# WHY CAN'T WE BE FRIENDS? A PROPOSAL FOR UNIVERSAL ETHICAL STANDARDS IN HUMAN SUBJECT RESEARCH

#### CALLI SCHROEDER\*

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#### INTRODUCTION

The Facebook emotional contagion experiment brought to light the inherent conflict and troubling loopholes that stem from federal agencies and private companies adhering to different ethical standards regarding human subject research. Specifically, it demonstrated that collaborations between federally-funded agencies and private companies can skirt the ethical requirements and oversight standards set forth by the Belmont Report and adopted by federal agencies.

It is no longer feasible to allow private companies to set their own

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ethical standards regarding human subject research. Advancements in technology and the pervasiveness of data sharing have allowed human subject research to expand far beyond its previous limitations. As long as there are ethical standards that apply only to select human subject research, there will be individuals and organizations that seek to exploit the loopholes created by this disparity. The public and academic outcry in the aftermath of the Facebook emotional contagion experiment demonstrates a need for imposing core ethical and oversight standards for all human subject research, which would apply regardless of the performing the research. While or company implementation of standards for human subject research may be adjusted for the specific needs of a business or organization, certain standards should be universal: there must be some level of outside oversight and accountability; there must be a specific and legitimate stated purpose of the experiment; and there must be as much informed consent as possible.

First, this paper will examine the format and implementation of the Facebook emotional contagion experiment and the ethical controversies that it brought to light. Next, it will analyze the varied reactions to the experiment from the public and the research community—general criticisms, potential legal action—as well as defenses that Facebook and the university researchers involved have raised. Finally, it will address the reasons why the overall ethical standard for human subject research must change, arguments against changing the ethical standards, and what the change could look like.

### I. BACKGROUND

### A. The Facebook Emotional Contagion Experiment

The Facebook emotional contagion experiment took place during a one-week period in January 2012. It was an experimental study carried out in collaboration with members of Cornell University and the University of California, San Francisco ("UCSF"). The university members were involved in the initial discussions of the experiment, analyzing the gathered data, and preparing the published paper. According to Cornell, the university researchers' role was "limited to initial discussions and collaboration with Facebook and analyzing the

<sup>1.</sup> James Grimmelmann, *As Flies to Wanton Boys*, THE LABORATORIUM (June 28, 2014, 4:33 PM), http://laboratorium.net/archive/2014/06/28/as\_flies\_to\_wanton\_boys.

<sup>2.</sup> John Carberry, *Media Statement on Cornell University's Role in Facebook 'Emotional Contagion' Research*, CORNELL U. MEDIA REL. OFF. (June 30, 2014), http://mediarelations.cornell.edu/2014/06/30/media-statement-on-cornell-universitys-role-in-facebook-emotional-contagion-research/.

research results."<sup>3</sup> The spokesperson for Cornell maintained that the university researchers were not involved in directly collecting user data. The published paper reveals that the university researchers designed the research and then gave it to Facebook to do the actual data manipulation and compilation.<sup>4</sup>

Subjects qualified for the research pool if they viewed Facebook in English and had logged on within the week before the experiment.<sup>5</sup> Facebook selected 689,003 users from its overall user pool and split them into four groups: a positive group; a negative group; and two control groups. Posts that a subject in the positive group would have seen were first filtered through a computer algorithm that removed posts containing negative keywords, such as "hate," "sad," or "nasty," blocking these posts from appearing in the subject's News Feed. ("News Feed" is Facebook's term for its primary product, which displays posts from the pages and individuals that the user chooses to follow. It is often the default first screen a user sees when she visits Facebook.) Likewise, the negative group's News Feeds filtered out the posts containing positive keywords. The study used the Linguistic Inquiry and Word Count ("LIWC") text analysis software program—commonly used in psychological studies relating to emotional expression in language—to determine whether terms were negative or positive.<sup>8</sup> Facebook maintained the feed manipulation algorithm on these groups for one week while gathering information on the content (positive or negative) and frequency of user posts in each of the groups throughout the experiment.9

After the initial data-gathering and manipulation period, Facebook data scientists and university researchers from Cornell and UCSF

<sup>3.</sup> Zoe Ferguson, Cornell Prof Involved in Facebook Study Affecting 700,000 Unknowing Users, CORNELL DAILY SUN (Aug. 27, 2014), http://issuu.com/cornellsun/docs/08-27-14\_entire\_issue\_lo\_res.

<sup>4.</sup> Adam D. I. Kramer, Jamie E. Guillory & Jeffrey T. Hancock, *Experimental Evidence of Massive-Scale Emotional Contagion Through Social Networks*, 111 PROC. NAT'L ACAD. SCI. U.S.A. 8788, 8788 (2014), http://www.pnas.org/content/111/24/8788.full.pdf.

<sup>5.</sup> *Id*.

<sup>6.</sup> Kashmir Hill, Facebook Doesn't Understand the Fuss About Its Emotion Manipulation Study, FORBES (June 29, 2014, 11:26 AM), http://www.forbes.com/sites/kashmirhill/2014/06/29/facebook-doesnt-understand-the-fuss-about-its-emotion-manipulation-study/; Jason Baldridge, Emotional Contagion: Contextualizing the Controversy, PEOPLE PATTERN (July 10, 2014), https://www.peoplepattern.com/emotional-contagion-one/.

<sup>7.</sup> Grimmelmann, supra note 1.

<sup>8.</sup> Baldridge, supra note 6.

<sup>9.</sup> See H. Roger Segelken & Stacey Shackford, News Feed: 'Emotional Contagion' Sweeps Facebook, CORNELL CHRON. (June 10, 2014), http://www.news.cornell.edu/stories/2014/06/news-feed-emotional-contagion-sweeps-facebook; Gregory S. McNeal, Facebook Manipulated User News Feeds to Create Emotional Responses, FORBES (June 28, 2014, 1:10 PM), http://www.forbes.com/sites/gregorymcneal/2014/06/28/facebook-manipulated-usernews-feeds-to-create-emotional-contagion/.

analyzed the collected data and published their findings in the *Proceedings of the National Academy of Sciences*. <sup>10</sup> According to a member of the Facebook legal team, the experiment was created in order to ascertain the accuracy of commentary and media reports suggesting that increased Facebook use caused people to be less happy. <sup>11</sup> In fact, the experiment results showed a more direct correlation between user emotions and the type of content users encounter than with their use of the site itself. Essentially, the results demonstrated that people whose friends' updates are more negative tend to become slightly sadder, and those whose friends' updates are more positive tend to become slightly happier. <sup>12</sup>

# B. Controversies Regarding the Experiment

There was widespread public outrage when news of the experiment broke. A good portion of the anger stemmed from privacy concerns and a sense of impermissible deviation from the normal expectations of users rather than from the potential violation of any legal principles. As public awareness of Facebook's breach of user trust and data privacy expectations has grown, so has hope for changes in the accepted standards regarding use of user data. Though overall public opinion and cultural understanding of these types of experiments is important, this note views the reactions to the experiment mainly as a catalyst for change, and instead focuses on legal arguments against the experiment. The criticisms examined here include the formation of the subject pool, the circumvention of Common Rule protections, the gap in ethical standards between academic and business research, and the lack of information given to consumers regarding what can be done with their data.

Several potential legal controversies exist regarding the experiment itself and how the data was manipulated. First, the subject pool formation for the experiment causes legal concern over both the age range of the subjects selected and their country of origin. Because there was no age filter in the criteria to qualify as a subject, some of the subjects may have been under the age of eighteen. Special regulatory requirements exist for any research study involving children, requiring more strict standards of informed consent and sometimes consent of guardians. <sup>15</sup> The researchers

<sup>10.</sup> Kramer, Guillory & Hancock, supra note 4.

<sup>11.</sup> Interview with Rob Sherman, Deputy Chief Privacy Officer, Facebook, in Boulder, Colo. (Dec. 4, 2014).

<sup>12.</sup> Kramer, Guillory & Hancock, supra note 4.

<sup>13.</sup> See, e.g., Research Ethics, XKCD, http://xkcd.com/1390/ (last visited Mar. 3, 2016).

<sup>14.</sup> Frank Pasquale, *Facebook's Model Users*, CONCURRING OPINIONS (July 3, 2014), http://www.concurringopinions.com/archives/2014/07/facebooks-model-users.html.

<sup>15.</sup> Special Protections for Children as Research Subjects, U.S. DEP'T OF HEALTH &

in this experiment did not meet those requirements. There may also have been citizens of other countries included in the subject pool, as there was no filter for nationality. This prompted inquiries by both the UK Information Commissioner's Office and France into whether the experiment violated international data protection laws, including the Safe Harbor agreement. At the time, the Safe Harbor agreement bridged the differences in approaches to privacy between the U.S. and European Union. Facebook was certified as agreeing to and following the Safe Harbor standards, and thus could be in legal trouble if the European entities determine that Facebook did, in fact, breach the standards.

A second criticism is that, even for legal adult citizens of the United States who were included in the subject pool, the experiment raises concerns because it circumvents the protection of Institutional Review Boards ("IRBs") and the Common Rule, put in place to protect subjects of human subject research.<sup>19</sup> The Common Rule originated after a series of highly publicized abuses of human subjects in research experiments prompted the 1974 National Research Act, which created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.<sup>20</sup> Based on these past abuses, the Commission issued the Belmont Report, a summary of ethical principles to which researchers should adhere to when performing human subject research.<sup>21</sup> The standards contained in the Belmont Report are now codified as the Federal Policy for the Protection of Human Research Subjects, or the "Common Rule."<sup>22</sup> In practice, this policy means that an IRB must

HUMAN SERVS., http://www.hhs.gov/ohrp/policy/populations/children.html (last visited Mar. 21, 2016).

<sup>16.</sup> Facebook Faces UK Inquiry over News Feed Emotion Study, GUARDIAN (July 2, 2014, 2:28 AM), http://gu.com/p/3qtk5/stw; Facebook Study May Have Violated Principles of Academic Research, Journal Says, HUFFINGTON POST (July 3, 2014, 6:07 PM), http://www.huffingtonpost.com/2014/07/04/facebook-academic-research n 5556429.html.

<sup>17.</sup> Welcome to the U.S.-EU & U.S.-Swiss Safe Harbor Frameworks, EXPORT.GOV, http://www.export.gov/safeharbor/ (last updated Mar. 2, 2016). The European Union Court of Justice invalidated the Safe Harbor agreement on October 6, 2015, but the Safe Harbor standards were still in place at the time Facebook ran its experiment and this note addresses Safe Harbor as it stood at the time of the experiment. Court of Justice of the European Union Press Release No. 117/15, The Court of Justice Declares that the Commission's US Safe Harbor Decision is Invalid (Oct. 6, 2015), http://curia.europa.eu/jcms/upload/docs/application/pdf/2015-10/cp150117en.pdf.

<sup>18.</sup> General EEA/CH-US Data Privacy: Safe Harbor Notice, FACEBOOK, https://www.facebook.com/safeharbor.php (last visited Mar. 4, 2016).

<sup>19. 45</sup> C.F.R. § 46 (2015). This is the version adopted by the Department of Health and Human Services, but the text is substantially the same as that adopted by all federal agencies.

<sup>20.</sup> H.R. Res. 7724, 93rd Cong., 88 Stat. 342 (1973). See Federal Policy for the Protection of Human Subjects ('Common Rule'), U.S. DEP'T OF HEALTH & HUMAN SERVS., http://www.hhs.gov/ohrp/humansubjects/commonrule/index.html (last visited Mar. 6, 2016).

<sup>21.</sup> Hill, supra note 6.

<sup>22.</sup> Federal Policy for the Protection of Human Subjects ('Common Rule'), supra note 20. The policy is referred to as the "Common Rule" because, though the statutory title may

ensure that any experiment with human subjects proposed by a federally-funded organization adheres to the Common Rule requirements before the experiment is conducted.<sup>23</sup> The Common Rule adheres to three main principles outlined in the Belmont Report regarding how to conduct human subject research: respect for the dignity and autonomy of subjects; beneficence in balancing benefits of research against potential harms; and ensuring justice by seeing that the knowledge gained through the research accrues to different sectors of the public.<sup>24</sup>

According to statute, these regulations apply to "all research involving human subjects conducted, supported or otherwise subject to regulation by any federal department or agency which takes appropriate administrative action to make the policy applicable to such research." According to the Food and Drug Administration:

The purpose of IRB review is to assure, both in advance and by periodic review, that appropriate steps are taken to protect the rights and welfare of humans participating as subjects in the research. To accomplish this purpose, IRBs use a group process to review research protocols and related materials (e.g., informed consent documents and investigator brochures) to ensure protection of the rights and welfare of human subjects of research. <sup>26</sup>

Experiments require subjects to give informed consent to those running the experiment and the subjects must be aware of the option to opt out at any time.<sup>27</sup> When determining whether to allow experiments to go forward, IRBs perform a careful analysis of the risks (conditions that make a situation dangerous *per se*) and the anticipated benefits of the experiment.<sup>28</sup> When considering an experiment, an IRB must:

vary by agency, the text is identical.

<sup>23. 45</sup> C.F.R. § 46 (2015).

<sup>24.</sup> NAT'L COMM'N FOR THE PROT. OF HUMAN SUBJECTS OF BIOMEDICAL AND BEHAVIORAL RESEARCH, BELMONT REPORT: ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION HUMAN **SUBJECTS** OF OF RESEARCH (1979).http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html Thereinafter REPORT]. The Menlo Report was issued more recently to deal specifically with computer and information security research. It adds the principle of "Respect for Law and Public Interest" to the three principles of the Belmont Report. MICHAEL BAILEY ET AL., THE MENLO REPORT: ETHICAL PRINCIPLES GUIDING INFORMATION AND COMMUNICATION TECHNOLOGY RESEARCH (2012), https://www.predict.org/Portals/0/Documents/Menlo-Report.pdf.

<sup>25. 45</sup> C.F.R. § 46.101(a) (2015).

<sup>26.</sup> Institutional Review Boards Frequently Asked Questions – Information Sheet, U.S. FOOD & DRUG ADMIN., http://www.fda.gov/regulatoryinformation/guidances/ucm126420.htm (last updated Jan. 25, 2016).

<sup>27. 45</sup> C.F.R. § 46.116(a)(1-8) (2015).

<sup>28.</sup> Institutional Review Board Guidebook: Chapter III, Basic IRB Review, U.S. DEP'T OF HEALTH & HUMAN SERVS., http://www.hhs.gov/ohrp/archive/irb/irb\_chapter3.htm (last updated 1993).

(1) identify the risks associated with the proposed research; (2) determine that the risks will be minimized as much as possible; (3) identify the anticipated benefits of the research; (4) determine that the risks are reasonable as related to the benefits to the subjects and/or the importance of the knowledge to be gained; (5) assure that potential subjects will be giving fully informed consent; and (6) determine intervals for periodic review and monitoring of the data collected.<sup>29</sup> These measures and the detailed structure of approval help to ensure that all research experiments are proper and that the subjects are giving fully-informed consent.

In contrast to federally-funded human subject research, industry practice for companies *not* funded by the government allows for almost any use of user data. Companies sometimes claim that they obtain consent from users based on terms-of-use agreements. Facebook's terms-of-use agreement did not include "research" until four months after this experiment had occurred, as discussed in Section II(C), *infra*.<sup>30</sup> The current standard of consent for private businesses is that there must be "available notice" to the potential subjects (often understood to be satisfied if users agree to the terms-of-use policies posted on sites, few of which are truly read or understood) and there is no requirement for opt-out.<sup>31</sup> Businesses also have implied consent for "internal use"—another ill-defined term.<sup>32</sup> Whether terms-of-use agreements function as true consent is still under debate, but it certainly does not reach the Common Rule criteria for informed consent.<sup>33</sup>

A substantial portion of the controversy surrounding this experiment lies in a third problem: The experiment highlights the gap between the ethical standards of industry practice and the ethical standards for the research community regarding human subject studies and research.<sup>34</sup> Essentially, Common Rule compliant organizations are held to a high

<sup>29.</sup> *Id*.

<sup>30.</sup> Kashmir Hill, Facebook Added 'Research' to User Agreement 4 Months After Emotion Manipulation Study, FORBES (June 30, 2014, 8:16 PM), http://www.forbes.com/sites/kashmirhill/2014/06/30/facebook-only-got-permission-to-doresearch-on-users-after-emotion-manipulation-study/; Naomi LaChance, Was Facebook's 'Emotional Contagion' Experiment Ethical?, U.S. NEWS & WORLD REP. (June 30, 2014, 4:20 PM), http://t.usnews.com/Z21vsi.

<sup>31.</sup> Edward Felten, U.S. Deputy Chief Tech. Officer, Presenter, Panel Two: The Changing Nature of Science and Research, Silicon Flatirons Symposium: When Companies Study Their Customers (Dec. 4, 2014), https://youtu.be/6gD2gwaDwU4; Daniel Solove, Facebook's Psych Experiment: Consent, Privacy, and Manipulation, LINKEDIN (June 30, 2014), https://www.linkedin.com/pulse/20140630055215-2259773-the-facebook-psych-experiment-consent-privacy-and-manipulation.

<sup>32.</sup> Felten, supra note 31.

<sup>33.</sup> Institutional Review Board Guidebook, supra note 28.

<sup>34.</sup> Edward Felten, *Facebook's Emotional Manipulation Study: When Ethical Worlds Collide*, FREEDOM TO TINKER (June 30, 2014), https://freedom-to-tinker.com/blog/felten/facebooks-emotional-manipulation-study-when-ethical-worlds-collide/.

standard of informed consent for the participants and for review of the experiment's goals regarding whether the research is worthwhile in the first place. Conversely, there does not appear to be any substantial legislation that addresses standards for consent or review regarding human subject research performed by businesses like Facebook.<sup>35</sup>

It should be noted that the Department of Health and Human Services ("HHS") recently put forward a Notice of Proposed Rulemaking that would, among other things, tighten rules on informed consent, adjust the level of review to correspond to severity of harm or risk, and expand exemptions to IRB review.<sup>36</sup> Though the tighter rules regarding informed consent should better protect subjects of human subject research, they are only helpful if applied, and the expanded exemptions to review will likely mean less oversight rather than more. This is especially true regarding data-intensive research because the proposal would exclude "research involving the collection or study of information that has been or will be acquired solely for non-research activities or was acquired for research studies other than the proposed research study . . . ."<sup>37</sup>

The practices that govern the design, application, and publication of human subject research vary from company to company and the process is often not transparent.<sup>38</sup> Based on the contrast between standards of IRB-compliant organizations and the industry standards applied to the Facebook emotional contagion experiment, there is virtually no argument from Facebook that there was any informed consent by the subjects. The subjects were purposefully left unaware that they were in an experiment, partly because Facebook did not consider it necessary to inform them and partly because it would have affected the outcome of the experiment if the users were aware of its existence.<sup>39</sup> Instead, the argument seems to be that this experiment was an internal test and therefore counted as an internal use for which users had given implied consent. This argument is addressed further in Section II(C) below.

Developments in technology over the past decade coupled with consumers' prevalent use of social media have led many academics to collaborate with data-driven companies. Significant ethical problems stem from such collaborations. The large number of users voluntarily

<sup>35.</sup> Solove, supra note 31.

<sup>36.</sup> Federal Policy for Protection of Human Subjects, 80 Fed. Reg. 53933 (proposed Sept. 18, 2015 and still under consideration at time of writing) (to be codified at 45 C.F.R. pt. 46), http://www.gpo.gov/fdsys/pkg/FR-2015-09-08/pdf/2015-21756.pdf.

<sup>37.</sup> Id. at 53952.

<sup>38.</sup> Matthew Salganik, *After the Facebook Emotional Contagion Experiment: A Proposal for a Positive Path Forward*, FREEDOM TO TINKER (July 7, 2014), https://freedom-to-tinker.com/blog/mjs3/after-the-facebook-emotional-contagion-experiment-a-proposal-for-a-positive-path-forward/.

<sup>39.</sup> Hill, supra note 30.

submitting data provides an enticing and ready-made pool of subjects for potential studies and experiments. However, this sort of collaboration raises two important points of concern.

First, when discussing this ready-made pool of subjects and the data those subjects voluntarily submit, it is important to note that users may be unaware of exactly how much information they reveal when they post. The amount of data put online by an individual can reveal details she may not wish to be made public. In one instance, data mining led to targeted ads revealing that a user was pregnant before anyone else in her social circles (including family members) was aware.<sup>40</sup>

In addition, big data analytics are now common and can allow analysis of a massive amount of data in a short time, making connections beyond what is possible with human analysis alone. <sup>41</sup> This level of user data analysis is more powerful than what most had imagined possible, and researchers must approach it with respect for the dangers of revealing too much.

Furthermore, collaboration between academics bound by Common Rule standards and businesses not held to those standards, like Facebook, opens up the problematic possibility of "IRB laundering." This term describes the phenomenon of academic researchers evading formal ethics review processes by collaborating with corporate researchers who conduct experiments and collect data within a company where ethics review processes are looser. IRB laundering is a problem because it renders the protections of the Common Rule essentially meaningless. As collaborations between academics and businesses are unlikely to cease (indeed, they will likely grow more frequent), the United States should update its ethical rules and extend them to these data-driven companies to strengthen the ethical standards for all human subject experiments that IRBs and the Common Rule were created to maintain in the first place. As

## II. REACTIONS TO THE EXPERIMENT

The responses from individuals, the public at large, and Facebook after publication of the article revealing the experiment fall into three major categories: criticisms of the experiment's ethical status and the involvement of academics; legal challenges to the experiment; and defenses of the experiment.

<sup>40.</sup> Kashmir Hill, *How Target Figured Out a Teen Girl Was Pregnant Before Her Father Did*, FORBES (Feb. 16, 2012, 11:02 AM), http://www.forbes.com/sites/kashmirhill/2012/02/16/how-target-figured-out-a-teen-girl-was-pregnant-before-her-father-did/.

<sup>41.</sup> Matthew Boeckman, Discussant, Panel One: A/B Testing and Manipulation Online: Should We Care?, Silicon Flatirons Symposium: When Companies Study Their Customers (Dec. 4, 2014), https://youtu.be/E55alZr716c.

<sup>42.</sup> Felten, supra note 34.

<sup>43.</sup> Pasquale, supra note 14.

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#### A. Criticisms

One of the primary criticisms of the experiment is that an IRB did not approve it, despite the experiment's similarity to experiments that do require IRB approval: it involved human subjects; some of the experiment's creators were university researchers; and a scientific journal published the results. He approval is only a requirement for federally-funded organizations (and organizations, including some corporations, which have chosen to adhere to the Common Rule), normally that requirement would not have applied to an experiment run by Facebook. However, the presence of university researchers in the formation of this experiment, the analysis of the gathered data, and the publication of the article detailing the results calls into question whether IRB clearance and outside oversight were required—or should have been.

The standards of this experiment absolutely did not meet informed consent rules as described in the Common Rule and applied by IRBs. 46 The structure of the experiment, the source, and the fact that the university researchers designed the research plan but had Facebook actually perform it points to a case of "IRB laundering." Facebook is not one of the few organizations that have voluntarily signed on to the same standards as federally-funded organizations. Thus, Facebook would not have been required to adhere to the Common Rule had it conducted the experiment completely on its own. However, the ethical problem stems from the involvement of university researchers who proposed, analyzed, and helped publish the experiment. These same researchers would have been required to adhere to the Common Rule and submit the experiment for IRB approval had they performed the experiment without the aid of Facebook.<sup>47</sup> The experiment as a whole was approved by Facebook's internal review process, not by any university's IRB. 48 Because Facebook's internal review process does not uphold the same standard of ethical responsibility as the Common Rule, the experiment was cleared under a lower ethical standard than it would have been under a university IRB.49

<sup>44.</sup> Baldridge, supra note 6.

<sup>45.</sup> ERIN D. WILLIAMS, CONG. RESEARCH SERV., RL32909, FEDERAL PROTECTION FOR HUMAN RESEARCH SUBJECTS: AN ANALYSIS OF THE COMMON RULE AND ITS INTERACTIONS WITH FDA REGULATIONS AND THE HIPAA PRIVACY RULE 10 (2005); ([S]tatutory policy applies to "all research involving human subjects conducted, supported or otherwise subject to regulation by any federal department or agency which takes appropriate administrative action to make the policy applicable to such research.") 45 C.F.R. § 46.101(a) (2015).

<sup>46.</sup> Institutional Review Boards Frequently Asked Questions, supra note 26, § V.

<sup>47.</sup> Michelle N. Meyer, *How an IRB Could Have Legitimately Approved the Facebook Experiment—and Why That May Be a Good Thing*, FACULTY LOUNGE (June 29, 2014, 11:05 AM), http://www.thefacultylounge.org/2014/06/how-an-irb-could-have-legitimately-approved-

It is also significant that the analysis of the data (after it had been collected) received outside oversight, but there was no oversight that specifically focused on or approved the proposed method for gathering user information (the actual manipulation of News Feeds). Once public outcry led to scrutiny of the methods for data collection and manipulation used in the experiment, along with details about the experiment's creators and formation, it was revealed that Cornell's IRB cleared the data analysis portion of the experiment, but not the data collection method or the experiment as a whole. After receiving criticism because of a university member's participation in the experiment, Cornell defended this decision, stating that

Because the research was conducted independently by Facebook and Professor Hancock had access only to results—and not to any individual, identifiable data at any time—Cornell University's Institutional Review Board concluded that he was not directly engaged in human research and that no review by the Cornell Human Research Protection Program was required. 52

In the wake of the public outcry and some direct criticisms from lawyers, the *Proceedings of the National Academy of Sciences* has also expressed concern over the ethical standards of the study.<sup>53</sup> In an Editorial Expression of Concern, they stated that the study "may have involved practices that were not fully consistent with the principles of obtaining informed consent and allowing participants to opt out."<sup>54</sup> It is concerning that the article analyzing the experiment and its results was not more seriously vetted prior to publication and the methods used and ethical standards adhered to appear to have been investigated only after public outcry.

One of the core problems with this experiment is that it should have

the-facebook-experimentand-why-that-may-be-a-good-thing.html.

<sup>48.</sup> Hill, supra note 6.

<sup>49.</sup> Josh Constine, Facebook Announces Stricter Guidelines for Research and Experiments on its Users, TECHCRUNCH (Oct. 2, 2014), http://tcrn.ch/1sPe7ti. This link shows the updated, stricter internal review process implemented since the experiment. Even this new process does not reach Common Rule standards and it stands to reason that the previous internal review process was more lax.

<sup>50.</sup> Hill, supra note 6.

<sup>51.</sup> *Id*.

<sup>52.</sup> Carberry, supra note 2.

<sup>53.</sup> Letter from James Grimmelmann, Professor of Law, Francis King Carey School of Law & Leslie Meltzer Henry, Assoc. Professor of Law, Francis King Carey School of Law, to Inder M. Verma, Editor-in-Chief, Proc. Nat'l Acad. Sci. U.S.A. (July 17, 2014), http://james.grimmelmann.net/files/legal/facebook/PNAS.pdf.

<sup>54.</sup> Inder M. Verma, Editor-in-Chief, Correction, *Editorial Expression of Concern and Correction*, 111 PROC. NAT'L ACAD. SCI. U.S.A. 10,779 (July 22, 2014), http://www.pnas.org/content/111/29/10779.1.full.pdf.

been the users (subjects) who determined whether the possible risks and negative effects were worth participating in the experiment (as they would have been able to do under an IRB-controlled experiment) rather than the researchers deciding for them. <sup>55</sup> Leaving the participation decision to an internal review system without even informing the subjects that they could be involved in an experiment is precisely the type of violation that the Common Rule was created to prevent. This is why IRBs have such a long and strict consideration process before approving human subject research. <sup>56</sup>

The results of this study point to some problematic future possibilities and manipulations. Some have questioned whether companies could use emotional manipulation through social media in more pointed ways, such as to foment civil unrest.<sup>57</sup> A prior experiment run by Facebook, which showed an effect on the voting behavior of the test group, supports this fear. 58 Facebook claimed that by adding a banner that allowed certain users to announce on Facebook that they had voted, they were able to increase the overall number of people voting through data manipulation.<sup>59</sup> This has frightening implications, including whether Facebook could solely target users of one or the other political party and attempt to change the course of an election. While the possibility of Facebook manipulating an election in one party's favor may seem farfetched, even a remote possibility of Facebook effecting such a substantial possible harm should give everyone pause. Such a use would have no external oversight or duty to disclose the experiment and its results in any way under current ethical standards for private businesses.

# B. Legal Action

Though there is one suit focusing on possible impermissible use of data, most of the legal actions arising from this experiment have focused on the formation of the subject pool and whether certain subjects were impermissibly included.<sup>60</sup> Within the United States, different states have

<sup>55.</sup> Felten, supra note 31.

<sup>56.</sup> Institutional Review Board Guidebook, supra note 28.

<sup>57.</sup> Robert Booth, Facebook Reveals News Feed Experiment to Control Emotions, GUARDIAN (June 29, 2014, 7:57 PM), http://gu.com/p/3qghp/stw; Clay Johnson (@cjoh), TWITTER (June 28, 2014, 6:43 AM), https://twitter.com/cjoh/status/482882070101106688.

<sup>58.</sup> Laurie Penny, Laurie Penny on Facebook's Manipulation: It Can Manipulate Your Mood. It Can Affect Whether You Vote. When Do We Start to Worry?, NEW STATESMAN (June 30, 2014, 12:23 PM), http://www.newstatesman.com/internet/2014/06/facebook-can-manipulate-your-mood-it-can-affect-whether-you-vote-when-do-we-start.

<sup>59.</sup> Eyder Peralta, That 'I'm a Voter' App at the Top of Your Newsfeed Actually Makes a Difference, NAT'L PUB. RADIO (Nov. 4, 2014, 1:25 PM), http://n.pr/1EfQJXL; Robert M. Bond et al., A 61-Million-Person Experiment in Social Influence and Political Mobilization, 489 NATURE 295, 295 (2012).

<sup>60.</sup> Robinson Meyer, Facebook's Mood Manipulation Experiment Might Have Been

different legislation relating to the use of their citizens' data or research performed within the state. Two law professors from the University of Maryland have sent a letter to the Maryland Attorney General alleging that the experiment violated House Bill 917, a Maryland state statute that extends the Common Rule to all human subject research conducted within the state. Because the pool of subjects was filtered only for users who posted in the English language and who had posted within the two weeks preceding the data manipulation of the experiment, residents of Maryland may well have been included in the subject group. If there were any Maryland residents included in the subject pool, then the research violated Maryland law and the question would shift to whether that law can be enforced against Facebook.

Facebook has responded to these claims by stating that "[t]he federal Common Rule and the Maryland law [the professors] cite were not designed to address research conducted under these circumstances and none of the authorities [they] cite indicates otherwise." This statement may serve as a temporary defense when dealing only with public opinion, but Facebook will need a more in-depth defense should this progress into formal legal action, as the Maryland statute seems clear about the use of its citizens' data. Based on the text of the Maryland statute, it seems that this type of experiment is exactly what the law was created to prevent. Facebook's best argument in this case would likely be the defense it has maintained since the experiment came to light: that the experiment falls under "product testing" (which is excepted under the statute) and was not primarily intended as a human subject experiment.

As previously mentioned, there may also have been citizens of other countries included in the subject pool, which may have been a violation of the Safe Harbor agreement regarding privacy and data use. The Safe Harbor framework stipulated a very specific method for U.S. companies to transfer personal data of European Union citizens outside of the EU, consistent with the EU Data Protection Directive.<sup>66</sup> There are many

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*Illegal*, ATLANTIC (Sept. 24, 2014), http://www.theatlantic.com/technology/archive/2014/09/facebooks-mood-manipulation-experiment-might-be-illegal/380717/.

<sup>61.</sup> Id

<sup>62.</sup> James Grimmelmann, *Illegal, Immoral, and Mood-Altering: How Facebook and OKCupid Broke the Law When They Experimented on Users*, MEDIUM (Sept. 23, 2014), https://medium.com/@JamesGrimmelmann/illegal-unethical-and-mood-altering-8b93af772688.

<sup>63.</sup> MD. CODE ANN., HEALTH-GEN. §§ 13-2001 to -2004 (LexisNexis 2016). See also Maryland Law on Human Subjects Research, MD. ATT. GEN., https://www.oag.state.md.us/Healthpol/humansubject.htm (last visited Mar. 6, 2016).

<sup>64.</sup> HEALTH-GEN. § 13-2002 (prohibiting "all research using a human subject" unless conducted "in accordance with the federal regulations on the protection of human subjects").

<sup>65.</sup> Interview with Rob Sherman, *supra* note 11; Meyer, *supra* note 60.

<sup>66.</sup> U.S.-EU Safe Harbor Framework, FED. TRADE COMM'N, http://www.business.ftc.gov/us-eu-safe-harbor-framework (last updated Nov. 6, 2015)

active Facebook users around the world and a substantial number outside the United States who use and view Facebook in English. This possibility has prompted an inquiry by privacy regulators in both France and the UK Information Commissioner's Office.<sup>67</sup> The UK inquiry has extended into communication with the Irish data protection body because Facebook's European headquarters are in Dublin.<sup>68</sup> Based on the United States-European Union Safe Harbor agreement (which Facebook had given formal notice that it adhered to at the time of the experiment), there may be a cause of action.<sup>69</sup>

As of this writing, it is unclear whether Facebook fully adhered to that agreement when performing the emotional contagion experiment. It is also unknown how many, if any, European Union citizens were included in the subject pool, though it is being investigated.<sup>70</sup> If the standards of the Safe Harbor agreement were violated, the United States Federal Trade Commission ("FTC") would have the power to penalize Facebook for the violation because the FTC was placed in a regulatory capacity over U.S. companies when the framework was drafted.<sup>71</sup>

Turning to the issue of proper or permissible use of user data, the Electronic Privacy Information Center ("EPIC") in the United States has filed a formal complaint with the FTC claiming that the Facebook emotional contagion experiment misused user data.<sup>72</sup> Though no formal legal action has been taken at this point, it is possible that this complaint may prompt an investigation. To what extent the FTC can control Facebook's (and other private companies') actions regarding human subject research still remains in question.

Even if the FTC is able to enforce human subject research standards on Facebook, it is doubtful whether any actions the FTC takes will be serious enough to curtail further violations. Facebook had already been sanctioned by the FTC and in 2012 entered into a mandatory twenty-year consent decree dictating how Facebook would protect users' data and address privacy issues in the future.<sup>73</sup> The decree requires Facebook to: (1) obtain express consent from users before overriding their privacy preferences; (2) cut off access to the user's data within thirty days of

<sup>[</sup>hereinafter FTC Safe Harbor Framework]. See supra note 17 for a note on the invalidation of the Safe Harbor agreement.

<sup>67.</sup> Regrets Over Facebook Emotion Contagion Experiment, BELFAST TELEGRAPH (July 5, 2014), http://www.belfasttelegraph.co.uk/life/technology-gadgets/regrets-over-facebook-emotion-contagion-experiment-30407259.html.

<sup>68.</sup> Facebook Faces UK Inquiry over News Feed Emotion Study, supra note 16.

<sup>69.</sup> General EEA/CH-US Data Privacy: Safe Harbor Notice, supra note 18.

<sup>70.</sup> Regrets Over Facebook Emotion Contagion Experiment, supra note 67.

<sup>71.</sup> FTC Safe Harbor Framework, supra note 66.

<sup>72.</sup> Samuel Gibbs, *Privacy Watchdog Files Complaint over Facebook Emotion Experiment*, GUARDIAN (July 4, 2014, 9:00 AM), http://gu.com/p/3qy25/stw.

<sup>73.</sup> Hill, supra note 30.

account deletion; (3) establish a comprehensive privacy program for new and existing products and services; and (4) submit to audits of the privacy program within 180 days and every two years after that for a twenty-year period (audits will be handled by an independent professional not yet named).<sup>74</sup> Despite knowing that the FTC was already accusing the company of failing to protect user data properly and that the consent order would soon be in place, Facebook still went through with the emotional contagion experiment, apparently with clearance from its internal review process.<sup>75</sup>

The FTC sanctions and consent decree stemmed from privacy violations. Facebook had been using the "like" buttons embedded in various websites to monitor the web surfing habits of users and had kept logs of the activity. Facebook contends that this experiment did not fall under the privacy criteria specifically named in the sanction agreement and so was not a violation. Because Facebook is apparently attempting to adhere to the consent decree issued by the FTC, it appears the FTC has authority to monitor Facebook's interactions with its users to some extent. However, the earlier sanctions addressed a more "pure" privacy and deception issue; this experiment falls into the somewhat gray area of possible internal testing. It is unclear whether the FTC will be able to take any action against Facebook or if it will choose to do so.

## C. Experiment Defenses

Defenses of the experiment fall into two broad categories: defending Facebook's role in the experiment and defending the academic researchers' involvement in the experiment. Facebook's defenders argued initially that when users signed its terms of service agreement, they gave Facebook consent to perform the experiment because the agreement included a portion stating that data could be used for "research." However, it turns out that the research clause did not exist in the terms of service agreement until four months after Facebook performed this experiment, when Facebook added a line stating that user data could be used for several internal operations purposes, including

<sup>74.</sup> Byron Acohido, *Facebook Settles with FTC over Deception Charges*, USA TODAY (Nov. 30, 2011, 5:29 PM), http://usatoday30.usatoday.com/tech/news/story/2011-11-29/facebook-settles-with-ftc/51467448/1.

<sup>75.</sup> Facebook Settles FTC Charges that it Deceived Consumers by Failing to Keep Privacy Promises, FED. TRADE COMM'N (Nov. 29, 2011), http://www.ftc.gov/news-events/press-releases/2011/11/facebook-settles-ftc-charges-it-deceived-consumers-failing-keep.

<sup>76.</sup> Acohido, supra note 74.

<sup>77.</sup> Jessica Guynn, *Privacy Watchdog Files Complaint over Facebook Study*, USA TODAY (July 3, 2014, 6:55 PM), http://usat.ly/1lCFs7W.

<sup>78.</sup> LaChance, supra note 30.

"troubleshooting, data analysis, testing, research and service improvement." The fact that the research clause was added *ex post facto* effectively eliminates the "terms of service" defense and brings up questions regarding why Facebook added the term months after the experiment had taken place and the results had already been published. One possibility is that Facebook was trying to retroactively protect itself from possible complaints and litigation after public outcry against the experiment began. Another is that this kind of testing was always covered, though less specifically, by the terms of service agreement and this was an effort to further transparency. However, speculation on Facebook's motivation, while entertaining, goes beyond the scope of this note.

Even if the term "research" had been included in the terms of service policy at the time of the experiment, it still would not have met the Common Rule standard for informed consent. 80 Informed consent requires affirmative consent that is sufficiently specific to the study in question. 81 There cannot be blanket "informed consent" for any possible use of data that may later occur to the company or any experiment that the company may wish to perform in the future. 82

Facebook claims that the emotional contagion experiment originated as product testing and therefore falls under an exemption. A Facebook representative said there had been statements in the media claiming that Facebook use negatively affected its users and Facebook had a responsibility to determine whether or not these allegations were true and, if so, to attempt to remedy the damage. However, regardless of where the original idea for the experiment came from, the study itself was designed by a professor of psychology and a postdoctoral associate who wished to test a scientific hypothesis about emotional contagion. Testing a hypothesis created by outside sources seems to point toward an outside experiment that merely used Facebook as the testing medium rather than purely internal product testing for Facebook. While it is possible that the experiment could have served both purposes, it creates a serious conflict and calls into question how many types of experiments could stem from outside sources and be implemented under the catch-all

<sup>79.</sup> McNeal, supra note 9; Hill, supra note 30.

<sup>80.</sup> Institutional Review Board Guidebook, supra note 28.

<sup>81.</sup> Id.

<sup>82.</sup> *Institutional Review Board Guidebook, supra* note 28. Chapter III, Section B of the guidebook says that informed consent requires that the subject be told about the research involved, the research purposes, and the duration. This means that the consent must either be specific to each research instance or it must be clearly explained that there is ongoing research about a particular area.

<sup>83.</sup> Meyer, supra note 60; see 45 C.F.R. § 46.101(b) (2015).

<sup>84.</sup> Interview with Rob Sherman, supra note 11.

<sup>85.</sup> Kramer, Guillory & Hancock, supra note 4.

umbrella of "internal testing." The argument that this was a research experiment and not simply internal product testing is bolstered by the fact that the article analyzing the results was published in a scientific journal.<sup>86</sup>

The primary defense raised for the involvement of the academic researchers is that they did not actually perform the data manipulation on subjects' News Feeds; they simply proposed the experiment and compiled the subsequent data into the published paper.<sup>87</sup> The university researchers were therefore insulated from the human element of the experiment, meaning that their work did not necessitate IRB clearance.<sup>88</sup> Facebook, with its separate ethical standards, was in charge of all actual contact with human subjects. The problem with this argument is that, while it may shield university researchers from sanctions in this particular instance, this defense merely highlights the discrepancy in ethical standards between federally funded organizations and private companies, effectively drawing focus to the need for more universal ethical standards. This pointed demarcation of roles in the different stages of the experiment is an indication of intentional IRB laundering and supports the argument that raising the ethical standards of consumerdriven companies to more closely adhere to those used by academics would help to close this loophole.

Another possible defense is that computer programs actually viewed and filtered the user data collected in the research, not people. Researchers could have claimed that this distinction between human and technical interaction with user information makes the data collection consistent with Facebook's data use and privacy policy. However, this argument would seem disingenuous because, technically, any interaction with data is performed by code transmission or requests for information rather than directly by humans. Online data cannot be simply picked up and viewed by people as if it were a tangible object (like a piece of paper), so necessarily it is computers, programs, algorithms and other programs that always interact with the data and people simply view the results once they appear on a screen. Devolving the argument into technicalities focused on a coding versus a physical perspective of data may serve to mount a defense to the strict letter of the policy, but it certainly does not serve as a defense that upholds the spirit or intent of the initial data policy.<sup>89</sup> Further, using technicalities in this way to claim

<sup>86.</sup> Id.

<sup>87.</sup> Carberry, supra note 2.

<sup>88.</sup> Hill, supra note 6.

<sup>89.</sup> STANLEY G. KORENMAN, TEACHING THE RESPONSIBLE CONDUCT OF RESEARCH IN HUMANS ch. 2 (2006), http://ori.hhs.gov/education/products/ucla/chapter2/Chapter2.pdf (explaining that the purpose of the policy is to protect all research subjects and especially vulnerable research subjects).

all data analysis is essentially done by computer programs rather than humans defeats the purpose of having a privacy policy that prohibits employees from interacting with or manipulating user data at all.

## III. ANALYSIS

## A. Reasons to Change Existing Ethical Standards

While some rules for business are necessary, it is not mandatory that the minute details of rules concerning ethical standards for human subject research be exactly the same for businesses as they are for government-funded agencies. Businesses have different structures, different needs, and different responsibilities to their users. To some extent, they must perform "internal tests" (testing possible layouts or product changes on a small user group initially before implementing the change, getting feedback on new products or designs, etc.) on their users in order to improve the product and stay competitive. However, without universal core principles in place for all groups engaged in human subject experiments, including businesses, the ethical rules will become so easy to circumvent that they are essentially meaningless in practice.

Large companies, especially those connected to technology or the Internet, perform as much human subject research as academic organizations with little to no oversight. 90 If the ethical standards on human subject research remain unchanged for corporations, it could lead to either of two potential problems. First, since the conflict between the two sets of standards—and the potential for related privacy violations has become more public, the ensuing public scrutiny could drive a wedge between company researchers and the outside research community. This may result in a situation where company researchers have trouble finding academic collaborators or publishing their work because their research methods fail to meet higher research-community ethics standards.<sup>91</sup> Public backlash alone could be a motivating factor for creating a more unified ethical standard for human subject experiments that would apply to both research communities. This case could be the catalyst. Alternatively, the discrepancy between the two ethical standards could continue to facilitate IRB laundering. This practice is a purposeful avoidance of the Common Rule and substantially weakens its effectiveness.

<sup>90.</sup> Jeff Leek, Rafa Irizarry & Roger Peng, *Do We Need Institutional Review Boards for Human Subjects Research Conducted by Big Web Companies?*, SIMPLY STATISTICS (Aug. 5, 2014), http://simplystatistics.org/2014/08/05/do-we-need-institutional-review-boards-for-human-subjects-research-conducted-by-big-web-companies/.

<sup>91.</sup> Felten, supra note 34.

Perhaps the collaboration in this instance meant more oversight on the emotional contagion experiment than would have been the case if Facebook had acted separately from academics, so the abuse of the loophole worked out in consumers' favor. 92 This is the gist of Professor Michelle Meyer's argument, which concludes that instead of raising the ethical standard for companies, we should lower the ethical standard for academics. However, closing the gap between the standards for companies and the standards for academics could also be achieved by raising the ethical standard of private companies to correspond more closely with that of academics and the federal government. These standards need not be identical in every way, but if they possess similar levels of ethical responsibility and oversight, it will avoid stifling collaboration, as Professor Meyer fears. Though it is still possible that these higher standards may mean the public is denied the results of an experiment like the emotional contagion experiment, if the methods of gathering information for an experiment are deemed unethical, then it is more valuable to societal good to refrain from subjecting test subjects to unnecessary risks than it is to gain whatever insight might be gleaned from going through with the unethical experiment.

The *Proceedings of the National Academy of Sciences* has already faced significant backlash from the public and the larger research community for publishing the Facebook emotional contagion experiment because the methods of gathering the data and the ethical clearance for the experiment were questionable. Based on this reaction, it is possible that the research community at large will be more cautious in the future when it comes to accepting any research from sources that do not adhere to the Common Rule. While this would be a positive sign of the research community as a whole showing a greater respect towards its own ethical standards, it may also prevent some collaborations that, when performed within a proper ethical framework, could provide society with beneficial knowledge and insights.

Though a common ethical standard between all groups engaged in human subject research is necessary, no one wants to completely stifle collaboration between corporations and academia. When properly conducted, those collaborations can produce social benefits. Businesses already have access to large amounts of data used to help develop new products and marketing strategies based on user feedback. Those companies can glean an immense amount of helpful social knowledge with that data. Promoting ethical standards that highlight transparency, lay out clear methods for maintaining user privacy, allow for some external oversight, and preserve as much informed consent as possible

<sup>92.</sup> Meyer, supra note 47.

<sup>93.</sup> Letter from Grimmelmann & Henry, supra note 53; Verma, supra note 54.

would allow the public to benefit from this vast amount of information and allow the companies to publish their research.

The second problem here is IRB laundering. The Facebook emotional contagion experiment is by no means the only instance of IRB laundering. The term was coined in reaction to the Facebook emotional contagion experiment because of its blatant use of the loophole, and since then the term has been used to refer to any circumstance where an organization uses a private company with lower ethical standards to avoid formal ethical review procedures. Hough IRB laundering may be a term created to address this specific experiment, it is a wide-reaching and pervasive practice between Common Rule organizations and organizations operating outside the Common Rule ethical standards.

Creating a common core of universal standards that bring essential parts of the Common Rule and IRB review standards into the private sector would help to solve both of these problems, among others. If such standards include mandatory outside oversight and accountability, specific and legitimate stated purposes for all human subject experiments, and as much informed consent as possible along with set transparency standards, there would be little reason for the research community to fear collaboration with private businesses on human subject research. Both the research community and corporations would be assured that both parties involved must act in compliance with the universal rules. IRB laundering would no longer be possible. In addition, consumers would be empowered to determine whether they are willing to take on the risks of an experiment and decide whether or not to participate in every human subject experiment, not just those run by federally-funded organizations. A unified standard would make rule enforcement easier and more consistent for either an agency, such as the FTC, or internal IRBs or human subject research Oversight Committees specifically tailored to the needs of technology companies. 95 While the current exceptions to full Common Rule adherence might require expansion to address needs specific to private companies or to meet the ever-changing nature of technology, this expansion could either be added into the current legislation or put into entirely new standards in order to maintain a uniform standard easily applied to all types of organizations and individuals that engage in human subject research.

<sup>94.</sup> See Felten, supra note 34; Lee (@ZLeeily), TWITTER (June 29, 2014, 9:34 PM), https://twitter.com/ZLeeily/status/483468578482819072; IRB Laundering, WORDSPY, http://wordspy.com/index.php?word=irb-laundering (last visited Mar. 6, 2016); Letter from Grimmelmann & Henry, supra note 53.

<sup>95.</sup> Salganik, supra note 38.

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## B. Arguments Against Changing the Ethical Standards

The main arguments against changing the ethical standards fall into three categories: (1) Private companies are too structurally and fundamentally different from federally-funded organizations for the same standards to apply to both; (2) the standards currently in place for private companies are sufficient to fix the problem; (3) and self-policing within the business industry would be sufficient to fix the problem. Ultimately, these arguments fall flat for three reasons, respectively: (1) some private companies already adhere to the Common Rule voluntarily; (2) if the standards were sufficient, IRB laundering would not be such a problem; and (3) blind trust in companies is not a true protection for users.

The first argument is that private companies are too different from federally-funded organizations to fall under substantially similar ethical standards. Private companies have different business structures and requirements; different responsibilities to their users, owners, and investors; and different goals that must sometimes be reached through internal tests on user data. It would be impossible to come up with a universal ethical standard that could apply to both private companies and federally-funded organizations that did not prevent one or the other from properly functioning. This argument fails because there are many private businesses that have already voluntarily adhered to the Common Rule.<sup>96</sup> These companies would not have signed on to a voluntary ethical standard that they determined incompatible with the model of the company or impossible to apply. While it is possible the rules were more easily applicable to the unique structure of the businesses that have signed on, this example at least shows that adhering to the Common Rule standards is not *per se* impossible for companies.

Another argument is that the current standards in place for private businesses are effective enough and there is no need to expand them. This has clearly not been the case, given the prevalence of IRB laundering and the reaction to the revelation that companies perform experiments on their users without user knowledge. After-the-fact sanctions are not effective deterrents because Facebook went through with the emotional contagion experiment even though the FTC had penalized it for mishandling user privacy just a couple of months before. Another serious problem with this argument is that, especially for technology companies, there are no consistent current standards regarding human subject research, and the individual policies for companies are often not transparent or open to oversight. Existing

<sup>96.</sup> WILLIAMS, supra note 45; 45 C.F.R. § 46.101(a) (2015).

<sup>97.</sup> Acohido, supra note 74.

<sup>98.</sup> Salganik, supra note 38.

consequences apparently did not make an impact on Facebook's decisions regarding careful treatment of users and user data, so more stringent and clearly defined ethical standards appear to be necessary to enact a change in behavior.<sup>99</sup>

Though Facebook is the most prevalent example used in this note due to the widespread public knowledge of the emotional contagion experiment, it is important to note that Facebook is not the only company to have performed large-scale research on it users and that Facebook has been attempting to rectify its privacy and research policies since the experiment. 100 These recent internal changes seem to point toward an attempt to use the third argument: companies can monitor themselves enough to protect consumers. Facebook has implemented a mandatory training program for all Facebook employees, regardless of department, to educate them on the company's policies regarding user privacy and on potential conflicts that may arise regarding user data use. 101 Specifically, this training program focuses on research practices and responsibility. The training emphasizes employees weighing the value and classification of research and privacy issues by looking at the population of users to be tested or affected, the reason for the research, whether the research covers a sensitive topic, and whether there is some collaboration involved in the research that may create a conflict (as there was in the Facebook emotional contagion experiment). 102 This training is more indepth for data scientists employed at Facebook, as they will have more direct contact with user data.

While training programs are a wonderful step in the right direction, there is no guarantee that they will continue in the future or that companies will not choose to discontinue them at some point, leaving users vulnerable to a lack of oversight again. A lack of external ethical standards leave these programs at the whim of the company and trusting in the goodness of the company is not an adequate safeguard for consumers.

Facebook also has an updated internal review process in place which provides that any proposed research project must consist of a research group that includes a senior researcher who has cleared the research project. The senior researcher must be available to oversee the research project and respond to any criticism. Each research project is

<sup>99.</sup> Acohido, supra note 74.

<sup>100.</sup> Rafa Irizarry, Roger Peng & Jeff Leek, *A (Very) Brief Review of Published Human Subjects Research Conducted with Social Media Companies*, SIMPLY STATISTICS (Aug. 20, 2014), http://simplystatistics.org/2014/08/20/a-very-brief-review-of-published-human-subjects-research-conducted-with-social-media-companies/.

<sup>101.</sup> Interview with Rob Sherman, supra note 11.

<sup>102.</sup> *Id*.

<sup>103.</sup> Id.

also subject to a cross-functional review process, meaning that the group reviewing the proposal must include people from different departments and disciplines within Facebook so they can raise concerns from other perspectives. This is extremely helpful in evaluating the potential benefits of proposals before implementing them, but it still falls prey to the problem that everyone reviewing the proposal is an employee of the same company. If it is well-known that a proposal is especially desirable to upper management, there is a strong likelihood that employees will not raise potential concerns in an effort to please their superiors. This problem could be solved if some input from outside the company was allowed regarding proposals.

The third argument that industry polices itself also points to voluntary transparency by companies. Even prior to this experiment and the accompanying criticism, Facebook had a public website posted with links leading to various research publications it had participated in and changes to the site and service. 105 Facebook has, however, heightened its focus on transparency since this conflict and is in an ongoing discussion with the public, Facebook users, and the legal community, even going so far as to send a member of the Facebook legal team to a panel discussion to engage with journalists and legal professionals regarding the ethics and ramifications of the experiment. 106 Facebook's efforts and willingness to be open in dialogue regarding how to improve are admirable, but the public cannot depend on the hope that other companies will express a similar willingness to be transparent and enter into discussion. Nor can the public count on Facebook's policies alone when there is still no outside oversight. Though it may be complex allowing outside access to these aspects of the business, it is necessary that employees of one company are not solely responsible for making all the ethical decisions. A more uniform policy must be put into place that addresses issues of outside oversight, transparency, clear purposes, and informed consent.

## C. Proposals for Implementing Change

A proposal by Professor Ryan Calo of the University of Washington School of Law posited the idea of creating separate Consumer Subject Review Boards ("CSRBs"), similar to, but distinct from, IRBs. CSRBs would be specifically tailored to deal with tests and experiments on consumers and would focus on sales organizations rather than academic or federal organizations. He proposes that the FTC, Department of

<sup>104.</sup> Id.

<sup>105.</sup> See Research at Facebook, FACEBOOK, https://research.facebook.com/ (last visited Feb. 8, 2016).

<sup>106.</sup> Interview with Rob Sherman, supra note 11.

Commerce, or industry as a whole commission an interdisciplinary report on consumer research ethics and draw up some principles stemming from the report. Those principles would then be codified, perhaps by adding them to the Federal Register. Additionally, companies that perform frequent consumer research would create diverse internal committees (similar to those currently in place at Facebook) which would review proposed initiatives, fast-tracking those clearly meant to benefit consumers and flagging for further review any with questionable motives or side effects. 109

Professor Matthew Salganik, who has performed online experiments, worked at a technology company, and served on a Princeton University IRB, has proposed that technology companies develop Human Subject Research Oversight Boards ("HSROB") that would function similarly to IRBs. 110 These could be tailored according to a few main principles that would make them more compatible with technology companies, such as being: "1) restricted in scope, 2) focused on balancing risks and benefits, 3) transparent, 4) dynamic, and 5) diverse." These boards could adapt more quickly to the ever-changing nature of technology and could address unanticipated issues that arise as new technology develops. This is similar to Professor Calo's CSRB idea (although Calo's proposal also includes internal review and statutory measures addressing ethical concerns) and could likewise be effective at accomplishing the overall goals of human subject research ethical rules: protecting the subjects of experiments with effective safeguards and protections while allowing for as much research as possible that may garner valuable information for society as a whole.

Professor James Grimmelmann's article clearly lays out some specific ideas regarding Facebook, privacy, and data use for the users. <sup>112</sup> He proposes public disclosure torts for violations of user privacy regarding data, rights of publicity where users control the information they reveal and who sees it, a reliable opt-out option for any surveys or experiments performed, predictability in what sorts of experiments are and are not acceptable, no chain letters (also referred to as "incentivized invites"), <sup>113</sup> and user-driven education (users explaining to other users

<sup>107.</sup> See Ryan Calo, Consumer Subject Review Boards: A Thought Experiment, 66 STAN. L. REV. ONLINE 97 (Sept. 3, 2013), http://www.stanfordlawreview.org/online/privacy-and-big-data/consumer-subject-review-boards.

<sup>108.</sup> Id.

<sup>109.</sup> Id.

<sup>110.</sup> Salganik, supra note 38.

<sup>111.</sup> Id.

<sup>112.</sup> James Grimmelmann, Saving Facebook, 94 IOWA L. REV. 1137 (2009).

<sup>113.</sup> *Id.* at 1203 (one example of an "incentivized invite" is a game like Farmville where a player receives special bonuses if they invite ten friends to join the game).

how to protect their own online privacy and data). 114

The Electronic Privacy Information Center ("EPIC") has proposed that Facebook should be forced to make its News Feed algorithm public in all of its present and future iterations. Theoretically, this would create more oversight of manipulations in the News Feed and the transparency would serve as some measure of protection for consumers.

Professor Calo's CSRB proposal could be effective at ensuring external oversight of human subject research conducted within businesses. Forcing researchers and companies to seriously think through the proposals before submitting them would help weed out potentially dangerous projects with low rewards and high risk. This proposal would allow for more focused purposes for experiments and would make the research more transparent by necessity. Further, this proposal goes the extra mile in looking past privacy to also consider "fairness, equality, and other civil liberty concerns." The CSRBs would also insist on as much informed consent as possible and could assist companies in determining how best to proceed with informed consent in each research circumstance.

Professor Salganik's proposal is useful and the HSROBs could likely combine with Calo's CSRB idea to create a strong reviewing entity for any human subject research conducted by companies. However, Salganik does not directly address whether there should be any internal action by the companies or what enforcement would make companies present their proposals to the review boards. More elaboration on these points could round out the proposal to make it realistically applicable and enforceable.

While Professor Grimmelmann tailored his proposals specifically to Facebook, they could have further-reaching applications for companies in general and could improve ethical standards for consumer-driven industries. However, the proposals seem to have more to do with data ownership and privacy rights than with ethical standards for human subject research. His proposals may be too specific for universal application and do not address review boards, internal review of proposals, or enforcement methods beyond torts that could provide legal recourse for consumers.

Though EPIC's proposal may be useful in this one instance, it is not universally applicable for other companies and businesses. In order to develop a truly effective framework that protects consumers from illadvised experiments before they happen, that framework must be based

<sup>114.</sup> Id. at 1137.

<sup>115.</sup> Gibbs, supra note 72.

<sup>116.</sup> Jules Polonetsky, Omer Tene & Joseph Jerome, *Beyond the Common Rule: Ethical Structures for Data Research in Non-Academic Settings*, 13 COLO. TECH. L.J. 337 (2015).

on overarching principles of business research. This proposal simply reacts as a new experiment is revealed.

Of these proposals, Professor Calo's seems the most comprehensive and widely applicable to use as a framework, though his ideas require expansion and practical contributions from corporations to determine how to make the rules most effective in real application. His CSRBs together with codified rules or standards regarding human subject research could provide outside oversight and accountability for the organizations performing the research. Diverse internal review boards provide for creating clear statements of purpose for each research proposal and aid in weeding out proposals that may be detrimental to users. Furthermore, the CSRBs would ensure that research plans incorporate as much informed consent as possible. While there are important questions to address in the specific writing and implementation of these rules, 117 Calo's proposal provides the research community with a workable framework from which to start. This framework could easily incorporate the standards which are absolutely necessary to include in any viable and effective protection of consumers in corporate human subject research: outside oversight and accountability, a specific and legitimate stated purpose of the experiment, and as much informed consent as possible.

#### **CONCLUSION**

The public outrage, lack of informed consent, and insufficient research parameters of the subject pool for the Facebook emotional contagion experiment demonstrate the need for more universal ethical standards when it comes to human subject research. Setting more universal standards would help to close the IRB laundering loophole present in the current standards and would assuage academics' concerns about collaborating with businesses. Though differences of structure and goals exist between academic institutions and corporations, standards could be put in place that work around those differences and are tailored to business needs while protecting consumers. Professor Calo's proposal sets out a feasible framework that shows how these standards could be put into practice. While taking into account the specific needs of the business or organization in question, it is possible and necessary that we

<sup>117.</sup> David B. Resnik, Closing Loopholes in the Federal Research Regulations: Some Practical Problems, 8 AM. J. BIOETH. 6 (2008), http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2650234/ (explaining need for hard statistics on how big the problem is, whether to include unregulated research with very low risk to subjects in the framework, and better definitions of both 'research' and 'minimal risk').

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adopt common standards for human subject research that incorporate outside oversight and accountability, a specific and legitimate stated purpose of the experiment, and as much informed consent as is possible.

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