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Humans in Computing: Growing Responsibilities for Researchers - Considering the role of institutional review boards in computing research.

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Description

A paper discussing the role of institutional review boards in overseeing research done using social media networks and the ethical questions they raise.

Body

Facebook found itself at the center of heated debate during the summer of 2014. Researchers manipulated Facebook's News Feed feature and published a paper in the *Proceedings of the National Academy of Sciences* showing those viewing positive posts expressed more positive emotions, while those viewing negative posts expressed more negative emotions.³ The paper's title proclaimed "experimental evidence of massive-scale emotional contagion" among the 689,003 people in the experiment.

Supporters claimed the results were useful, that the researchers had done nothing wrong, and that Facebook users agreed to such uses when they signed up. Critics claimed the experiment had mistreated people by including them in the research without prior knowledge or opportunity to give informed consent to their

participation. Companies such as Facebook can conduct research without the oversight of institutional review boards, or IRBs. This was cited in critiques, suggesting that problems would have been avoided if an IRB had reviewed the plan. What role, if any, should IRBs play in computing research?

Research funding is increasingly predicated on human welfare, establishing a connection that is growing stronger for computing researchers. Thinking about IRBs is useful because they have become a touchstone for ethics in research. IRBs govern much research at universities, medical centers, and other organizations. Federal research agencies sometimes require IRB approval or exemption before making awards. Some computing researchers (for example, human-computer interaction and information technology for health treatment) have worked with IRBs for years. Researchers who work in education or with people under 18 years of age are in or are heading into the IRB zone. Computing research can show ethical leadership by getting ahead of the curve rather than merely reacting to it. For those who must now deal with IRBs this column suggests a point of view that will help. For others it suggests a way to get out in front.

The point of view is to recognize the sound justification for the role of the IRB and the power of public opinion behind it. IRBs are the product of evolving political will regarding humane treatment of research subjects. The Nuremberg Trials gathered much public interest following WWII, and put the topic on the table.⁶ Protocols evolved as public concern grew. The disclosure of the U.S. Public Health Service's Tuskegee Syphilis Experiment between the early 1930s and the early 1970s caused public alarm, and led to the U.S. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. In 1978 the commission issued "The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research." This was soon followed by the U.S. Federal Policy for the Protection of Human Subjects (the "Common Rule"), the creation of the Office of Human Research Protections (OHRP) within the Department of Health, Education and Welfare (now Health and Human Services), and the establishment of IRBs to approve, monitor, and review research involving humans.^{2,4,10}

Between the Tuskegee Syphilis Experiment and the Belmont Report the focus on human welfare expanded. Psychologist Stanley Milgram's experiments at Yale University in the early 1960s caused public alarm when authority figures ordered subjects to shock others electrically. No one was actually shocked, but subjects believed they had harmed others. Similarly, the public was concerned about

psychologist Philip Zimbardo's experiments at Stanford University in the early 1970s in which students acting as guards in a mock prison psychologically tortured student prisoners. The Belmont Report included mental welfare of research subjects, and IRBs followed suit.

The passage of time does not necessarily reduce public concerns. The papers of Dr. John Charles Cutler disclosed that researchers with the U.S. Public Health Service deliberately infected human subjects in Guatemala with sexually transmitted diseases in the 1940s.^a President Barack Obama apologized to the government and people of Guatemala, and ordered a thorough investigation. More than half a century had elapsed since the research was done. Cutler gave his papers to the University of Pittsburg library in 1990s. They remained unexamined until 2010 when a researcher read them and notified library leaders. The records were transferred to the National Archives and Records Administration (NARA), which informed President Obama. The events were controversial even though they were decades old.

The definition of human welfare has continued to expand. *HeLa*, an "immortal" human cell line (the cells can be reproduced indefinitely), was taken from Henrietta Lacks, a cervical cancer patient who died in 1951. *HeLa* became widely used in medical research, including that of Jonas Salk in his efforts to develop the polio vaccine. Rebecca Skloot's best-selling 2010 book explains that neither Lacks nor her family benefited from *HeLa*.⁹ Permission to use cells in this way was not required of the patient or the family at the time. Yet in 2013, more than 60 years after the cells were taken, Lacks' descendants reached an agreement with the National Institutes of Health regarding access to *HeLa* DNA code and acknowledgment in scientific papers.⁸ The agreement did not award financial compensation to Lacks' descendants, but the question of who benefits is now open. This area of law and policy is not settled, but the definition of human welfare is expanding.

Information technology is important for human welfare. Connecting computing research to human welfare raises important ethical issues that go beyond avoiding direct physical harm to research subjects. The regulations already include "behavior." Next steps might be finances and reputation (the latter has already arisen in Europe⁵). The regulatory reach of IRBs can grow: a few alterations in legislation or regulations can require funding agencies to demand that researchers seek IRB review or satisfy other requirements *before their proposals will be considered*. While regulatory reach can increase or diminish, computing researchers should get in front of the trends. The simple plea of "Trust Us" does not work. The

reputations of the many researchers who know right from wrong and can make good human welfare decisions with no review can be damaged by a few who do the wrong thing and get caught. Arguments to leave researchers alone usually lose. Being proactive is smart.

Two examples illustrate contemporary ethical dilemmas involving computing research and human welfare. One is how research done in the digital world should be treated. Research done using Twitter might be like and unlike research done in the past. If new rules apply, who makes such rules? Many IRBs are grappling with this. Another is “cyberoffense,” mimicking those who unlawfully hack into computer systems.⁷ Such work might be needed to better secure computing systems against real threats, but what tests should be done, by whom, under whose authority, and for what purposes? Researchers do not become serial murderers to better understand how serial murderers behave. How is this different? How far should efforts to mimic unlawful hackers go? How should the knowledge be used? What if students become expert and unlawful hackers themselves? Such questions need attention. There are no simple answers. Computing researchers can help.

The Facebook story suggests that computing researchers should consider *possible* connections between their research and human welfare. Computing research that goes regularly to the IRB will continue to go there. What about computing research that might now be declared exempt from IRB consideration, or at least be puzzling to IRB experts? It is difficult to pin down the moving “front” between the IRB’s established territory and where the IRB will be in the future. The IRB is not the only mechanism to consider, but public opinion has tended toward more strict control of research, and the IRB is often the most experienced source of guidance available. Computing researchers should watch the IRB and think proactively about important ethical issues.

Although going through IRB review can be a disincentive to writing and submitting proposals, the history of IRBs shows sensitivity to the needs of research. Many institutions have created separate IRBs to deal with biomedical research and behavioral research in recognition of important differences between those research domains. One protocol does not fit all research. In time there might be additional IRBs created. Computing researchers should be engaged at the beginning to forestall senseless regulation and promote ethical practice. The IRB has been at the forefront of ethical discussions regarding the researcher’s “duty of care” toward research subjects and others in the broad realm of “human welfare.” There is much

to be learned from the IRB. Finally, the IRB mechanism is likely to persevere and grow in importance as the *primary* device for settling matters of research and human welfare, at least in Federally supported research. Computing researchers should become closer to the IRB, not to accelerate IRB control over computing research, but to understand IRB concerns and establish a sensible and sustainable trajectory for the future.

Open issues regarding human welfare will not be settled using an authoritarian approach. Computing researchers in universities and companies cannot do whatever they like. Doctoral students and postdoctoral fellows should be aware of science and engineering ethics. Ethical concerns must lead professional practice and regulation, not the other way around. IRBs have not discovered all the ethical issues that should be in the foreground of research. For example, there are major uncertainties regarding what constitutes “informed” consent, many of them brought on by advances in IT.¹ Technological capabilities and social attitudes continue to change. Uncertainties remain, and learning to manage research involving human welfare is not a one-time proposition. Many researchers who assumed they would never be included in IRB review now routinely take their proposed work to the IRB. Computing researchers have the opportunity to develop ethical directions for their work that exemplify humane and responsible conduct. To do so requires individual initiative and institutional support. This is not because IRB control over computing research is inevitable (it might not be), but because this is the right thing to do.

Footnotes

[a.](http://www.archives.gov/press/press-releases/2011/nr11-94.html) The Cutler Papers were released online in March 2011:
<http://www.archives.gov/press/press-releases/2011/nr11-94.html>.

References

- [1.](#) Barocas, S. and Nissenbaum, H. Big data’s end-run around procedural privacy protections. *Commun. ACM* 57, 11 (Nov. 2012), 31–33.
- [2.](#) Childress, J.F., Meslin, E.M., and Shapiro, H.T., Eds. *Belmont Revisited: Ethical Principles for Research with Human Subjects*. Georgetown University Press, Washington, D.C. (2005); <http://www.hhs.gov/ohrp/humansubjects/commonrule/>.

- [3.](#) Kramer, A.D.L, Guillory, J.E., and Hancock, J.T. Experimental evidence of massive-scale emotional contagion through social networks. In *Proceedings of the National Academy of Sciences* 111, 8 (June 17, 2014), 8788–8790.
- [4.](#) Jones, J. *Bad Blood: The Tuskegee Syphilis Experiment*. Free Press, New York, 1981; <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>.
- [5.](#) Mantelero, A. The EU proposal for a general data protection regulation and the roots of the ‘right to be forgotten.’ *Computer Law and Security Review* 29, 3(Mar. 2013), 229–235.
- [6.](#) Marrus, M.R. *The Nuremberg War Crimes Trial 1945–46: A Documentary History*. St. Martin’s Press, Boston, 1997.
- [7.](#) Nakashima, E. and Soltani, A. The ethics of hacking 101. *Washington Post Live*, (Oct. 7, 2014); http://www.washingtonpost.com/postlive/the-ethics-ofhacking-101/2014/10/07/39529518-4014-11e4-b0ea-8141703bbf6f_story.html.
- [8.](#) National Institutes of Health. NIH, Lacks family reach understanding to share genomic data of HeLa cells; <http://www.nih.gov/news/health/aug2013/nih-07.htm>.
- [9.](#) Skloot, R. *The Immortal Life of Henrietta Lacks*. Crown Publishers, New York, 2010.
- [10.](#) Vollmer, S.H. and Howard, G. Statistical power, the Belmont Report, and the ethics of clinical trials. *Science and Engineering Ethics* (Dec. 2010), 675–691.

Notes

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