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THE ‘THORNINESS’ OF SOCIAL MEDIA RESEARCH: IDENTIFYING INTERNET RESEARCH ETHICS (IRE) CHALLENGES AND AMBIGUITIES IN THE CANADIAN CONTEXT

Abstract

In this paper, we take stock of research being conducted and published in Canada in the past five years that engages with social media data to identify emerging and ongoing ethical challenges and ambiguities. Through examples drawn from the contemporary research landscape, we demonstrate that the ‘thorniness’ of social media research ethics stems from three main issues: 1) the evolution of existing platform and emergence of new platforms, introducing affordances that encourage personal disclosure in pervasive datafied environments; 2) new methods and tools that prioritize data *access* over research *ethics*; and 3) new topics of study that engage with sensitive data about vulnerable groups online. We argue that the rise of pervasive datafication and platform affordances that encourage spontaneous, vulnerable content production creates increased risks to human subjects, and that research ethics guidelines and practices must evolve to address these new and increased risks. Our goal is to provide direction for future work on social media research ethics that will empower researchers to navigate the complex terrain of thorny ethics. This work builds on debates about Internet research ethics best practices, and suggests that in addition to case-by-case approaches to research ethics, there should be increased attention paid to the unstable nature of social media and power of big data research. We suggest that research ethics should adopt a human-centered approach that privileges an individual’s desire to limit, control, examine, or engage with the data they have produced online, and that we must develop practices and methods that allow researchers to engage with these desires in the research process. Our analysis responds to work that surfaces public opinion regarding social media research and trustworthiness – work that argues that the standards by which REB/IRBs delineate public vs. private data are insufficient given the evolving contexts within which people are producing data and participating online. Maintaining privacy, anonymity and consent requires increased attention to the changing and unstable platform landscape in which researchers are conducting their studies.

Keywords

Internet research ethics; datafication; research ethics boards; social media; platform studies.

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1. INTRODUCTION

Over the past two decades, online social media posts, including tweets, online discussion group interactions, Facebook updates, and listerv archives, have provided a rich source of “naturally occurring, everyday talk”¹ – precisely the kind of data that, according to Potter and Wetherell², offer deep insight into social phenomena. Despite some concerns about the quality of these data³, the advantages of social media data for research purposes are widely recognized⁴, and many researchers apply qualitative and quantitative analytic techniques to harvest social media data to explore attitudes and reported practices that relate to deeply sensitive and highly personal issues.

There can be no doubt that these data can support tremendous insight on these issues, particularly since our increasingly pervasive datafied environments encourage individuals to reveal personal and sensitive information about themselves or others, often in ostensibly ‘public’ social media environments. The harvesting of these data for research purposes, however, raises complex ethical questions⁵ relating to privacy, consent, and protection against unintended harms. These challenges are only exacerbated by the complexity and diversity of the online social spaces where researchers conduct their work⁶

This paper examines the ethical implications of changes in social media and Internet-based research within the Canadian context over the past five years. By presenting examples from recent research, we illustrate that the challenges of social media research ethics can be attributed to three key factors: 1) the evolution of existing platforms and the emergence of new platforms, which encourage personal disclosure in data-rich environments; 2) the adoption of new methods and tools that prioritize data access over research ethics; and 3) the exploration of sensitive data concerning vulnerable online groups. We contend that the pervasive datafication trend and platform features promoting spontaneous and vulnerable content creation pose heightened risks to human subjects. Consequently, research ethics guidelines and practices need to adapt to effectively address these new and amplified risks. Our aim is to provide guidance for future social media research, empowering researchers to navigate constantly evolving and ‘thorny’ ethical landscapes.

¹ J. Sixsmith, C.D. Murray, “Ethical Issues in the Documentary Analysis of E-Mail Posts and Archives”, *Qualitative Health Research*, 11, 3 (2001): 423-432 (424).

² J. Potter, M. Wetherell, “Natural Order: Why Social Psychologists Should Study (a Constructed Version of) Natural Language, and Why They Have Not Done So”, *Journal of Language and Social Psychology*, 14, 1-2 (1995): 216-222.

³ See e.g. D. Ruths, J. Pfeffer, “Social Media for Large Studies of Behavior”, *Science*, 346, 6213 (2014): 1063-1064. <http://www.sciencemag.org/content/346/6213/1063.short>; H. Smith *et al.*, “Can Online Discussion Sites Generate Quality Data for Research Purposes?”, *Frontiers in Public Health*, 5 (2017). <https://doi.org/10.3389/fpubh.2017.00156>.

⁴ M. Kosinski, S.C. Matz *et al.*, “Facebook as a Research Tool for the Social Sciences: Opportunities, Challenges, Ethical Considerations, and Practical Guidelines”, *The American Psychologist*, 70, 6 (2015), American Psychological Association (APA), September 2015, 543-556. <https://doi.org/10.1037/a0039210>.

⁵ L. Dencik, A. Hintz, J. Redden, J.E. Treré, *Data justice*, London: SAGE, 2022.

⁶ J.G. Warrell, M. Jacobsen, “Internet Research Ethics and the Policy Gap for Ethical Practice in Online Research Settings”, *Canadian Journal of Higher Education*, 44, 1 (2014): 22-37. <https://doi.org/10.47678/cjhe.v44i1.2594>.

2. BACKGROUND

Many of the ethical issues facing social media and Internet research are not new. Researchers and those focused on the ethics of human subjects' research have long recognized that online research surfaces historical issues under new guises. Negotiating these challenges requires a situated understanding of both the familiar complexity of research ethics and the unfamiliar territory of online interaction, potentially requiring new ethical approaches⁷. Ethical review of research is typically governed by national research ethics guidelines⁸. There are also many organizations and associations that have developed ethics guidelines to advise their members, or those conducting research under their auspices, on research ethics considerations⁹, and ethics guidelines produced by the British¹⁰ and American¹¹ Sociological Associations).

The original versions of many guidelines pre-date online research, and thus provide no specific discussion or recommendations relevant to online data collection and subject recruitment. Under many of these guidelines, and as interpreted by many researchers and REBs, harvesting of online social media data is a form of observational research that, if carried out in a 'public' venue, can be as a result exempt from ethical review. The discussions of and definitions of observational research are, however, rooted in real-world observation and real-world definitions of what constitutes a 'public' place, and as a result may not be appropriate for consideration of the public/private nature of online spaces¹².

As research ethics guidelines are updated, they are often revised to address expressly the ethical concerns and issues that arise in research in the online context¹³. One set of ethics guidelines that was, by contrast, 'born digital' is that developed by the Association of Internet Researchers in 2002, updated in 2012, and again in 2020¹⁴. These

⁷ See e.g. D. Elgesem, "What Is Special about the Ethical Issues in Online Research?", *Ethics and Information Technology*, 4 (2002): 195-203. 10.1023/A:1021320510186; G. Eysenbach, J.E. Till, "Ethical Issues in Qualitative Research on Internet Communities", *BMJ*, 323, 7321 (2001): 1103-1105. DOI:10.1136/bmj.323.7321.1103; S. Flicker, D. Haans, H. Skinner, "Ethical Dilemmas in Research on Internet Communities. Qualitative Health Research", 14, 1 (2004): 124-134. <https://doi.org/10.1177/1049732303259842>; F. Neuhaus, T. Webmoor, "Agile Ethics for Massified Research and Visualization", *Information, Communication and Society*, 15, 1 (2012): 43-65, <https://doi.org/10.1080/1369118x.2011.616519>; E.S. Swirsky *et al.*, "Using Social Media in Research: New Ethics for a New Meme?", *The American Journal of Bioethics: AJOB*, 14, 10 (2014): 60-61. <https://doi.org/10.1080/15265161.2014.948302>; J. Taylor, C. Pagliari, "Mining Social Media Data: How Are Research Sponsors and Researchers Addressing the Ethical Challenges?", *Research Ethics*, 14, 2 (2018): 1-39. <https://doi.org/10.1177/1747016117738559>.

⁸ E.g. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, "Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans", December 2022. Accessed by: <https://ethics.gc.ca/eng/documents/tcps2-2022-en.pdf>; the Norwegian National Research Ethics Committee "Guidelines for Research Ethics in the Social Sciences, Humanities, Law and Theology", 2016.

⁹ e.g., World Health Organization, "Standards and Operational Guidance for Ethics Review of Health-Related Research with Human Participants", 2011.

¹⁰ 2003.

¹¹ 1999.

¹² J. Pater *et al.*, "No Humans Here", *Proceedings of the ACM on Human-Computer Interaction*, 6 (2022): 1-13, <https://doi.org/10.1145/3492857>; C. Fiesler *et al.*, "Engaging the Ethics of 'Public' Data in Social Media Research", Presented at International Conference on Web and Social Media (ICWSM), Virtual, 2021.

¹³ E.g., the Ethics of Conducting Qualitative Research in Social Virtual Worlds; E. McElhinney *et al.*, "Undertaking Qualitative Health Research in Social Virtual Worlds", *Journal of Advanced Nursing*, 70, 6 (2014): 1267-1275. <https://doi.org/10.1111/jan.12281>.

¹⁴ See the Introduction of the special issue.

guidelines provide a particularly cogent and thorough discussion of “ethical decision making and Internet research”¹⁵, offering insight not only into the trajectory of this field, but also into different aspects of Internet-based research. There are other collections on Internet research ethics¹⁶ that provide case studies, keywords, methodological interventions as well as discussions on new and emerging ethical issues that researchers face related to negotiating privacy, anonymity, consent and harms in digital contexts.

3. CANADIAN CONTEXT

In Canada, university-based research is subject to the ethical considerations and principles outlined in the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*¹⁷. That document provides guidelines that focus on respect for persons, concern for welfare, and justice. As of 2022, the TCPS-2 does not include a dedicated section on Internet research ethics, despite a growing community of scholars dedicated to identifying best practices¹⁸. Some guidance is provided by a section in the TCPS-2 that deals with “cyber-material,” including “documents, images, audio or video recordings, records, performances or online archival materials available in digital form on the Internet”¹⁹. The section states that “REB review is not required for cyber-material... [or] where research uses exclusively information in the public domain that may contain identifiable information, and for which there is no reasonable expectation of privacy”²⁰.

Under the TCPS-2, social media research at Canadian universities may be considered exempt from institutional review if: 1) there are no human participants in the study (by TCPS-2, Article 2.1); 2) the online discussion is public; and 3) efforts made to de-identify or anonymize the users included in the study²¹. Additionally, where platform terms and conditions include the provision that public data could be viewed and used by third parties – a group which implicitly or explicitly included researchers – there is in some cases assumed to be implicit prior consent for data collection and use.

In some cases, Research Ethics Boards (REB) at Canadian Institutions, similar to Institutional Review Boards (IRB) in the US, limit the definition of ‘human participants’ so as to only require review when direct contact is made with individuals, or when data pertains to specific and identifiable individuals (e.g., the review of medical records). This strict inclusion criterion for ethical review does not take into account the many

¹⁵ C.M. Ess and the AoIR Ethics Working Committee, *Ethical Decision-Making and Internet Research: Recommendations from the AoIR Ethics Working Committee*, 2002; A. Markham, E. Buchanan, *Ethical Decision-Making and Internet Research: Recommendations from the AoIR Ethics Working Committee (Version 2.0)*, 1-18. 2012. Accessed July 13, 2023. <https://aoir.org/reports/ethics2.pdf>; a.s. franzke et al., *Internet Research: Ethical Guidelines 3.0*, 2020, 1-82. Accessed July 13, 2023. <https://aoir.org/reports/ethics3.pdf>.

¹⁶ E.g., M. Zimmer, K. Kinder-Kurlanda, *Internet Research Ethics for the Social Age*, New York: Peter Lang Publishing, 2017; L.L. Christensen, M.C. Larsen, *Ethical Challenges in Digital Research: A Guide to Discuss Ethical Issues in Digital Research*, 2. ed., 2020.

¹⁷ Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, “TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans”, December 2022.

¹⁸ Zimmer, Kinder-Kurlanda, *Internet Research Ethics for the Social Age*.

¹⁹ Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, “TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans”, 266.

²⁰ *Ibid.*, 17.

²¹ *Ibid.*, 13.

ways in which issues such as privacy, anonymity and consent are complicated through research with social media data.

Interpretations of the TCPS-2 are made at the local level, and universities across Canada vary in their position as it relates to the research use of social media data. For example, material on Internet Research Ethics developed by the University of Alberta emphasizes the importance of ‘participant’ expectations in determining whether research use of data should be allowed: “Researchers should bear in mind that Internet users do not expect to be research subjects. Individuals participating in online discussion groups cannot be assumed to perceive their information will be used for research purposes”²². Other universities across the country have similarly prepared documents for researchers that outline requirements and guidelines for best practices. Even where research may be exempt from review based on the TCPS-2 guidelines, there are additional steps some universities take to engage in questions of social media research ethics²³.

4. EMERGING THORNY ETHICS ISSUES

4.1. *Evolution of platforms*

There are changes that have occurred within the social media platform ecosystem that bring forth new ethical challenges that researchers and ethics boards must grapple with. The earliest online social media environments were chat rooms or discussion groups where users interacted in text-based conversations. Currently, the dominant social media platforms fall under what many researchers refer to as GAFAM (Google, Amazon, Facebook, Apple, Microsoft). Over time, online sharing has grown to include many different forms of media (e.g., video, audio) as well as platform interactions (e.g., ‘likes’), raising new ethical issues. Moreover, changing platform ownership and governance policies affect the types of user data production and the potential scope and scale of research projects. Additionally, new social media platforms continue to emerge that can present new ethical concerns around differing expectations of use of platforms.

TikTok has also become a dominant platform for the examination of user behaviour and social media commentary. In two Canadian studies²⁴ researchers used data from TikTok created by young people to understand eating disorder recovery and techniques used to garner support for sexual minority youth. The data provided valuable insight into these issues, and while the users may be familiar with the types of academic studies on older platforms like Facebook²⁵, there is less awareness of how newer social media data, like TikTok, may be used.

²² “Internet Research”, 2023.

²³ Y. Seko, S.P. Lewis, “We Tend to Err on the Side of Caution. Ethical Challenges Facing Canadian Research Ethics Boards When Overseeing Internet Research”, in *Internet Research Ethics for the Social Age*, edited by M. Zimmer and K. Kinder-Kurlanda, New York: Peter Lang Publishing, 2017, 133-147; Franzke et al., *Internet Research: Ethical Guidelines 3.0*.

²⁴ S.S.C. Herrick, L. Hallward, L.R. Duncan, “‘This Is Just How I Cope’: An Inductive Thematic Analysis of Eating Disorder Recovery Content Created and Shared on TikTok Using #EDrecovery”, *The International Journal of Eating Disorders*, 54, 4 (2021), 516-526. <https://doi.org/10.1002/eat.23463>; A. Hiebert, K. Kortess-Miller, “Finding Home in Online Community: Exploring TikTok as a Support for Gender and Sexual Minority Youth throughout COVID-19”, *Journal of LGBT Youth*, 2021: 1-18. <https://doi.org/10.1080/19361653.2021.2009953>.

²⁵ S. Gilbert, J. Vitak, K. Shilton, “Measuring Americans’ Comfort with Research Uses of Their Social Media Data”, *Social Media Society*, 2021. <https://doi.org/10.1177/20563051211033824>.

Information posted on TikTok that can be captured as research data, for example, includes bundled video content (which can include text and images), video captions and hashtags, comments, likes, saves and shares, as well as usernames. The social norms and affordances of TikTok encourage the sharing of personal and private information through platform support for spontaneous capture of information, a social norm of emotional and physical vulnerability, and the practice of responding to and participating in trends, particularly through the use of sounds. Social media posts that include video and audio, particularly when 'captured' spontaneously rather than carefully edited and produced, are rich with incidental as well as intended content, and will also often implicate individuals beyond those who are posting the content. When these productions are harvested for research purposes, the researcher has access to information that the poster might not have realized was included in online posts, let alone used for research purposes – and this risk only increases as more sophisticated analytic tools (e.g., facial recognition technologies) are developed and applied by researchers to glean additional information from harvested data.

Another complexity related to anonymity and privacy is the social practice of developing persistent pseudonymous identities, with the same identity often used across multiple platforms. Social media users in some cases put significant effort into careful crafting of a pseudonymous identity²⁶ and the history of actions and expressions attributed to a pseudonymous identity create reputation and associated social capital within online communities²⁷. By default, anonymity and confidentiality in research ethics protects real-world identities through the assignment, by the researcher, of pseudonyms. In some cases, similar protections have not been provided for enduring pseudonyms, but researchers and ethics boards must carefully consider whether these chosen names also deserve and indeed demand anonymity and confidentiality protections in research²⁸. Good practice in this respect, while dependent on the methods, research questions and methodologies in question, generally requires at minimum the replacement of user-chosen pseudonyms with pseudonyms generated by the researcher; better practice would couple this technique with those discussed above that ensure content is not traceable back to the original online source. These measures ensure that pseudonyms used by social media users across multiple platforms are protected.

More general changes to the online environment, including increased data analytic capacity and the ability to link data across sources, raises issues for research ethics.

Ayers *et al.*²⁹, for example, demonstrated that the majority of tweets published verbatim in research articles could be traced to their original source by means of a simple online search – and increasingly inter-related data sources coupled with enhanced search techniques will only increase the risk of reidentification. Various strategies have been suggested to limit this risk, including the elimination of usernames from research reports and the requirement that researchers test whether the source of quoted content

²⁶ N.C. Krämer, S. Winter, "Impression Management 2.0: The Relationship of Self-Esteem, Extraversion, Self-Efficacy, and Self-Presentation within Social Networking Sites", *Journal of Media Psychology*, 20, 3 (2008): 106-116.

²⁷ R. Martey, J. Stromer-Galley, "The Digital Dollhouse Context and Social Norms in the Sims Online", *Games and Culture*, 2, 4 (2007): 314-334.

²⁸ Y. Gerrard, "What's in a (Pseudo) Name? Ethical Conundrums for the Principles of Anonymisation in Social Media Research", *Qualitative Research*, 21, 5 (2021): 686-702; S. Shannon, L. Singh, "Reporting and Discoverability of 'Tweets' Quoted in Published Scholarship: Current Practice and Ethical Implications", *Research Ethics*, 18, 2 (2022): 93-113. <https://doi.org/10.1177/17470161221076948>.

²⁹ J.W. Ayers, T.L. Caputi, C. Nebeker, "Don't Quote Me: Reverse Identification of Research Participants in Social Media Studies", *npj Digital Med.*, 1, 30 (2018). <https://doi.org/10.1038/s41746-018-0036-2>.

is revealed through online searches. An even higher level of protection can be achieved through ‘fabrication’ of content in qualitative reports in the form of “bricolage-style transfiguration of original data into composite accounts or representational interactions”³⁰.

4.2. *New tools*

Another change to social media and Internet based research has been the development of tools that work with and against the restrictions of social media platforms. Researcher API programs that facilitate access to platform data exist at the whim of social media company’s CEOs, and while new programs continue to emerge – such as TikTok Research API announcement in November, 2022³¹ – others are closed with little notice. Between 2006-2022, for example, Twitter had a researcher-API program to assist in the collection of tweets for academic study, with an approval system for interested applicants through the Academic Research Access Application³². The Twitter approval system requested academic credentials, such as Google Scholar pages, and then asked applicants to complete 8 brief questions about the research methodology and outcomes. A decision on the application was made on the basis of this information, with no feedback or opportunity for revision. The decision-making process was opaque and vague, which left researchers without much support or guidance.

Corporations and institutions are reducing platform support for research access to data, and as a result researchers have begun developing their own tools to access proprietary data: e.g., PykTok on Github, the chrome plug-in webscraper.io, or Apify. Researchers can use these tools to collect data from social media platforms like TikTok and Twitter, among others. These tools can operate without notice to the users whose data is being extracted for academic study, because they work on the premise that platforms like Twitter and Facebook contain data that is published in the public sphere, and therefore those posting this material have no reasonable expectation of privacy.

One interesting development is a ‘public good’ approach to the archiving of publicly available content online. The Internet Archive’s Wayback Machine (IAWM)³³ saves historical versions of websites to allow a retrospective review of online content. ‘Documenting the Now’³⁴ has adopted a related mandate for Twitter, developing “open source tools and community-centred practices that support the ethical collection, use, and preservation of publicly available content shared on web and social media”³⁵. Documenting the Now (DocNow) launched this new initiative and program in 2022 to seek consent from users for Twitter collection, which is a novel development that responds to growing concerns around the ethics of social media collection and archiving.

Nonetheless, there are ethical concerns around new technologies replicating historic harms and modes of sorting and classification that inscribe harm. We are, increasing-

³⁰ A.N. Markham, “Fabrication as Ethical Practice: Qualitative Inquiry in Ambiguous Internet Contexts”, *Information, Communication, and Society*, 15 (2012): 334-353 (334).

³¹ TikTok United States News, “Newsroom”, *Newsroom | TikTok*, accessed May 1, 2023. <https://newsroom.tiktok.com/en-gb/api-for-researchers>.

³² Twitter, “Twitter Data for Academic Research”, accessed May 1, 2023. <https://developer.twitter.com/en/use-cases/do-research/academic-research>.

³³ <https://archive.org/web/>.

³⁴ <http://www.docnow.io/>.

³⁵ <http://www.docnow.io/>.

ly, in a world where private and sensitive personal characteristics can be inferred with an extremely high degree of accuracy from publicly available information³⁶. For example, in 2021 a group of researchers in the United States published a paper that demonstrated how to use Machine Learning to identify and categorize LGBTQ+ members in their data³⁷. They argued that instead of asking anyone to self-identify, which would pose ethical risks as it would involve engaging with human participants, the machine learning processes could determine sexuality and gender without their awareness or involvement, therefore eliminating risks. Given the accuracy of these inferences, it is difficult to argue that they do *not* constitute personal information – and personal information that many might choose to protect or refuse to release to researchers.

4.3. *New topics*

Lastly, the types interactions taking place in/on social media platforms provide new insights into significant current cultural and political events – particularly in the past decade. There is a tension, however, between the urgency of near-real-time study of such events and the vulnerability of social media ‘participants’ who are the sources of the harvested data. Ethical decision making can be challenging in this context of competing values. In our overview of studies conducted in Canada, we found studies that were engaging in data collection and analysis from social media platforms on topics that previously were concealed from the researchers’ gaze.

For example, in recent years we have seen increases in online hate speech³⁸ and other forms of online violence, motivating researchers to study online hate groups such as white supremacists, members of the dark web, and sex offenders. While more ‘vulnerable’ groups are protected through the removal of any identifying characteristics of their social media accounts, groups that are considered to be more harmful in nature are not often afforded the same protections. One study, for instance, explored Darkode, a cybercrime forum on the dark web to highlight its social and market dynamics³⁹. As this group had been dismantled by the FBI in 2015, the researchers used a leaked database to examine the conversations within the forum. Screenshots of user comments were used, and the pseudonymous identities of contributors were not replaced or otherwise obscured, leaving these ‘participants’ vulnerable to re-identification. In another study exploring the online discussions of white supremacists, researchers identified the forum that was the focus of the study, and included verbatim quotations accompanied by the user names⁴⁰. In neither case was there discussion of the ethical issues that could arise with respect to anonymity or confidentiality.

³⁶ M. Kosinski, D. Stillwell *et al.*, “Private Traits and Attributes Are Predictable from Digital Records of Human Behavior”, *Proceedings of the National Academy of Sciences of the United States of America*, 110, 15 (2013): 5802–5805. <https://doi.org/10.1073/pnas.1218772110>.

³⁷ A. Karami *et al.*, “Automatic Categorization of LGBT User Profiles on Twitter with Machine Learning”, *Electronics*, 10, 1822 (2021). <https://doi.org/10.3390/electronics10151822>.

³⁸ E.g. M. Cinelli *et al.*, “Dynamics of Online Hate and Misinformation”, *Scientific Reports*, 11, 22083 (2021). <https://doi.org/10.1038/s41598-021-01487-w>.

³⁹ B. Dupont, A.M. Côté, J. Boutin, J. Fernandez, “Darkode: Recruitment Patterns and Transactional Features of ‘the Most Dangerous Cybercrime Forum in the World’”, *The American Behavioral Scientist*, 61, 11 (2017): 1219–1243. <https://doi.org/10.1177/0002764217734263>.

⁴⁰ M.A. Wong, R. Frank, R. Allsup, “The Supremacy of Online White Supremacists: An Analysis of Online Discussions by White Supremacists”, *Information & Communications Technology Law*, 24, 1 (2015): 41–73. <https://doi.org/10.1080/13600834.2015.10118451>.

Other studies that focus on vulnerable groups, even those engaging in behaviour that could be viewed as socially unacceptable, undertake a more nuanced examination of ethical implications. Harding, Whittingham, and McGannon⁴¹, for example, explored how new mothers document their alcohol consumption on Instagram. To address potential ethical challenges, they reported only aggregated data, did not link their analysis to any individual post(s), did not use platform user ‘handles’, and describe but do not share the actual posts.

Studies examining how young women recovered from eating disorders, the social media platform through which this vulnerable group was studied in some cases resulted in increased susceptibility to harm⁴². On Instagram or Twitter, for example, users may engage under their *actual* as opposed to pseudonymous identities. On platforms such as Instagram and Twitter identifying characteristics about a user can be revealed through profile pictures, usernames, and/or posted photos that can appear on multiple platforms and can be linked through increasingly sophisticated image search capabilities. As a result, researchers could have access to a user’s full name, age, and physical characteristics, even if those were not shared with an original post.

The data that researchers collect and use to identify relevant information on social media include hashtags or topic identifiers that are developed and deployed by community members. These hashtags help members to come together by signaling content, and thus users, who are part of a community. Their textual analysis of these online communities are important contributions to the clinical study of these medical issues, however there is little consideration for how these communities might respond to the academic study of their stories and experiences. These hashtags also allow researchers to collect related content that might not otherwise be identifiable. Thus, for example, TikTok hashtags are user-generated categorizations of uploaded content, and researchers can capitalize on this categorization to gain additional insight from other data associated with the posts that might be less carefully curated, including captions assigned to photos or the audio content of videos.

One study explored how individuals recovering from eating disorders used the hashtag #EDrecovery to discuss their journey on TikTok⁴³. While the researchers included comments that were anonymized, the discussions made by users within their TikTok videos were also included verbatim within the study. While a caption or comment can be well-thought out or deliberate, discussions made in videos can be more improvisational and revealing. As such, researchers using such data to supplement their studies are often capitalizing on the most vulnerable commentary that users may express on TikTok, which are typically intended for use and sharing within their specific online community. Although social media and internet researchers may consider these “public statements” acceptable for analysis, we recommend exercising greater caution when

⁴¹ K.D. Harding, L. Whittingham, K.R. McGannon “#sendwine: An Analysis of Motherhood, Alcohol Use and #winemom Culture on Instagram”, *Substance Abuse: Research and Treatment*, 15 (2021), 11782218211015195.

⁴² A. Lamarre, C. Rice, “Hashtag Recovery: #EatingDisorder Recovery on Instagram”, *Social Sciences*, 6, 3 (2017); A. Basterfield *et al.*, “‘I Would Love to Have Online Support but I Don’t Trust It’: Positive and Negative Views of Technology from the Perspective of Those with Eating Disorders in Canada”, *Health & Social Care in the Community*, 26, 4 (2018): 604-612. <https://doi.org/10.1111/hsc.12557>; T.E. Kenny, S.L. Boyle, S.P. Lewis. “#recovery: Understanding Recovery from the Lens of Recovery Focused Blogs Posted by Individuals with Lived Experience”, *The International Journal of Eating Disorders*, 53, 8 (2020): 1234-1243. <https://doi.org/10.1002/eat.23221>.

⁴³ S.S.C. Herrick, L. Hallward, L.R. Duncan, “‘This Is Just How I Cope’: An Inductive Thematic Analysis of Eating Disorder Recovery Content Created and Shared on TikTok Using #EDrecovery”.

incorporating spontaneous and revealing conversations about sensitive topics, that are brought about by the affordances of TikTok, into academic articles⁴⁴.

This recommendation builds from recent literature that explores user's preferences and responses to academic uses of social media posts. In "This isn't your data, friend,"⁴⁵ demonstrate how social media users perceive and respond to the use of their data and content for academic study on Black Twitter. For use of a single tweet, a participant identified that they would want to know which tweet would be included, the context around the tweet, whether their consent was acquired and the positionality of the author of the academic paper in relation to Black Twitter. Similarly, Shilton et al.⁴⁶ refer to this thorny issue as a question of research 'trustworthiness,' as they identify the relationships between academic research and corporate datafication and surveillance in the era of big data. They suggest a method borrowed from ethnography that encourages reflection on awareness, impact and power, and a focus on *trustworthy processes*.

The three areas of development and change across platform ecosystems identified above indicate the 'thorniness' of social media research that must be taken into consideration, particularly as it concerns social media users' notions of privacy and ethical use. Within the Canadian context, we can see how there are complex challenges arising from the evolving nature of the online research landscape. We characterize the ethical issues that arise from the collection and use of these data as 'thorny,' in that they do not have immediate solutions or answers that are simple extensions of long-held ethical assumptions and guidelines. The collection and use of social media data to present complex potential negative implications for individuals who have produced, and are the subjects of, these data. The practice of harvesting data from social media and subjecting those data to analysis without the awareness or consent from social media users is not anticipated in many existing ethical frameworks and requires further critical inquiry into methodology and tool development.

5. CONCLUSION

In examining contemporary social media and internet-based research within the Canadian context over the past five years, this paper has highlighted three key factors contributing to the challenges of social media research ethics: the evolution of platforms, the adoption of new tools, and the exploration of sensitive data concerning vulnerable online groups. The paper argues that the pervasive datafication trend and platform features promoting spontaneous and vulnerable content creation pose heightened risks to human subjects in research. It emphasizes the need for research ethics guidelines and practices to adapt to effectively address these new and amplified risks.

A case-by-case approach to ethical decision making advocated by many ethicists and researchers works best if paired with on-going awareness of changes in platform

⁴⁴ K. Leurs, "Feminist Data Studies: Using Digital Methods for Ethical, Reflexive and Situated Socio-Cultural Research", *Feminist Review*, 115, 1 (2017): 130-154. <https://doi.org/10.1057/s41305-017-0043-1>.

⁴⁵ S. Klassen, C. Fiesler, "Run Wild a Little With Your Imagination": Ethical Speculation in Computing Education with Black Mirror", in *Proceedings of the 53rd ACM Technical Symposium on Computer Science Education V. 1 (SIGCSE 2022)*, March 3-5, 2022, Providence, RI, USA.

⁴⁶ K. Shilton et al., "Excavating Awareness and Power in Data Science: A Manifesto for Trustworthy Pervasive Data Research", *Big Data & Society*, 8, 2 (2021): 205395172110407. <https://doi.org/10.1177/20539517211040759>.

ecosystems and research agendas⁴⁷. We call for ongoing dialogue and collaboration among researchers, ethics boards, and social media platforms to develop robust guidelines and practices that prioritize the protection of human subjects in research. By navigating this intricate ethical landscape, researchers can conduct valuable and insightful studies while upholding ethical principles and ensuring the well-being and privacy of individuals involved.

⁴⁷ Seko, Lewis, “We Tend to Err on the Side of Caution. Ethical Challenges Facing Canadian Research Ethics Boards When Overseeing Internet Research”; A.S. Franzk *et al.*, *Internet Research: Ethical Guidelines 3.0*; Zimmer, Kinder-Kurlanda, *Internet Research Ethics for the Social Age*.