

## Science and Social Media

ALAN REGENBERG 

Johns Hopkins Berman Institute of Bioethics, Baltimore, Maryland, USA

### SUMMARY

He Jiankui et al. conducted an experiment that resulted in the birth of the first human babies with germline gene editing. Initial and predominant communications of their work occurred via social media and outside of the norms for reviewing, approving, and engaging around work in science. This case provides an opportunity to reflect on the evolving and increasing presence of social media in science, its strengths, weaknesses, and the potential to develop applications that improve how we review, approve, and engage around the work of science. Social media use in science presents significant challenges. The potential benefits of addressing these challenges and developing new social media tools include greater transparency, access, and engagement—and could nurture the public's trust. *STEM CELLS TRANSLATIONAL MEDICINE* 2019;8:1226–1229

### SIGNIFICANCE STATEMENT

As demonstrated by the recent case of He Jiankui et al., using social media as a primary means of introducing colleagues and the public alike about their controversial work, social media use in science is increasing and evolving. Its use presents complex challenges that will need to be fully explored and addressed. It also presents unique opportunities for developing new tools that can improve the ways in which the work of science is reviewed, approved, and communicated. These improvements could nurture the public's trust.

On November 25, 2018, an article was posted detailing efforts of a team led by He Jiankui to recruit couples to participate in creating the first gene-edited baby [1]. Precise and accessible new gene-editing technologies, notably CRISPR, have generated excitement about their uses, including potential regenerative medicine applications [2–4]. In addition to hopes for novel interventions, they have also generated controversies over appropriate uses and oversight. News of the birth of intentionally gene-edited babies arrived in the context of seemingly broad consensus within the scientific community that the use of this technology for modifying the human germline should not be allowed at this time, if ever [5].

Facing intense media scrutiny, the He lab took the unusual step of describing their work, and confirming the birth of twin girls, via five brief videos on YouTube [6]. A few days later, He used a previously scheduled appearance at the Second International Summit on Human Genome Editing in Hong Kong to offer a somewhat more formal presentation of his work and address questions from colleagues and journalists [7]. At the event, He alluded to a second “potential pregnancy” involving different parents, which was subsequently confirmed by Chinese government officials [8]. He's presentation was shared not just through traditional media coverage, but also via social

media, in real time via live-tweeting attendees and posted video recordings [9–11].

Social media play an increasing role in communicating about science, but typically as more of an adjunct to traditional processes, and not the sole or primary mode for communicating, particularly for work that has not been otherwise reviewed or approved by scientific/professional communities. Furthermore, while the attributes of social media make them seem like a natural tool to bridge a gap allowing scientists to engage with nonexpert communities, the current overall impact of social media on science is not clear [12–14]. Some of the uncertainty comes from challenges in defining appropriate proxies for measuring impact in this context, and this highlights the core challenges that social media may help address. For example, in looking at how to assign appropriate values to social media-based interactions with content from scientific publications, looking at mentions in tweets may overly value very shallow engagement, whereas looking at the number citations may undervalue engagement with groups outside of the expert scientist communities (who are substantially less likely to respond to their engagement with an academic publication that cites the original paper). Efforts to address uncertainty are further complicated by the continuing evolution of social media, the rise

Correspondence: Alan Regenberg, MBE., Johns Hopkins Berman Institute of Bioethics, 1809 Ashland Ave, Baltimore, Maryland, USA. Telephone: (410)614-5391; e-mail: alanr@jhu.edu Received March 5, 2019; accepted for publication June 20, 2019; first published July 7, 2019. <http://dx.doi.org/10.1002/sctm.19-0066>

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

and fall of various platforms, and changes in their use in science.

The arrival of social media has begun to spur some change, but, for now, the overall process for review and approval in science still largely involves professional peers in mediating a frequently veiled process of discussion, review, and modification of new work prior to acceptance (or not) as a legitimate part of the larger body of work in a particular area of science. Ideally, approved work can then be shared with a broader community of professionals and peers through presentations of papers at meetings of societies and the publication of papers in peer-reviewed, scholarly journals.

A subset of this approved work becomes core content for outreach to public audiences, typically by seeking amplification through earning media coverage in traditional print or broadcast news media outlets. Earned media remains an invaluable coin of the realm in evaluating success and impact in public outreach and engagement. This is pursued through established tools such as press releases and direct contact with journalists/science writers. At the same time, traditional communication/dissemination pathways exist in ever-increasing symbiosis with social media, and boundaries between traditional and social media are blurry. Print and broadcast media are commonly accessible online and easily shared and discussed via social media platforms. Professional meetings are often partially “broadcast” in real time via live-tweeting.

The troubling, and still-unfolding narrative of He Jiankui et al. disrupted science norms, and social media play a very central role in the story. Although He informally discussed his intentions with a number of colleagues [15, 16], his work may have eluded any formal review or approval processes prior to enrolling patients. It is possible to downplay and dismiss this as just the story of a rogue, bad actor and a marked outlier for current practice. Instead, in addition to reconsidering failed regulatory mechanisms, I think that we are provided with an opportunity to pause and reflect on evolving norms for social media use in science. What are future possibilities and the appropriate roles for social media in science? What are their strengths and limitations, particularly for science that evokes broad public interest and concern?

Evolving processes for review, approval, and engagement with the work of science include a sweep of distinct but entangled elements, such as peer review for presentation or publication, ethical review, and efforts to broadcast and promote engagement around particular findings. Social media present opportunities that could result in improvements for these processes. These could come through features such as increased transparency and expanded engagement, a sort of democratization of the processes. This can yield better, more widely disseminated products, within practical limits. Realizing these opportunities will also require navigating some significant challenges while developing new norms, tools, and processes. The aim of this paper is to reflect on the current and potential future relationships between elements within this sweep of entangled elements and social media.

#### STRENGTHS

Social media are dynamic electronic content that are easily shared, filtered, commented upon, and recommended. Popular

social media platforms regularly used for science communication include Twitter, Facebook, YouTube, and blogs. Most social media are freely available. It can have an enormous impact, reaching global audiences, and providing an open portal to events unfolding in real time. The potential removal of mediators and distance from between participants who can engage quickly and directly is notable, and has been described as apomediation [17]. With these attributes, social media can provide a transformative platform for direct engagement between participants who may have otherwise been unlikely to communicate with each other. And, of course, their use leaves behind a fairly constant trail of evidence that can easily be revisited.

The drive to use social media to find new tools for improving how we engage with the work of science is understandable. Incentives include more broadly sharing work about which scientists may be passionate, professional recognition, funding, selling products, and more. The He Lab also had a more elusive incentive to use social media, the imminent virality that comes with a topic of deep public interest, while avoiding a time-consuming review process. Each of the He Lab videos has received many thousands of views; one exceeded 385,000 views in just a few months [18]. This, in comparison to the average readership for scientific publications, which is commonly thought to be way below this mark [19–22]. This same virality helped disseminate responses and debate among members of global scientific and regulatory communities.

#### LIMITATIONS

Social media engagement is messy and noisy. The apomediated playing field may bring as many challenges as benefits. As social media use grows, it will be increasingly important to explore and address its limitations (as well as its strengths) in different contexts including ethical and peer review processes and broader engagement around the work of science.

For example, live tweeting from professional society meetings as a bridge for those unable to attend raises concerns. Public sharing of elements of already brief presentations may be unwelcome and result in misrepresentations of the views of the authors [23–25]. This may not only be the result of direct errors, but can also result from snippets of work that are isolated from essential context for understanding. Discomfort with social media may discourage some members of professional communities from sharing their work at conferences, particularly for early or controversial work.

Current mediated methods of peer reviewing and approving the work of science remain imperfect [26], but, mediators can serve a vital role of filtering out problematic work that is low quality, replete with errors, or fraudulent. Imagining a future that hastily replaces this system with an apomediated process would leave the task of evaluating science undefined and in the hands of an ad hoc community of online responders. Many of these responders may lack the tools or expertise to make some of the necessary judgments. The absence of an established and well-understood social media-based process with clear roles that operate in a way that is sufficient to replace existing mechanisms is problematic and can make it exceedingly hard for those outside of the professional community to distinguish the work of scientists from that of hucksters and rogues. This is apparent in the way the story about the He

Lab's work unfolded both via traditional media and through social media conversations. Narratives were replete with uncertainties and relied heavily on terms like "claims" and "alleges" as the work was presented without access to typical tools that provide (imperfect) indicators for validating the quality and separate science fact from science fiction provided by the peer review and publication process.

Although it is feasible to develop a set of new expectations, understandings, and apomediated systems through which review, modification, and approval can happen transparently in and a social media workspace, the necessary foundations would need to be negotiated and established. This would represent a significant change, and we should expect a confusing and challenging transition. A range of macro-level hurdles would need to be navigated, from promoting openness in the context of government censorship [27] to navigating for-profit instincts toward trade secrets [28].

### NEW NORMS AND TOOLS

Scientific communities have largely been responsive to social media incursions, with the development of policies and norms following in the wake of newly arrived challenges. More forward-looking and creative explorations of the potential for social media tools could yield far greater benefits.

Professional conferences can be costly and require days in travel and attendance. They are designed for limited audiences, but could be reimagined as more inclusive and accessible events via ever more immersive social media connections. Social media use, particularly via Twitter, is already common, if not always welcome at conferences [29–31]. Next generation social media engagement could be designed to more closely emulate the in-person experience for remote connectors, while seeking enhancements for all involved. New norms and occasionally formal policies are already emerging to facilitate clear communication by presenters regarding their preferences for sharing of their work in this context. Policies should encourage broad engagement via social media platforms as the default and challenge social media users to be vigilant in ensuring that the content they share is clear, accurate, and shared in accordance with the preferences of the content creator. All professional societies should develop and share social media policies for meetings and conferences.

Current review processes designed before the advent of social media are far from perfect. They can be slow and inconsistent. Quality indicators to distinguish among approved (i.e., published) work can be elusive and opaque, particularly to those outside of specific fields within science. Bad actors create additional confusion, and a full spectrum of shady to fraudulent publishers abound, as evidenced by regular sting operations [32, 33]. Resource limitations and inequities can severely limit access to top journals both for scientists and for those trying to access published work.

Although elements of open science like increasingly open access and open peer review have begun to take root, shifting the review, feedback, and approval processes more fully out into the frighteningly transparent and messy social media space may provide a much-needed boost to combat these challenges. It could yield a faster, more transparent, higher quality, more accessible process for reviewing and approving

the work of science [34]. The use of apomediated social media could also facilitate the introduction of important perspectives that are currently missing from the process.

Scientific communities should challenge themselves to reimagine how to format the content itself to optimize the benefits of this new environment. For example, authors recently published a "computationally reproducible article" where visitors can manipulate and rerun code, accessing results in real time, as a new way to communicate their work [35]. In addition, a social media infusion could enhance mechanisms for rapidly integrating apomediated feedback from diverse audiences into the story of the work itself. This feedback could include responses not only to the specific work, but also to various aspects of its review, such as the regulatory processes meant to ensure ethical integrity. Rapid uptake and response to this feedback could serve to enhance trust in both the work and the elements of the review processes.

Finally, social media engagement should be funded and valued by institutions [36]. The importance of these efforts should be reflected in evaluations and promotions. Social media metrics reporting such as altmetrics [37] can provide some evidence of impact, but as noted earlier, the measuring impact is challenging and requires further exploration.

### SOCIAL MEDIA AS A PLATFORM FOR DELIBERATIVE ENGAGEMENT

Even before the work of the He Lab became known, accessible, precise, new tools, notably CRISPR-Cas9, prompted a new wave of responses and recommendations from members of the scientific community [5]. Common among these is a call for some form of broad public engagement. It is noteworthy that this call for public engagement is coming from members of the scientific community who are using academic publications to communicate guidance assembled by experts for experts, without any direct efforts at public engagement. Despite the irony, the inclusion of calls for broader public engagement remains a hopeful and positive step.

Given the rapidly changing, and complex science behind these important societal debates, a deliberative engagement method [38] might provide a perfect fit. Through it, community members would be supplied with the needed background information and a setting for civil conversations with peers with occasional access to experts to resolve technical challenges. Deliberative engagement methods bring some limitations. They typically rely on expensive and time-consuming in-person meetings. The process can be slow and result in small sample sizes, which may not adequately represent the range of views held by broader communities of stakeholders.

Although there is no dearth of experience with the use of a wide variety of deliberative engagement methods to take on a wide variety of topics in person [39, 40], integrating new social media tools to replicate face-to-face meetings may provide an alternative to address these challenges. Although tales of trolls and bad online behavior might suggest that this setting is incompatible with civility, experience with the use of similar methods in live events suggests that there is a public appetite for safe spaces for civil, deliberative engagement that could be replicated online with appropriate rules and

structures in place. At the very least, it is a goal worth pursuing given the potential benefits.

## CONCLUSION

Social media have an important role to play in increasing transparency and promoting apomediated communication around complex and challenging issues. As the He Lab demonstrated, the use of social media in science is rapidly evolving and increasingly significant with or without thoughtful consideration of its use by the scientific community. As currently deployed, social media offer a useful adjunct, but not a plausible substitute, for

existing structures for reviewing, approving, and communicating the work of science. A full range of activities could be substantially reimagined and enhanced by social media. This transition requires new structures and the navigation of diverse and significant challenges, but the payoff is the development of new tools to promote transparency, access, and engagement—and nurture the public's trust.

## DISCLOSURE OF POTENTIAL CONFLICTS OF INTEREST

The author indicated no potential conflicts of interest.

## REFERENCES

- 1 EXCLUSIVE: Chinese Scientists are Creating CRISPR Babies. Available at <https://www.technologyreview.com/s/612458/exclusive-chinese-scientists-are-creating-crispr-babies/>. Accessed March 3, 2019.
- 2 Vassena R, Heindryckx B, Peco R et al. Genome engineering through CRISPR/Cas9 technology in the human germline and pluripotent stem cells. *Hum Reprod Update* 2016;22:411–419.
- 3 de Wert G, Heindryckx B, Pennings G et al. Responsible innovation in human germline gene editing. Background document to the recommendations of ESHG and ESHRE. *Hum Reprod Open* 2018;1:hox024.
- 4 Razzouk S. CRISPR-Cas9: A cornerstone for the evolution of precision medicine. *Ann Hum Genet* 2018;82:334–357.
- 5 Brokowski C. Do CRISPR germline ethics statements cut it? *CRISPR J* 2018;1:115–125.
- 6 The He Lab. Available at [https://www.youtube.com/channel/UCn\\_Elifynj3LrubPKHXecwQ](https://www.youtube.com/channel/UCn_Elifynj3LrubPKHXecwQ). Accessed March 3, 2019.
- 7 National Academies of Sciences, Engineering, and Medicine. Second International Summit on Human Genome Editing: Continuing the Global Discussion: Proceedings of a Workshop—In Brief. Washington, DC: The National Academies Press, 2019.
- 8 Second Woman Carrying Gene-Edited Baby, Chinese Authorities Confirm. Available at <https://www.theguardian.com/science/2019/jan/22/second-woman-carrying-gene-edited-baby-chinese-authorities-confirm>. Accessed March 3, 2019.
- 9 Presentation of Dr He Jiankui on the Second International Summit on Human Genome Editing. Available at [https://www.youtube.com/watch?v=pcGALqX\\_YD8](https://www.youtube.com/watch?v=pcGALqX_YD8). Accessed March 3, 2019.
- 10 November 28, 2018—International Summit on Human Genome Editing—He Jiankui Presentation and Q&A. Available at <https://www.youtube.com/watch?v=tLZufCrjrNO>. Accessed March 3, 2019.
- 11 #geneeditsummit. Available at <https://twitter.com/search?q=%23geneeditsummit&src=typd>. Accessed March 3, 2019.
- 12 Lamb C, Gilbert S, Ford A. Tweet success? Scientific communication correlates with increased citations in ecology and conservation. *PeerJ* 2018;6:e4564.
- 13 Fox C, Gurary E, Ryan J et al. Randomized controlled trial of social media: Effect of increased intensity of intervention. *J Am Heart Assoc* 2016;5:e003088.
- 14 Tonia T, Van Oyen H, Berger A et al. If I tweet will you cite? The effect of social media exposure of articles on downloads and citations. *Int J Public Health* 2016;61:513–520.
- 15 Kofler N. Why were scientists silent over gene-edited babies? *Nature* 2019;566:427.
- 16 U.S. Nobel Laureate Knew About Chinese Scientist's Gene-Edited Babies. Available at <https://www.nbcnews.com/health/health-news/u-s-nobel-laureate-knew-about-chinese-scientist-s-gene-n963571>. Accessed March 3, 2019.
- 17 O'Connor D. The apomediated world: Regulating research when social media has changed research. *J Law Med Ethics* 2013;41:470–483.
- 18 About Lulu and Nana: Twin Girls Born Healthy After Gene Surgery As Single-Cell Embryos. Available at <https://www.youtube.com/watch?v=thOvnOmFltc>. Accessed March 3, 2019.
- 19 The STM Report: An Overview of Scientific and Scholarly Publishing. Available at [https://www.stm-assoc.org/2018\\_10\\_04\\_STM\\_Report\\_2018.pdf](https://www.stm-assoc.org/2018_10_04_STM_Report_2018.pdf). Accessed May 24, 2019.
- 20 Can it Really be True That Half of Academic Papers are Never Read? Available at <https://www.chronicle.com/article/Can-It-Really-Be-True-That/243564>. Accessed March 3, 2019.
- 21 Meho L. The rise and rise of citation analysis. *Phys World* 2007;20:32–36.
- 22 Academics Write Papers Arguing Over How Many People Read (And Cite) Their Papers. Available at <https://www.smithsonianmag.com/smart-news/half-academic-studies-are-never-read-more-three-people-180950222/>. Accessed March 3, 2019.
- 23 Sugimoto C, Work S, Lariviere V et al. Scholarly use of social media and altmetrics: A review of the literature. *J Assoc Inf Sci Technol* 2017;68:2037–2062.
- 24 Roland D, May N, Body R et al. Are you a SCEPTIC? SoCial mEdia Precision & uTility In Conferences. *Emerg Med J* 2015;32:412–413.
- 25 Pemmaraju N, Mesa R, Majhail N et al. The use and impact of Twitter at medical conferences: Best practices and Twitter etiquette. *Semin Hematol* 2017;54:184–188.
- 26 Csizsar A. Peer review: Troubled from the start. *Nature* 2016;532:306–308.
- 27 'Gene-Edited Babies' is One of the Most Censored Topics on Chinese Social Media. Available at <https://www.nature.com/articles/d41586-019-00607-x>. Accessed March 3, 2019.
- 28 Di Gangi P, Johnston A, Worrell J et al. What could possibly go wrong? A multi-panel Delphi study of organizational social media risk. *Inf Syst Front* 2018;20:1097–1116.
- 29 Wilkinson S, Basto M, Perovic G et al. The social media revolution is changing the conference experience: Analytics and trends from eight international meetings. *BJUI* 2015;115:839–846.
- 30 Mohammadi D. Conference organisers swimming against the tide of Twitter. *BMJ* 2017;358:j3966.
- 31 Ghose A, Warren H, Raison N et al. The controversy of social media at conferences. *BJUI* 2018;21:823–824.
- 32 Al-Khatib A, Teixeira da Silva J. Stings, hoaxes and irony breach the trust inherent in scientific publishing. *Publ Res Q* 2016;32:208–219.
- 33 Predatory Publishers: The Journals That Churn Out Fake Science. Available at <https://www.theguardian.com/technology/2018/aug/10/predatory-publishers-the-journals-who-churn-out-fake-science>. Accessed March 3, 2019.
- 34 Munafò M, Nosek B, Bishop D et al. A manifesto for reproducible science. *Nat Hum Behav* 2017;1:0021.
- 35 Introducing eLife's First Computationally Reproducible Article. Available at <https://elifesciences.org/labs/ad58f08d/introducing-elifes-first-computationally-reproducible-article>. Accessed March 3, 2019.
- 36 Regenberg A, Schall T. Outreach and engagement: Evolving media and the public obligations of science. *Curr Stem Cell Rep* 2015;1:219–226.
- 37 Warren H, Raison N, Dasgupta P. The rise of altmetrics. *JAMA* 2017;317:131–132.
- 38 Daugherty Biddison E, Gwon H, Schoch-Spana M et al. The community speaks: Understanding ethical values in allocation of scarce lifesaving resources during disasters. *Ann ATS* 2014;11:777–783.
- 39 Bächtiger A, Dryzek J, Mansbridge J et al. *The Oxford Handbook of Deliberative Democracy*. Oxford, UK: Oxford University Press, 2018.
- 40 d'Entreves M. *Democracy as Public Deliberation*. New York, NY: Routledge, 2006.