittedly difficult area for applying these frameworks is when the circumstances of data collection and informed consent are more quotidian. The examples used above are dramatic when compared with most of the common research practices such as collecting public social media data from places like Facebook, Reddit, or Twitter. When the consent obtained is ambiguous, when the data being collected isn’t particularly sensitive, or when the potential for significant social benefit is high, applying these theoretical tools isn’t straightforward. Reasonable people can, and often do, disagree as to what ethical values are at stake and how to adjudicate them. The unfortunate ethical gray area this produces is still better than having clear but inequitable guidelines.

## Final Thoughts

It is highly unlikely that any rules developed to address the growing complexities of research ethics, especially in technology spaces, will be able to address every possible ethical dilemma that arises. The four areas offered above are tools that can help with some of the gaps currently found in research ethics, but they need to be constantly reexamined and supplemented as new issues present themselves. Ethical research is a horizon, not a place; we never arrive. By prioritizing the wellbeing of the most vulnerable and marginalized people in our communities and continually inventing better models of informed consent, we can take more confident steps towards that horizon.

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