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## INTRODUCTION

### Over Twenty Years of Internet Research Ethics: Key Concepts and Future Challenges\*\*

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Since the late 1990s, Internet Research Ethics (IRE) has emerged as a burgeoning field, fueled by an ever-growing variety of ethical challenges and concerns<sup>1</sup>. Since then, the societal and technological landscape has changed and expanded: platforms such as social media and apps aggregate a significant number of users, generating new social, cultural, and media practices to study. In this context, Research Ethics (RE) has had both a problematic and nonetheless highly important role. In this special issue, we examine how research ethics can be applied to the ever-changing digital platform environment. This topic is consistent with the tradition of the journal and its attention to the research on media and its context. The aim is to make a useful collection of research experiences as well as theoretical reflections that can serve as a guide and reference in the academic community.

#### 1. A SHORT HISTORY OF IRE

It is argued that Greek philosophers laid the foundation for research ethics thousands of years ago. Values such as Informed Consent then were intended to protect the integrity of the person, protect the patient from harm, and reduce the power imbalance between doctor and patient<sup>2</sup>. This strong connection between research ethics and medicine ethics expanded dramatically after the Second World War and the Nazi era with the first known code of conduct, the Nuremberg Code of Ethics<sup>3</sup>, designed to prevent cruelty in

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<sup>1</sup> M. Zimmer, E. Buchanan, “Internet Research Ethics”, *Stanford Encyclopedia of Philosophy*, 2016. <https://plato.stanford.edu/entries/ethics-internet-research>. Accessed July 14, 2023.

<sup>2</sup> N. Eyal, “Informed Consent”, *The Stanford Encyclopedia of Philosophy*, Spring 2019 Edition, edited by E.N. Zalta, Stanford: Stanford University, 2019. Accessed 18 July, 2023. <https://plato.stanford.edu/archives/spr2019/entries/informed-consent/>.

<sup>3</sup> International Military Tribunal, *The Nuremberg Code. Trials of War Criminals before the Nuremberg Military Tribunals under Control Council Law, Nuremberg, October-April 1949*, Washington, DC: US Government Printing Office, 1949-1953, 181-182. Accessed July 14, 2023. <https://lcn.loc.gov/2011525364>.

the name of advancing medical science. From there on researchers are meant to fully disclose the aims of their research, ask for permission, and thereby safeguard the dignity of the patient.

In 1979, the Belmont Report<sup>4</sup> laid the foundation for contemporary research ethics, initially in the American context, but its articulation of central Human Subjects Protections, starting with rights to informed consent, confidentiality, and anonymity have become central to subsequent research ethics guidelines internationally<sup>5</sup>. The Nuremberg Code was also crafted in response to inhumane research, conducted during the Tuskegee Syphilis Study, in which some 400 African-American subjects were intentionally left untreated and uninformed - resulting in their continued degeneration and more than 100 deaths. As a preventive measure, the Belmont Report outlined a series of core values of scientific research, such as respect for research subjects, beneficence, and justice<sup>6</sup>.

Research Ethics and Internet Research Ethics are both intertwined and distinct. IRE is connected in many of the values of RE – but not necessarily focused on a medical setting. IRE is closely connected to computers, computational networks and communication and technological developments. Due to the rise of the Internet in the 1990s, increasingly accessed via portable devices in the 2000s, and the monopolization of platforms, IRE became increasingly important for researchers examining people, data, and digital spaces. Humanity's most important new habitat<sup>7</sup>, the Internet became increasingly important and compelling to research scientifically – including Internet-facilitated engagements, both between humans as well as between humans and their machines. At the same time, these new communicative spaces and possibilities posed a challenge to traditional values of research, starting with informed consent. In response to the demand for ethical reflection specifically tailored to research on and in the Internet, the Association of Internet Researchers (AoIR) established their first ethics working group in 2000, which issued its first of three guiding documents, hereafter referred to as IRE 1.0<sup>8</sup>.

Historically, there were classical ethics guidelines that protected Human Subjects (Human Subject Protection - HSP) and on the other hand there were guidelines for text-oriented disciplines such as for journalism, and linguistic analysis. On the Internet these two domains overlap, which made guidelines for IRE so needed. The distinction between the historical roots as outlined remained visible in the first set of guidelines. To contextualize the moment, at the time there was a prevailing emphasis on important differences between offline, real-world, embodied human beings *vis-a-vis* their virtual/online expressions, e.g., as pseudonymous posters in a listserv or an avatar in a MUD (Multi User Dungeon) or MOO (MUD Object Oriented): this distinction thus compli-

<sup>4</sup> National Commission for the Protection of Human Subjects of Biomedical, & Behavioral Research of the United States, *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research* (Vol. 1), Department of Health, Education, and Welfare, National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979.

<sup>5</sup> See National Commission for the Protection of Human Subjects of Biomedical, & Behavioral Research, 1978.

<sup>6</sup> J.M. Sims, "A Brief Review of the Belmont Report", *Dimension of Critical Care Nursing*, 29, 4 (2010): 173-1744. DOI: 10.1097/DCC.0b013e3181de9ec5.

<sup>7</sup> J. Durham Peters, *The Marvelous Clouds: Toward a Philosophy of Elemental Media*, Chicago: University of Chicago Press, 2015; A. Lagerkvist, *Existential Media. A Media Theory of the Limit Situation*, New York: Oxford University Press, 2022.

<sup>8</sup> C.M. Ess, the AoIR Ethics Working Committee, *Ethical Decision-Making and Internet Research: Recommendations from the AoIR Ethics Working Committee*, 2002. Accessed July 13, 2023. <https://aoir.org/reports/ethics.pdf>.

cated the question of whether or not – and if so, how – HSP might apply to researchers studying such persons and phenomena. The global reach of the Internet further complicated matters as traditional RE were strongly rooted in modern Western\*<sup>9</sup> frameworks – frameworks often in tension, if not contradiction (at least on the surface) with many other “non-Western” frameworks defining peoples, cultures, and thus their ethics around the globe. To address such challenges, the first guidelines applied an approach that recognized *ethical pluralism* and *cross-cultural awareness*. This means first of all fostering deep familiarity with national frameworks, cultures, traditions, and legal norms in dealing with IR. Just to give an example, European and Scandinavian researchers characteristically rely on a deontological approach, while in Anglo-Saxon contexts a utilitarian framework tends to prevail. This does not lead to relativism because IRE 1.0 entails significant restrictions of what may be done or not and puts at the center the protection of the human subject but highlights the importance of making *judgments* within specific contexts and circumstances (specifically, *phronēsis*)<sup>10</sup>.

The second and third documents are regarded as amendments and expansions on IRE 1.0 as their foundation – and as catalyzed by new ethical challenges evoked by constantly changing technologies and ever-growing uses of the Internet. The second document<sup>11</sup>, hereafter referred to as IRE 2.0, followed upon the emergence of social media (ca. 2005), the mobility revolution (ca. 2008), and early Big Data approaches. In addition, Annette Markham’s emphases on “ethics are methods – methods are ethics”<sup>12</sup> became central: this mantra deftly captures the need to move past a positivist separation between the natural and social sciences on the one hand versus ethics, philosophy, and the humanities more broadly on the other hand. Indeed, *contra* the positivist view and a one-time concern that ethics would only get in the way of good research – by this time, more and more researchers were finding that the ethical approaches in IRE 1.0, as providing them and their ethical review authorities resources for taking on their ethical responsibilities as researchers, often resulted in better research.

The third iteration<sup>13</sup>, referred to here as IRE 3.0, likewise retained the groundings in HSP, pluralistic and dialogical-processual approaches (now significantly expanded and refined via their *applications* in nearly two decades’ worth of real-world research), and an emphasis on cross-cultural awareness. IRE 3.0 was catalyzed. First of all, by the demonstration that initially US/Anglophone needs for IRE had indeed become global: for the first time in their history, the majority of the participants in the ethics panels of the 2016 AoIR conference represented countries and cultures beyond these initial boundaries. At the same time, new developments were required

<sup>9</sup> We are acutely aware of the complexities surrounding such umbrella terms as “Western,” “non-Western” etc., most especially following several decades of postcolonial and now decolonial work. Following a convention introduced by Grodzinsky, Miller and Wolf, we use the asterisk at the end of the word to signal its historically damaging, contested, and potentially misleading meanings: at the same time, it serves as useful shorthand, if only in as a heuristic – i.e., one that must constantly be critically re-examined etc. F.S. Grodzinsky, K. Miller, M.J. Wolf, “The Ethics of Designing Artificial Agents”, *Ethics and Information Technology* 10, 2-3 (2008): 115-121. doi: 10.1007/s10676-008-9163-9.

<sup>10</sup> Ess, the AoIR Ethics Working Committee, *Ethical Decision-Making and Internet Research: Recommendations from the AoIR Ethics Working Committee*.

<sup>11</sup> A. Markham, E. Buchanan, *Ethical Decision-Making and Internet Research: Recommendations from the AoIR Ethics Working Committee (Version 2.0)*, 2012, 1-18. Accessed July 13, 2023. <https://aoir.org/reports/ethics2.pdf>.

<sup>12</sup> A. Markham, “Method as Ethic, Ethic as Method”, *Journal of Information Ethics*, 15, 2 (2006): 37-55.

<sup>13</sup> a.s. franzke et al., *Internet Research: Ethical Guidelines 3.0*, 2020, 1-82. Accessed July 13, 2023. <https://aoir.org/reports/ethics3.pdf>.

by the explosion of Big Data approaches; multiple data scandals and disinformation disasters such as Cambridge Analytica; spectacular hacks of databases demonstrating the fragility – if not the impossibility – of privacy protections; and #Gamergate and related phenomena indexing deep-seated hostility towards women - including journalists and researchers. Coupled with increasing research on hate speech, the alt-right movements, various forms of terrorism, and many other situations, these phenomena foregrounded the urgent need to consider the ethics of *protecting the researchers*, not just the *researched*.

Recent regulatory developments, such as the General Data Protection Regulation (GDPR) of the European Union, have given Internet Research Ethics and Research Data Protection added significance. Due to strict legal requirements, journals have increased submission requirements and added pressure on researchers. It is undeniable that IRE are relevant and help to protect research standards and quality of studies. In addition, they bridge the gap between traditional ethics committees, IRBs (Internal Review Board) and researchers. Research subjects and researchers are increasingly entangled with third parties such as platforms, resulting in greater legal requirements to protect them. We will also need to extend our ethical reflections on Artificial Intelligence (AI)-related work, both as AI-enabled approaches become more common in research and as new laws and policies emerge, such as the recent EU regulation on AI<sup>14</sup>.

## 2. KEY CONCEPTS OF IRE

Most of the key concepts in IRE are also relevant for Research Ethics in general. *Integrity of the researcher*, for example, implies rigorous methodological approaches; *informed consent* of the research subjects and truthful representation of the results. *Reliability and reproducibility* have likewise been core elements. Similar to traditional research ethics, these values still have tremendous relevance. Informed consent for example is premised on the *autonomy* of the research subject. To *avoid harm* to anyone that is involved in the study and foreground *beneficence* is more relevant than ever. While the listed values are not specific to the domains of Internet Research Ethics they frequently require translation into the digital environment.

The question about how to approach a research subject for example is one that has drastically changed in an online environment. While privacy is a common concept, the online environment makes it difficult to differentiate between social media users' expectations and *de facto* privacy rules and conditions. For example, the IRE 2.0 guidelines<sup>15</sup> have addressed how to approach these venues and deal with users' expectations, as doing so has constantly presented researchers with integrity issues. In order to keep research subjects sufficiently informed, informed consent might not only be obtained once the data is gathered but also before the data is published. It can also be difficult to keep track of what data is being collected and when it is being merged, but progress has been made in these discussions. The ethical implications of power imbalances have been raised not only between research subjects and researchers, but

<sup>14</sup> European Parliament, "EU AI Act: First Regulation on Artificial Intelligence", *European Parliament News*, June 8, 2023. Accessed July 13, 2023. <https://www.europarl.europa.eu/news/en/headlines/society/20230601STO93804/eu-ai-act-first-regulation-on-artificial-intelligence>

<sup>15</sup> Markham, Buchanan, *Ethical Decision-Making and Internet Research: Recommendations from the AoIR Ethics Working Committee (Version 2.0)*.

also within research teams. In particular, feminist data ethics has raised awareness that people's lives are always more than data, and that dialogical approaches may prove helpful. Again, in terms of political pressure directed towards researchers, as during the Trump administration, but equally for researchers who study messenger apps for example, questions of power imbalances and how to protect researchers have become increasingly critical<sup>16</sup>.

### 3. THE RELEVANCE OF THE SPECIAL ISSUE AND ITS MAIN TOPICS

To summarize, we can say that the fields of Internet and social media research ethics must constantly adapt to their subjects' ever-changing nature, while recognizing a common set starting principles and guidelines. This is to say that guidelines and practices should be in constant dialogue to find the best solutions for each context, not that rules shouldn't exist or that relativism should be an option.

The idea for this special issue came from the work of the three editors done together in the splendid open laboratory represented by the Ethics Working Group of the Associations of Internet Researchers that was briefly described above in sketching out the development of the IRE guidelines.

Scholars were invited to reflect about IRE and to collect research experiences as well as theoretical reflections that could serve the academic community as examples and references. The intended audience is both established scholars and PhD students who have just started confronting these issues. The objective is to provide scholars from humanities and social sciences useful insights for dealing with IRE also in the light of the fact that when participating in public grants and fundings such as Horizon Europe, the evaluation of the ethics of research is an aspect required from the very beginning, also for social sciences and humanities.

The question, or the *fil rouge* ("red thread" - the central conceptual theme), that guides this special issue is: how the norms, the guidelines, and the rules that govern IRE can be applied to the specificity of each context and research without losing their strengths but at the same time without making the research process itself impossible? This special issue contributes to the overall field of IRE by providing new and contemporary research situations that may challenge other researchers and by giving insights from an international perspective, offering new topics to think about.

Data collection and informed consent are two of the most important issues when doing Internet research. The fact that the publicity of data does not automatically imply that researchers can use it is well settled after years of debate. On the other side, informed consent is not always easily obtained, as in the cases of big data or ephemeral/live events in which it is difficult to keep track of the participants.

Strictly connected with informed consent, there is the theme of privacy. As IRE 1.0 noted, privacy perceptions may be changing and ambiguous<sup>17</sup>. Thus, researchers should not take for granted that what is public is perceived as public by who published it. The intertwining of the ever more nuanced context of privacy among Internet and social

<sup>16</sup> Franzke et al., *Internet Research: Ethical Guidelines 3.0*.

<sup>17</sup> Ess, the AoIR Ethics Working Committee, *Ethical Decision-Making and Internet Research: Recommendations from the AoIR Ethics Working Committee*.

media, the methodology used, and the context of research make it necessary to carefully examine these issues<sup>18</sup>.

The paper of Risi and Di Fraia focuses on the ethics aspects connected with the “7 days for 7 friends” research project, highlighting the steps that led them to choose to ask each informant the consent required to analyze their posts and stories. This was motivated by the need to analyze their contents in depth and to make them aware of the ongoing research. This decision was also done as a part of the students’ training: the project was developed inside a university course devoted to research methodology skills. In the light of critical pedagogy, the article, thus, points out the importance to properly train the students in evaluating research materials and in obtaining consents, to minimize the power imbalance and to give them elements of social science methodology and IRE.

Risi and Di Fraia together with Jones, suggest rethinking the role of the researcher as a part of the research environment and research as a process of co-construction with the informants. According to this perspective, the informants (i.e. social media creators or activists) may help the researchers to evaluate whether it is necessary to ask for an informed consent also from their audience and to obtain it if needed. Another point, already established in the IRE 1.0, is to evaluate *a priori* the entire process of research and the needs connected by the dissemination and publication of research as well as the method. For example, discourse analysis may need to quote the exact text, for which an informed consent would be needed, while with other methodologies, anonymization strategies or paraphrases should be viable solutions<sup>19</sup>.

Analyzing the German context, Zillich *et al.* point out different possible ways adopted by researchers to address privacy and informed consent, highlighting the presence of different positions also connected to the scientific sector of the researchers (for example social sciences or computer science), distinguishing what is accessible and what is public. The solutions proposed include aggregated diffusion of data, anonymization, paraphrasing, and consent to reproduce texts or images.

Informed consent and privacy are strictly connected with harm minimization. It has long been observed that algorithms and big data may lead to reidentifying users from a text or an image, or again to profile people aggregating data from more sources, so particular attention should be devoted to data storage and diffusion<sup>20</sup>.

Harm minimization, however, concerns researchers as well as informants. Zillich *et al.* describe various solutions adopted to protect especially students or young scholars involved such as selection, training, support are essential to guarantee a safe research environment.

Again, on this topic, Özkula’s paper confronts the intertwining between informants’ and researcher’s protection, illustrating an investigation into an anti-climate change Facebook group that later appeared to be a far-right group, with potential threats to the researcher. The paper also proposes concrete examples of harms reconsideration and a “vulnerability triad” model useful to be employed as a reference.

These measures, together with the critical pedagogy approach mentioned before,

<sup>18</sup> d. boyd, K. Crawford, “Critical Questions for Big Data: Provocations for a Cultural, Technological, and Scholarly Phenomenon”. *Information Communication and Society*, 15, 5 (2012): 662-679. <https://doi.org/10.1080/1369118X.2012.678878>; F. Giglietto, L. Rossi. “Ethics and Interdisciplinarity in Computational Social Science”. *Methodological Innovations Online*, 7, 1 (2012): 25-36. <https://doi.org/10.4256/mio.2012.003>.

<sup>19</sup> franzke *et al.*, *Internet Research: Ethical Guidelines 3.0*, 10 s.

<sup>20</sup> M. Zimmer, “‘But the Data is Already Public’: On the Ethics of Research in Facebook”, *Ethics and Information Technology*, 12, 4 (2020): 313-325. <https://doi.org/10.1007/s10676-010-9227-5>.



should also help to reduce the power imbalances between researchers and informants, and between teachers and students.

Another interesting shift that is occurring in Internet research is the emergence of “small data”<sup>21</sup> or “digital small stories”<sup>22</sup> as a way to conceptualize ethnography and data collection among social media. Instead of collecting big quantities of unstructured data, the researchers decided to concentrate on a smaller quantity of data, analyzing them in-depth. This approach can also offer a view on the issue of data minimization<sup>23</sup> because it can be chosen in each situation which data to collect and which not<sup>24</sup>. Of course, the disadvantage is that complex procedures of data anonymization may not be performed. Despite this objection, the research about small data can be really fruitful, as Di Fraia, Risi and Jones point out.

Jones’ paper also opens a reflection on the relevance of platforms’ technological evolution into IRE. The paper is about a study of Instagram live (a feature with which Instagram users can live stream) addressing privacy, access, and collection issues as well as ephemerality and storage issues, providing insightful solutions for dealing with them.

Another topic that emerges across the articles is the importance of the research context and the country (or the countries) in which the research is done. Of course, while research guidelines like AoIR ones are meant to be transnational, each country may have its own guidelines issued by research institutions and governments. As the AoIR guidelines also insist, local legal and ethical norms are a fundamental and unavoidable starting point to be put in dialogue with scientific and international guidelines<sup>25</sup>.

The papers of Zillich *et al.*, Zainab *et al.*, and Mackinnon *et al.* deepen our understanding of the specificities of three countries: Germany, Pakistan, and Canada. The first paper analyzes researchers’ perception of IRE and how they deal with it during research practices. Zainab *et al.* pose this issue in the Global South, offering an invaluable insight into the Pakistani situation and how researchers balance between the freedom of research and national constraints. Last, but not least, Mackinnon and colleagues critically analyze the Canadian context, its national IRE guidelines and sensitive IRE issues around what they define as “thorny” questions of Internet research. They are “thorny” as long as there is not an immediate solution nor an automatic application of rules.

To solve the various tensions, many contributors to this special issue recall the concept of Nissenbaum’s “contextual integrity”<sup>26</sup> which remains one of the most powerful ones in guiding researchers to apply guidelines and norms. The notion of context actually lets us widen the frame of the research and consider the elements of which it is composed and to evaluate the various aspects of IRE involved in order to find a viable solution.

With this special issue we hope to provide thoughtful elements to contribute to the IRE discussion. Despite the many issues already raised, many more will need to be dealt

<sup>21</sup> G. Latzko-Toth, C. Bonneau, M. Millette, “Small Data, Thick Data: Thickening Strategies for Trace-Based Social Media Research”, in *The SAGE Handbook of Social Media Research Methods*, edited by A. Quan-Haase, L. Sloan, London: Sage, 2017, 199-214.

<sup>22</sup> L. Bainotti, A. Caliendo, A. Gandini, “From Archive Cultures to Ephemeral Content, and Back: Studying Instagram Stories with Digital Methods”, *New Media & Society*, 23, 12 (2017): 3656-3676. <https://doi.org/10.1177/1461444820960071>.

<sup>23</sup> C.M. Ess, Y. Hård af Segerstad, “Everything Old is New Again: the Ethics of Digital Inquiry and its Design”, in *Designs for Experimentation and Inquiry: Approaching Learning and Knowing in Digital Transformation*, edited by Å. Mäkitalo, T.E. Nicewonger, M. Elam, London: Routledge, 2019, 179-196.

<sup>24</sup> Franzke *et al.*, *Internet Research: Ethical Guidelines 3.0*, 20.

<sup>25</sup> *Ibid.*, 12 ss.

<sup>26</sup> H. Nissenbaum, *Privacy in Context: Technology, Policy, and the Integrity of Social Live*, Stanford, CA: Stanford University Press, 2010.

with in the future. We try to sketch out some of them as an invitation for future fora of discussion.

In the next few years, it will be urgent to develop Internet research ethics in the age of Artificial Intelligence and of the always more frequent interaction between humans and technology. The philosopher Luciano Floridi offers, for example, five principles for developing Artificial Intelligence: beneficence, non-maleficence, autonomy, justice, and explicability<sup>27</sup>. As far as Artificial Intelligence and its applications are expected to permeate more aspects of society and also of research, new reflections should be undertaken in order to extend the principles of IRE also into this new realm. We pose some very general questions useful to start a reflection: which are the boundaries between human and machine? What is the contribution of the subject and of the algorithms? Which kind of profiling will be possible with online and social media data? How are we to protect both the need for research into these new frontiers and the users' privacy?

Another topic that should be addressed is the ethical implications of open access research - this is to say, how do protect users' privacy and anonymity while making the research open and reproducible in the light of the common good?

Again, with the de-westernization of Internet studies more local research context will emerge to be considered with their local norms and ethics, requiring a constant dialogue between researchers across all over the world. Primary topics of discussion are likely to include censorship, access to data, and security, as well as others we may not foresee.

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<sup>27</sup> L. Floridi, *The Ethics of Artificial Intelligence. Principles, Challenges, and Opportunities*, Oxford: Oxford University Press, 2023.