

# The Greatest Generational Impact: Open Neuroscience as an Emerging Knowledge Commons

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## INTRODUCTION

Neuroscience is transforming. Brain data collected in multitudes of individuals and institutions around the world are being openly shared, moved from office desks and personal storage devices to institutionally supported cloud systems and public repositories – effectively bringing Neuroscience into the era of Big Data. This is an important evolution in Neuroscience, since the value of open data sharing has not always been recognized.<sup>1</sup>

It is “truth” commonly asserted that research scientists participate in an ethos of knowledge sharing by virtue of customary norms and practices within the scientific community.<sup>2</sup> However, the reality in many scientific research settings can be quite different. The area of neuroscience research provides a timely case study of an incipient knowledge commons in the process of formation against a background of sometimes fierce competition for reputational rewards and results. Partly because of new large-scale intergovernmental

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<sup>1</sup> Franco Pestilli, Test-retest measurements and digital validation for in vivo neuroscience, 2 *Sci. Data* 1 (2015).

<sup>2</sup> David Bollier, The Growth of the Commons Paradigm, in *Understanding Knowledge as a Commons: From Theory to Practice* 27 (Charlotte Hess and Elinor Ostrom eds., MIT Press 2006), at 37

initiatives<sup>3</sup> and sources of funding, it is fair to state that the neuroscience research community is in a process of active institutional change on local, regional and global levels.

This chapter describes what some in the neuroscience research community are calling the “open neuroscience movement.”<sup>4</sup> It situates this case study within the intersecting scholarly literatures on knowledge infrastructure<sup>5</sup> and knowledge commons,<sup>6</sup> both of which are related to open innovation research.<sup>7</sup> By focusing on how institutional actors cooperate (or not) to form a knowledge commons and under what circumstances cooperation can occur,<sup>8</sup> this case study of sharing neuroscience data can shed light on enabling conditions for the emergence of these types of governance arrangements. It may be particularly useful in illuminating the dynamics in research environments dominated by an ethos of competitive, individual lab-based achievement.

According to Ostrom and Hess, the so-called action arena that is “at the heart of the [Institutional Analysis and Development [IAD] framework] . . . is an appropriate place to start when trying to think through the challenges of creating a new form of commons.”<sup>9</sup> The open neuroscience movement is characterized by disparate institutional actors who have a common recognition: the importance of sharing data. Yet even when this acknowledgement is accompanied by a commitment to open access

<sup>3</sup> Press Release, Office of the Press Secretary, The White House, Fact Sheet: BRAIN Initiative (Apr. 2, 2013), [www.whitehouse.gov/the-press-office/2013/04/02/fact-sheet-brain-initiative](http://www.whitehouse.gov/the-press-office/2013/04/02/fact-sheet-brain-initiative); Press Release, European Commission, Graphene and Human Brain Project Win Largest Research Excellence Award in History, as Battle for Sustained Science Funding Continues (Jan. 28, 2013), [http://europa.eu/rapid/press-release\\_IP-13-54\\_en.htm](http://europa.eu/rapid/press-release_IP-13-54_en.htm); Press Release, RIKEN Brain Science Institute, Japan Brain/MINDS Project Launches at the RIKEN Brain Science Institute (Nov. 11, 2014), [www.brain.riken.jp/en/announcements/20141029.html](http://www.brain.riken.jp/en/announcements/20141029.html); David Cyranoski, “Neuroscience in China: growth factor,” *Nature* 476, 22–24 (Aug. 3, 2011); David Cyranoski, “Chinese science gets mass transformation,” *Nature* (Sept. 23, 2015), [www.nature.com/news/chinese-science-gets-mass-transformation-1.15984](http://www.nature.com/news/chinese-science-gets-mass-transformation-1.15984).

<sup>4</sup> Suparna Choudhury et al., Big data, open science and the brain: lessons learned from genomics, 8 *Frontiers in Human Neurosci.* 1, 3 (May 16, 2014), [www.ncbi.nlm.nih.gov/pmc/articles/PMC4032989/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4032989/); see also Kate Murphy, Should all research papers be free? *New York Times* (Mar. 12, 2016), [www.nytimes.com/2016/03/13/opinion/sunday/should-all-research-papers-be-free.html](http://www.nytimes.com/2016/03/13/opinion/sunday/should-all-research-papers-be-free.html); Taking the online medicine, *Economist* (Mar. 19, 2016), [www.economist.com/news/science-and-technology/21694990-old-fashioned-ways-reporting-new-discoveries-are-holding-back-medical-research](http://www.economist.com/news/science-and-technology/21694990-old-fashioned-ways-reporting-new-discoveries-are-holding-back-medical-research); Brian Owens, Montreal institute going “open” to accelerate science, *Science* (Jan. 21, 2016), [www.sciencemag.org/news/2016/01/montreal-institute-going-open-accel-erate-science](http://www.sciencemag.org/news/2016/01/montreal-institute-going-open-accel-erate-science)

<sup>5</sup> Brett M. Frischmann, *Infrastructure: The Social Value of Shared Resources* (Oxford University Press 2012).

<sup>6</sup> Brett M. Frischmann, Michael J. Madison, and Katherine J. Strandburg (eds.), *Governing Knowledge Commons* (Oxford University Press 2014); Bollier, note 2.

<sup>7</sup> Jeremy De Beer, “Open” innovation policy frameworks: Intellectual property, competition, investment and other market governance issues (“Table 2: Various terms describing open innovation concepts”) (Report prepared for Industry Canada, 2015).

<sup>8</sup> Elinor Ostrom and Charlotte Hess, A Framework for Analyzing the Knowledge Commons, in *Understanding Knowledge as a Commons: From Theory to Practice* 34 (Charlotte Hess and Elinor Ostrom eds., MIT Press 2007).

<sup>9</sup> *Ibid.* at 44–45, 53–57.

to research data by major actors, many impediments to the formation of a widely available, accessible and comprehensive neuroscience data commons still exist. By focusing primarily on action situations and actors within this particular action arena, this chapter also addresses why (despite prevailing disincentives) there is growing impetus for broader participation in a neuroscience data commons.

As noted elsewhere in this chapter, the primary actors (or stakeholders) in a knowledge commons include the individual scientists who both generate and use data, the institutions they work for or with, the research funders, and those representing the public who benefit from (and as taxpayers sometimes indirectly fund) the research.<sup>10</sup> Methodologically, this chapter buttresses its observations with interviews of selected actors within key institutions that are attempting to bring forward this emerging knowledge commons; the interviewees include representatives of the stakeholder groups.<sup>11</sup> The chapter first outlines some of the benefits of and then some of the primary obstacles to participation in the desideratum of a neuroscience data commons. It concludes with some suggestions about how to expand a neuroscience data commons that will allow scientists to share data more optimally than current institutional arrangements permit.

## 8.1 OVERVIEW OF THE EMERGING NEUROSCIENCE DATA COMMONS

In spite of the vigorous development of neuroinformatics, and the many techniques for data collation, archiving, annotation, and distribution developed over the last decade, the amount of neuroscience data available is only a small fraction of the total. The solution depends upon commitments from both data providers across neuroscience and funding agencies to encourage the open archiving and sharing of data.<sup>12</sup>

Brett Frischmann, Michael Madison and Katherine Strandburg define a “knowledge commons” as arrangements for overcoming social dilemmas related to sharing and producing information, innovation and creative works,<sup>13</sup> and they further define the term “knowledge” as a set of intellectual and cultural resources.<sup>14</sup> These scholars characterize a knowledge commons as an institutional arrangement of resources “involving a group or community of people.”<sup>15</sup> The governance of a commons addresses obstacles related to sustainable sharing<sup>16</sup> and is based upon the foundational recognition that multiple uses do not always lead to depletion or scarcity of

<sup>10</sup> Jorge L. Contreras, *Data Sharing, Latency Variables, and the Science Commons*, 25 *Berkeley Tech. L. J.* 1601, 1629 (2010).

<sup>11</sup> See Appendix (“App.”) for a brief description of methodology.

<sup>12</sup> Daniel Gardner et al., *The Neuroscience Information Framework: A Data and Knowledge Environment for Neuroscience*, 6 *Neuroinform.* 149, 154 (2008).

<sup>13</sup> Brett M. Frischmann, Michael J. Madison and Katherine J. Strandburg, *Governing Knowledge Commons*, in *Governing Knowledge Commons* 1 (Brett M. Frischmann, Michael J. Madison, and Katherine J. Strandburg eds., Oxford University Press 2014), at 1.

<sup>14</sup> *Ibid.* at 2. <sup>15</sup> *Ibid.* <sup>16</sup> *Ibid.*

those resources.<sup>17</sup> The research on knowledge commons is a subset of the large body of scholarship on open innovation.<sup>18</sup>

To be sure, some intellectual resources can be affected negatively by those who free-ride on the ideas and efforts of others. This behavior can undermine creativity and innovation by making it more difficult for individual artists and inventors to benefit from their efforts. And of course this policy concern forms the rationale for exclusive rights such as copyrights and patents, as well as other forms of intellectual property. However, unlike biologist Garrett Hardin who forecast only tragic results from over-use of shared resources,<sup>19</sup> other scholars see myriad consequences, not all of which are negative. For example, legal scholar Carol Rose sees many “surprises” in commons-based arrangements for resource management, especially in the area of knowledge resources. Tragic examples such as acid rain are counterbalanced by surprising examples such as neglected disease consortiums<sup>20</sup> or Wikipedia.<sup>21</sup> And unlike the late political scientist Elinor Ostrom, who tended to view a commons of shared resources management as involving a limited community of participants with rather defined membership,<sup>22</sup> Rose views some resource-sharing arrangements as having porous rather than fixed boundaries for participation.<sup>23</sup>

Rose’s perspective on commons-based resource management aligns well with the definition of openness propounded by Frischmann et al. as “the capacity to relate to a resource by accessing and using it. In other words, the openness of a resource corresponds to the extent to which there are barriers to possession or use.”<sup>24</sup> Thus the IAD framework originally created by Ostrom can be adapted to analyze not only emerging rather than pre-existing collaborative arrangements but also “open science” initiatives such as the open neuroscience movement discussed here.

### 8.1.1 *The Open Neuroscience Movement*

The Human Genome Project (HGP) demonstrated the power of sharing research results. Jorge Contreras has noted that “according to one recent study, the U.S. economic output attributable to advances made by the HGP and follow-on projects

<sup>17</sup> See generally Carol M. Rose, *Surprising Commons*, 2014 *BYU L. Rev.* 1257 (2015).

<sup>18</sup> De Beer, note 7, at 27 (“Table 2: Various terms describing open innovation concepts”).

<sup>19</sup> Garrett Hardin, *The Tragedy of the Commons*, 162 *Science* 1243 (Dec. 1968).

<sup>20</sup> Katherine J. Strandburg et al., *The Rare Diseases Clinical Research Network and the Urea Cycle Disorders Consortium as a Nested Knowledge Commons*, in *Governing Knowledge Commons* 155 (Brett M. Frischmann, Michael J. Madison, and Katherine J. Strandburg eds., Oxford University Press 2014).

<sup>21</sup> Rose, note 17, at 27.

<sup>22</sup> Elinor Ostrom, *Governing the Commons: The Evolution of Institutions for Collective Actions* (Cambridge University Press 1990).

<sup>23</sup> Rose, note 17, at 28. <sup>24</sup> Frischmann et al., note 13, at 29.

totalled \$65 billion in 2012 alone”<sup>25</sup> – demonstrating the powerful effect of knowledge infrastructure in generating economic and innovative activity. As he also documents:

The fact that the genome commons is today a global, public resource owes much to a 1996 accord reached in Bermuda by scientific leaders and policy makers. The groundbreaking “Bermuda Principles” required that all DNA sequences generated by the HGP be released to the public a mere twenty-four hours after generation, a stark contrast to the months or years that usually preceded the release of scientific data (Bermuda Principles 1996). The Bermuda Principles arose from early recognition by scientists and policy makers that rapid and efficient sharing of data was necessary to coordinate activity among the geographically dispersed laboratories working on the massive project.<sup>26</sup>

Likewise, recent calls to make the growing banks of brain data, analytic tools and protocols publicly and freely accessible have been increasing in strength and visibility. They pervade the texts released by the committee for the U.S.-funded BRAIN Initiative<sup>27</sup> and other Big Data projects emerging in neuroscience.<sup>28</sup>

The ethos of the open neuroscience movement is to disseminate the data quickly – in a format that is accessible, useful and unrestricted – and encourage others to use it. This type of collaborative, large-scale basic scientific research has precedents outside of biology including the CERN particle accelerator project<sup>29</sup> and the Hubble Telescope. Certainly, the success of the HGP, which was biology’s first large-scale project, stemmed from “strong leadership from the funders; the shared sense of the importance of the task; and the willingness of the researchers involved to cede individual achievements for the collective good.”<sup>30</sup> In addition to government agencies funding neuroscience research, this era of Big Data is notable for the involvement of nonprofit organizations (NPOs), including private foundations, public charities, and other newer entrants into the science arena – colloquially dubbed “big philanthropy.”<sup>31</sup>

<sup>25</sup> Jorge L. Contreras, Constructing the Genome Commons, in *Governing Knowledge Commons* 99 (Brett M. Frischmann, Michael J. Madison, and Katherine J. Strandburg eds., Oxford University Press 2014), at 100.

<sup>26</sup> *Ibid.* at 101.

<sup>27</sup> Advisory Committee to the Director, *Interim Report: Brain research through advancing innovative neurotechnologies* 47–51 (September 16, 2013), [http://www.braininitiative.nih.gov/pdf/09162013\\_interim\\_report\\_508C.pdf](http://www.braininitiative.nih.gov/pdf/09162013_interim_report_508C.pdf).

<sup>28</sup> Choudhury et al., note 4, at 2.

<sup>29</sup> Peter Galison, The Collective Author, in *Scientific Authorship: Credit and Intellectual Property in Science* 325 (Mario Biagioli and Peter Galison eds., Routledge 2d ed. 2013), at 327. CERN is the acronym for the French Conseil Européen pour la Recherche Nucléaire.

<sup>30</sup> Eric Green, Francis Collins, James Watson, Human Genome Project: twenty-five years of big biology, 526 *Nature* 29, 30 (2015).

<sup>31</sup> William J. Broad, Billionaires with big ideas are privatizing American science, *New York Times* (Mar. 15, 2014), [www.nytimes.com/2014/03/16/science/billionaires-with-big-ideas-are-privatizing-american-science.html](http://www.nytimes.com/2014/03/16/science/billionaires-with-big-ideas-are-privatizing-american-science.html)

Openly accessible neuroscience data is valuable. As several open neuroscience advocates have asserted:

Datasets from neuroimaging studies generally contain more information than one lab has the methodological and interpretive expertise to extract; data sharing therefore maximizes the utility of data and skills of researchers, accelerating the pace of investigations around particular questions [and is therefore a] crucial imperative from a scientific point of view to increase statistical rigor and open up interpretive possibilities.<sup>32</sup>

Interview participant Dana Bostrom, executive director, Orbis Cascade Alliance and former executive director of Data Commons LLC, observed that openly accessible data also provides an opportunity to generate bigger data sets through a combination of studies.<sup>33</sup> Open neuroscience advocates claim furthermore that

neuroscience research yields enormous quantities of complex data at various levels of study and open access to data in shared repositories offers the potential to integrate, re-use and re-analyze data[;]... [thus d]ata-sharing not only affords much greater sample sizes and therefore better quality of data, correcting for effects of noise or other errors; [but] it also becomes an economic imperative at a moment in which funding institutions and universities have limited resources.<sup>34</sup>

Interviewee Michael Hawrylycz, PhD, investigator at the Allen Institute, asserted that open data sharing allows a more valid historical record to be created of work that has been done – essentially, an archive of what is available and what is completed.<sup>35</sup> Data sets stored in laboratory archives suggest the absence of appreciation for the potential value of the data beyond the aim of the first study and are sometimes lost to the scientific community forever.<sup>36</sup> This is particularly true with “long tail dark data,” which is “unpublished data that includes results from failed experiments and records that are viewed as ancillary to published studies.”<sup>37</sup> When this dark data is not made accessible to other researchers, it leaves an incomplete and possibly biased record, needless duplication of scientific efforts and contributes to failures in scientific replication and translation.<sup>38</sup>

Furthermore, to facilitate reproducibility of the research, scientific data must be shared to help mitigate issues related to fraud and perceptions of misconduct.<sup>39</sup> Interviewee Craig Wegner, PhD, executive director and head, Boston Emerging Innovations Unit, Scientific Partnering & Alliances at AstraZeneca IMED Biotech Unit stated that participation in the neuroscience data commons for organizations

<sup>32</sup> Choudhury et al., note 4, at 2. <sup>33</sup> See App. (interview with Dana Bostrom).

<sup>34</sup> Choudhury et al., note 4, at 2. <sup>35</sup> See App. (interview with Michael Hawrylycz).

<sup>36</sup> Michael Peter Milham, Open neuroscience solutions for the connectome-wide association era, 73 *Neuron* 214 (2012).

<sup>37</sup> Adam R. Ferguson, Big data from small data: data sharing in the “long tail” of neuroscience, 17 *Nature Neurosci.* 1442, 1443 (2014).

<sup>38</sup> *Ibid.* <sup>39</sup> *Ibid.*

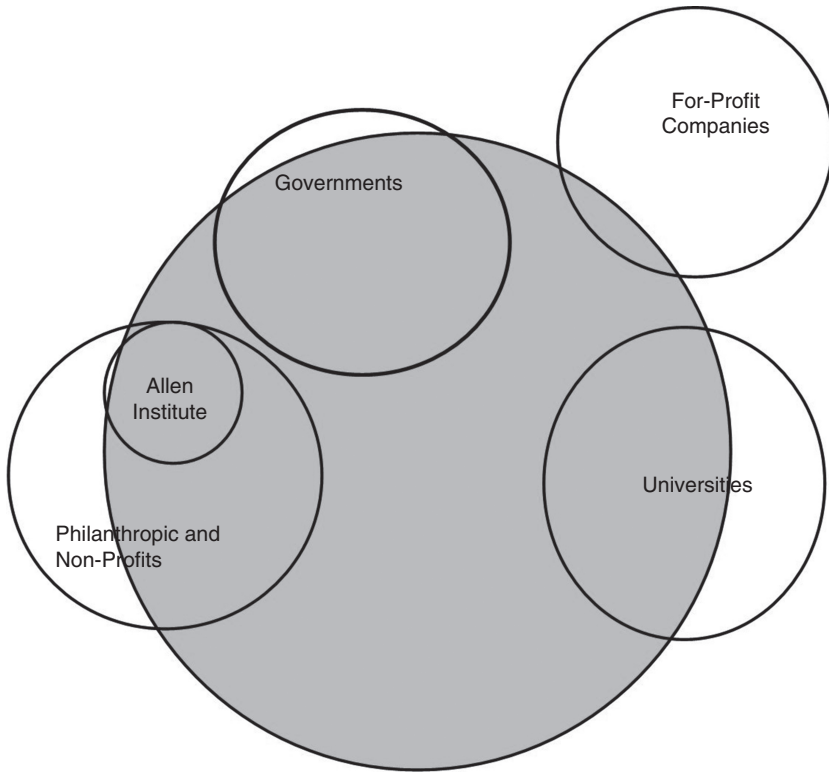


FIGURE 8.1 Actors in the neuroscience data action arena.

involved in clinical research can allay fears that the organization only publishes the positive research results and hides the adverse effects or negative results that are important for patients to know.<sup>40</sup> This openness can gain greater trust of patients and doctors for the research.<sup>41</sup>

Nonprofit research institutes, public and private universities and colleges, and for-profit biotechnology and pharmaceutical companies all have the ability to participate in a neuroscience data commons, yet not every organization chooses to participate as fully as it could, if at all (Figure 8.1). The next section explores some of the reasons affecting participation.

### 8.1.2 *Institutional Incentives to Participate in the Neuroscience Data Commons*

Three important organizational factors can incentivize (or de-incentivize) participation in the neuroscience data commons: (1) the mission of the organization, (2)

<sup>40</sup> See App. (interview with Craig Wegner). <sup>41</sup> Ibid.

primary funding for the organization's research, and (3) the focus of the organization's research within the research and development (R&D) cycle.

#### 8.1.1.1 Mission

An organization's mission and core values are critical to its willingness to participate in open data sharing. For example, participating and contributing to open science is key to the mission of the Allen Institute – a 501(c)(3) medical research organization formerly known as the Allen Institute for Brain Science. The original mission statement for the Allen Institute for Brain Science asserts that it exists “to accelerate the understanding of how the human brain works in health and disease [and generate] useful public resources.”<sup>42</sup> The mission statement of another nonprofit research institute involved in neuroscience research – the Eli and Edythe L. Broad Institute of Harvard and MIT (Broad Institute) – is to “propel progress in biomedicine through research aimed at the understanding and treatment of disease, and the dissemination of scientific knowledge for the public good.”<sup>43</sup> Janelia Research Campus, also a neuroscience research institute, “believes that the more collaborative and open it can be, the greater will be its ability to move science forward.”<sup>44</sup> The missions of all three of these nonprofit organizations go hand in hand with active participation in a neuroscience data commons.

Research universities also have missions that allow for broad participation in the neuroscience data commons. For example, Colorado State University (CSU) is “committed to excellence, setting the standard for public research universities in teaching, research, service and extension for the benefit of the citizens of Colorado, the United States and the world.”<sup>45</sup> According to interviewee Kathryn Partin, PhD, director, Office of Research Integrity and former assistant vice president for research and a professor of biomedical sciences at CSU, the university's mission – focused on education, service, and outreach – is consistent with data sharing since it is dedicated to applying new knowledge to real-world problems, and to translating that new knowledge economically and/or to the benefit of humanity.<sup>46</sup>

<sup>42</sup> Allen Institute, <https://alleninstitute.org/our-science/brain-science/about/vision-mission/> (last visited Dec. 26, 2015).

<sup>43</sup> Broad Institute, [www.broadinstitute.org/](http://www.broadinstitute.org/). Eli and Edythe L. Broad Institute of Harvard and MIT (Broad Institute), is a Boston-based collaborative research institute funded primarily via a nonprofit foundation.

<sup>44</sup> Janelia Research Campus, founded by Howard Hughes Medical Institute in 2005, is a collaborative research center in Ashbury, Virginia. Janelia Research Campus, [www.janelia.org/about-us](http://www.janelia.org/about-us) (last visited Dec. 26, 2015).

<sup>45</sup> Colo. State University, <http://csu-cvmb.colostate.edu/academics/bms/Pages/default.aspx> (last visited Dec. 26, 2015).

<sup>46</sup> See App. (interview with Kathryn Partin).



And while it may be counter-intuitive that a for-profit company would participate in open data sharing, the pharmaceutical industry is moving toward this model.<sup>47</sup> As Wegner stated, by participating at some level in open data sharing and increased transparency, these for-profit actors are also contributing to a change in culture for the research industry.<sup>48</sup> For example, AstraZeneca wants to make publicly accessible in an appropriate format all raw data that is generated in its clinical studies (rather than just a summary of results) so that the scientific community can look for trends and commonalities across multiple clinical studies and avoid duplication in future studies.<sup>49</sup> According to Wegner, AstraZeneca shares this data without fear of financial repercussion because by the time something is published, AstraZeneca is far ahead of a competitor who could reproduce the research.<sup>50</sup> The purpose of this is not just to advance science but also (as stated in the previous section) “to allay the fear that pharmaceutical companies will not just publish and show positive results while hiding adverse effects and other results important for patients to know.”<sup>51</sup> By becoming more transparent, pharmaceutical companies hope to gain additional trust.<sup>52</sup>

### 8.1.2.2 Funding

Sharing data and other research results is expensive and time consuming. It requires a commitment from funders, researchers, and their institutions. Many funders of neuroscience research understand the importance of participation in the data commons. And as funders, they are in the position to strongly encourage participation as a prerequisite for receiving funding. But while some grants include funding to make the research data openly available, that funding does not generally include the cost of long-term maintenance of that data in the commons. To address this need, there has been a steady increase of initiatives for openness by national and international, public and private funders in recent years.

#### 8.1.2.2.1 GOVERNMENT FUNDING

The National Institutes of Health (NIH) is one of the largest funders of neuroscience research in the world. According to it, “The era of ‘Big Data’ has arrived, and it is vital that the NIH play a major role in coordinating access to and analysis of many different data types that make up this revolution in biological information.”<sup>53</sup> Through financial support, the NIH seeks to enable scientific research that improves

<sup>47</sup> Jeff Tolvin, Data sharing in pharmaceutical industry shows progress, *Rutgers Today* (Oct. 16, 2014), <http://news.rutgers.edu/qa/data-sharing-pharmaceutical-industry-shows-progress/20141015>.

<sup>48</sup> See App. (interview with Craig Wegner). <sup>49</sup> Ibid. <sup>50</sup> Ibid. <sup>51</sup> Ibid. <sup>52</sup> Ibid.

<sup>53</sup> Press Release, Francis S. Collins, Director, Nat'l Institutes of Health, *NIH Names Dr. Philip E. Bourne First Associate Director for Data Science* (Dec. 9, 2013), [www.nih.gov/news-events/news-releases/nih-names-dr-philip-e-bourne-first-associate-director-data-science](http://www.nih.gov/news-events/news-releases/nih-names-dr-philip-e-bourne-first-associate-director-data-science).

health and mitigates the burden of illness or disability.<sup>54</sup> In 2003, the NIH announced its broad data-sharing policy that applies to all data resulting from, among other things, basic and clinical research.<sup>55</sup> This policy encourages researchers to make their data as widely and freely accessible as feasible.<sup>56</sup> The NIH also encourages openness through its public access policy, which requires all publications funded by the NIH to be made publicly available within 12 months.<sup>57</sup> In 2007, the National Science Foundation (NSF) announced similar guidelines, encouraging open data sharing and allowing the costs of such data sharing to be allowable charges against an NSF grant.<sup>58</sup> And in 2013, the Office of Science and Technology Policy (OSTP) reiterated the U.S. government's commitment to transparency of scientific data.<sup>59</sup> On the heels of this commitment was the Obama administration's announcement of its BRAIN Initiative: a large-scale initiative designed to revolutionize the understanding of the human brain.<sup>60</sup> Data funded by the BRAIN Initiative is subject to OSTP's memorandum. The Defense Advanced Research Project Agency (DARPA) is another U.S. government agency that supports the BRAIN Initiative and has an open data initiative. DARPA's Open Catalog was launched in 2014 and is meant as an open resource for publicly accessible research results that are funded by DARPA.<sup>61</sup>

Other national government funders have also increased attention toward open data sharing. The Engineering and Physical Sciences Research Council (EPSRC), which is a main UK government agency for funding research and training in engineering and the physical sciences, is committed to open data sharing. In May 2015, the EPSRC announced its policy, which is founded on seven core principles, the first being that "EPSRC-funded research data is a public good produced in the public interest and should be made freely and openly available with as few restrictions as possible in a

<sup>54</sup> Nat'l Institutes of Health, *Grants & Funding* (Sept. 24, 2015), [http://grants.nih.gov/grants/grant\\_basics.htm](http://grants.nih.gov/grants/grant_basics.htm).

<sup>55</sup> Nat'l Institutes of Health, *NIH Data Sharing Policy and Implementation Guidance* (March 5, 2003), [http://grants.nih.gov/grants/policy/data\\_sharing/data\\_sharing\\_guidance.htm](http://grants.nih.gov/grants/policy/data_sharing/data_sharing_guidance.htm).

<sup>56</sup> *Ibid.* ("There are many reasons to share data from NIH-supported studies. Sharing data reinforces open scientific inquiry, encourages diversity of analysis and opinion, promotes new research, makes possible the testing of new or alternative hypotheses and methods of analysis, supports studies on data collection methods and measurement, facilitates the education of new researchers, enables the exploration of topics not envisioned by the initial investigators, and permits the creation of new datasets when data from multiple sources are combined. In NIH's view, all data should be considered for data sharing. *Data should be made as widely and freely available as possible while safeguarding the privacy of participants, and protecting confidential and proprietary data*" (emphasis in the original).

<sup>57</sup> *NIH Data Sharing Policy and Implementation Guidance*, see note 55.

<sup>58</sup> Nat'l Science Foundation, *Award and Admin. Guide* Chapter IV, Nat'l Sci. Found., [www.nsf.gov/pubs/policydocs/pappguide/nsf11001/aag\\_6.jsp](http://www.nsf.gov/pubs/policydocs/pappguide/nsf11001/aag_6.jsp) (last visited Oct. 15, 2015).

<sup>59</sup> Memorandum from Office of Sci. & Tech. Policy, Exec. Office of the President on Increasing Access to the Results of Federally Funded Scientific Research (Feb 22, 2013) (on file with White House).

<sup>60</sup> Office of The Press Sec'y, The White House, Fact Sheet: Brain Initiative (April 2, 2013), [www.whitehouse.gov/the-press-office/2013/04/02/fact-sheet-brain-initiative](http://www.whitehouse.gov/the-press-office/2013/04/02/fact-sheet-brain-initiative).

<sup>61</sup> Defense Advanced Research Project Agency, Our Research, [www.darpa.mil/our-research](http://www.darpa.mil/our-research) (last visited Dec. 26, 2015).

timely and responsible manner.<sup>62</sup> The European Commission also has indicated its support of open access to scientific information in its Europe 2020 Initiative.<sup>63</sup> In this initiative, similar to the NIH, the European Commission required a data management plan for funded projects under the Guidelines for Data Management in Horizon 2020.<sup>64</sup> The Organisation for Economic Co-operation and Development (OECD) added its voice with a policy report on the benefits of Big Data.<sup>65</sup>

#### 8.1.2.2.2 PHILANTHROPIC FUNDING

This push for data sharing of publicly funded research comes when government funding for such research has been in decline. During the same period of time, however, philanthropic funding has been on the rise.<sup>66</sup> Individual philanthropists and foundations can provide a research organization with the funding needed to participate in the neuroscience data commons. Some examples of nonprofit organizations that participate in the neuroscience data commons are the Wellcome Trust, One Mind, and the Allen Institute.

The Wellcome Trust is a global charitable foundation supporting biomedical science, innovations, public engagement, and humanities and social sciences.<sup>67</sup> More than £700 million (or approximately US\$900 million) are provided annually to support these research areas.<sup>68</sup> Its open access policy ensures that the research that it funds will ultimately foster a richer research culture by maximizing the distribution of these publications.<sup>69</sup> One Mind is a nonprofit organization dedicated to “benefiting all affected by brain illness and injury through fostering fundamental changes that will radically accelerate the development and implementation of improved diagnostics, treatments and cures – while eliminating the stigma that comes with mental illness.”<sup>70</sup> One Mind published several principles on open science for projects it funds:

1. Provide informed consents for collection of medical data obtained from patients, which should permit use of their de-identified (anonymous) data for research

<sup>62</sup> Engineering and Physical Sciences Research Council, ERSC policy framework on research data, [www.epsrc.ac.uk/about/standards/researchdata/principles/](http://www.epsrc.ac.uk/about/standards/researchdata/principles/) (last visited Sept. 24, 2015).

<sup>63</sup> European Commission, Open Access to Scientific Information, <https://ec.europa.eu/digital-agenda/en/open-access-scientific-information> (last visited Dec. 26, 2015).

<sup>64</sup> European Commission, Guidelines on Data Management in Horizon 2020 (Feb. 15, 2016), [http://ec.europa.eu/research/participants/data/ref/h2020/grants\\_manual/hi/oa\\_pilot/h2020-hi-oa-data-mgt\\_en.pdf](http://ec.europa.eu/research/participants/data/ref/h2020/grants_manual/hi/oa_pilot/h2020-hi-oa-data-mgt_en.pdf)

<sup>65</sup> OECD Policy Note, Data-driven Innovation: Big Data for Growth and Well-Being: What Implications for Governments and Businesses? (Oct. 2015), <http://oe.cd/bigdata4>

<sup>66</sup> Our Approach, *Broad Inst.*, [www.broadinstitute.org/what-broad/our-approach/our-approach](http://www.broadinstitute.org/what-broad/our-approach/our-approach) (last visited Oct. 15, 2015).

<sup>67</sup> Funding, *Wellcome Trust*, [www.wellcome.ac.uk/funding/](http://www.wellcome.ac.uk/funding/) (last visited Sept. 24, 2015). <sup>68</sup> *Ibid.*

<sup>69</sup> Policy and Position Statements, *Wellcome Trust* [www.wellcome.ac.uk/About-us/Policy/Policy-and-position-statements/WTX035043.htm](http://www.wellcome.ac.uk/About-us/Policy/Policy-and-position-statements/WTX035043.htm) (last visited Sept. 24, 2015).

<sup>70</sup> About Us, *One Mind*, [www.onemind.org/About-Us](http://www.onemind.org/About-Us) (last visited Dec. 2, 2015).

related to a broad range of conditions – this is consistent with protecting patient privacy.

2. Use widely accepted common data elements and conform to the highest possible standards when clinical data is collected. This enables it to be used by the widest possible array of users, whether academic, medical, clinical or commercial.
3. Make data available to the research community as soon as possible after study completion, with the goal of opening data access within 6 months whenever possible.
4. Make data accessible to external researchers during the course of a study (subject to relevant data use agreements).
5. Give data generators proper attribution & credit from those who use their data.
6. Do not delay the publication of findings, as it may affect patient care. Intellectual property should not stand in the way of research, but be used to incentivize material participation.<sup>71</sup>

Within the neuroscience data commons, the Allen Institute provides a prime example of data sharing by virtue of its ongoing open science policy and practices, which are strongly encouraged by its primary philanthropic funder.<sup>72</sup> In an article published in *Nature*, for example, the initial scientists involved in the inaugural Allen Institute for Brain Science project that mapped the mouse brain wrote the following:

The Allen Brain Atlas project has taken a global approach to understanding the genetic structural and cellular architecture of the mouse brain by generating a genome-scale collection of cellular resolution gene expression profiles using ISH ... These methods enable global analysis and mining for detailed expression patterns in the brain. *The entire Allen Brain Atlas data set and associated informatics tools are available through an unrestricted web-based viewing application (emphasis added) (www.brain-map.org).*

This published research paper considers the data dissemination component to be integral to its scientific purpose. Thus these particular actors seem to be acutely aware of their role in the larger neuroscience and data-sharing commons within which the Allen Institute is nested,<sup>73</sup> illustrating that an institution's commitment to data sharing can permeate organizational culture and advance norms of open science. In 2014, the funding for neuroscience research done by the Allen Institute

<sup>71</sup> Our Solutions, *One Mind*, <http://onemind.org/Our-Solutions/Open-Science> (last visited Sept. 24, 2015).

<sup>72</sup> Paul Allen, Commentary: why we chose open science, *Wall St. J.* (Nov. 30, 2011), [www.wsj.com/articles/SB10001424052970204630904577058162033028028](http://www.wsj.com/articles/SB10001424052970204630904577058162033028028)

<sup>73</sup> Jonah Lehrer, Scientists map the brain, gene by gene, *Wired Magazine* (Mar. 28, 2009), [http://archive.wired.com/medtech/health/magazine/17-04/ff\\_brainatlas](http://archive.wired.com/medtech/health/magazine/17-04/ff_brainatlas)

(approximately US\$60 million) rivaled government funding by the NIH (approximately US\$46 million) in the BRAIN Initiative's first year (2014).<sup>74</sup>

While it has a greater emphasis on infectious diseases than on neuroscience, the Bill & Melinda Gates Foundation (Gates Foundation) is a private foundation that makes enormous investments in global health<sup>75</sup> and thus has influenced the acceptance of open data access more generally through its global access policy.<sup>76</sup> This policy has been in effect for the past decade and requires that information (including data) arising from its funding be made rapidly accessible.<sup>77</sup> In 2012, it started a pilot project for grants in excess of US\$500,000 and required grantees to provide a data access plan.<sup>78</sup> Since 2013, the Gates Foundation shifted its focus from dissemination of data to access to data. The Gates Foundation has an interest in data access for at least three reasons: (1) the data around early stage development of a drug, for example, to treat malaria, is relevant to showing scientific achievement or recognition that a particular drug is safe and effective; (2) the global, national, and local case data (e.g., mortality/morbidity granular data) is relevant to showing a reduction in the burden of disease, and to the extent that data can be overlaid with an introduction of new therapies, it helps make the case that the new therapy was the one that caused the reduction in burden and disease; and (3) the data that reflects the global level of effort in attacking a problem is important to ensure that the R&D spent by all funders – government, industry, private foundations – is funding work that is not duplication of effort but instead is complementary and consistent.<sup>79</sup>

#### 8.1.2.2.3 RESEARCH AND DEVELOPMENT CYCLE

The extent to which an organization participates in the neuroscience data commons may also depend on its research focus. The typical R&D cycle for scientific research starts with basic research and moves to clinical and/or translational research. The research categories are not fixed or rigid and an organization may be involved in

<sup>74</sup> Press Release, Nat'l Institutes of Health, NIH awards initial \$46 million for BRAIN Initiative research (Sept. 30, 2014), [www.nih.gov/news-events/news-releases/nih-awards-initial-46-million-brain-initiative-research](http://www.nih.gov/news-events/news-releases/nih-awards-initial-46-million-brain-initiative-research); Valerie Bauman, Allen Institute a key research partner in Obama's BRAIN initiative, *Puget Sound Business J.* (Apr. 2, 2013), [www.bizjournals.com/seattle/blog/techflash/2013/04/allen-institute-a-key-research-partner.html](http://www.bizjournals.com/seattle/blog/techflash/2013/04/allen-institute-a-key-research-partner.html).

<sup>75</sup> Bill and Melinda Gates Foundation, [www.gatesfoundation.org/](http://www.gatesfoundation.org/) (last visited Oct. 13, 2015).

<sup>76</sup> See App. (interview with Richard Wilder).

<sup>77</sup> Gates Foundation announces open access policy for grantees, *Philanthropy News Digest* (Nov. 28, 2014), <http://philanthropynewsdigest.org/news/gates-foundation-announces-open-access-policy-for-grantees>. (“Open-access policy to enable[s] unrestricted access to and reuse of all peer-reviewed published research, including underlying data sets, that it funds in whole or in part.”).

<sup>78</sup> See App. (interview with Richard Wilder). As a funder, the Gates Foundation generally does not have restrictions that potentially affect data sharing for the organizations it funds; rather, from a global access policy perspective, the overarching desire is to broadly and rapidly disseminate in an open fashion.

<sup>79</sup> *Ibid.*

categories at varying points along the continuum.<sup>80</sup> The cost to move research from the bench to the bedside is very high, and few funders are willing to invest in that research without knowing that they will be able to reap the financial benefits of commercialization. Therefore, it is intuitive that an institution that focuses primarily on basic research would be more inclined to participate in the neuroscience data commons than an institution that works on translational and/or clinical research. Perhaps one outlier in terms of data sharing is the rare disease context, which typically falls under translational and clinical research and where open approaches may be more attractive because of the small numbers and geographical dispersion of potential research participants, as well as the inapplicability of the “blockbuster drug” business model.<sup>81</sup>

It is not intuitive, however, that a for-profit pharmaceutical company would participate in the neuroscience data commons at any level, but if it did, one would expect it to also participate with its basic research. Pharmaceutical companies may improve research and development efficacy by making the process transparent, such that researchers can have access to data on a certain molecule or compound or other limited situations such as for rare diseases that have more limited commercial interest. Indeed, the industry has adopted a “hybrid mode” whereby a pharmaceutical developer still owns the patent rights on a drug and retains the associated trade secrets but can still freely share study protocols, data analysis techniques, results, communications with regulatory agencies, and interactions with insurance companies.<sup>82</sup> At least one pharmaceutical company, AstraZeneca, has gone even further and is more likely to share data in a translational state as opposed to basic science.<sup>83</sup> Interviewee Wegner believes that its competitive edge rests in coming up with a novel target and pursuing it with hypothesis testing.<sup>84</sup>

## 8.2 OBSTACLES TO FORMING A NEUROSCIENCE DATA COMMONS

A recent survey about data-sharing practices among scientists revealed considerable unwillingness to disclose whether or not they share data. Nearly half of the respondents said they do not share data, citing reasons of lack of time, underdeveloped standards, and inadequate infrastructure. Interestingly, 85% of these respondents indicated an interest in having access to other researchers’ datasets.<sup>85</sup>

The obstacles to participation in a neuroscience data commons are nontrivial. While any organization *can* participate in the neuroscience data commons at some level, the neuroscience organizations (and the scientists within the

<sup>80</sup> See generally Donald Stokes, *Pasteur’s Quadrant: Basic Science and Technological Innovation* (Brookings Institution Press 1997); Steven H. Woolf, The Meaning of Translational Research and Why it Matters, 299 *JAMA* 211 (2008).

<sup>81</sup> Strandburg et al., note 20; Chapters 15 and 16, this volume.

<sup>82</sup> Timothy King, Can open science help patients and save pharma? OpenSource.com, (June 19, 2014), <http://opensource.com/health/14/6/can-open-science-help-patients-and-save-pharma>.

<sup>83</sup> See App. (interview with Craig D. Wegner). <sup>84</sup> *Ibid.* <sup>85</sup> Choudhury et al., note 4, at 4.

organizations) must be convinced that it is in their best interest to do so. Many of the barriers to access of routinely collected public health data are also relevant to the challenges in participation in the neuroscience data commons: (1) technical, (2) motivational, and (3) legal considerations.<sup>86</sup>

### 8.2.1 Technical

In the past, it was not logistically feasible to publish raw data. Now that data sharing is possible through the power of digital and network technologies, the concern is to ensure quality and integrity of the data and to have the data in a useful format. Definitions of “open data” vary, but they all have the same characteristics: it must be accessible, free of restrictions, and interoperable among systems.<sup>87</sup>

Scholars have defined data quality as “the extent to which a database accurately represents the essential properties of the intended application, and has three distinct properties: 1) data reliability, 2) logical or semantic integrity, and 3) physical integrity (the correctness of implementation details).”<sup>88</sup> While seemingly straightforward, the need for high-quality data has been a long-standing issue among users of organizational databases that put out data of poor quality.<sup>89</sup> An organization can practice open data sharing, but if it lacks standards, including interchangeability and a common language, the data it shares will not be useful to (or used by) other organizations.

Furthermore, as others have noted, common standards require time to understand and implement.<sup>90</sup> The potential for reuse for certain types of data varies.<sup>91</sup> Moreover, a lack of consensus on the data quality standards, which puts quality control in the hands of the users,<sup>92</sup> makes the data less useful. There are also issues of cleanliness in data production. As Bostrom observed, if the data is not interesting or clean enough, people will be unable to interpret it, and this will generate more questions or work that people do not want to spend time doing.<sup>93</sup> It can take a significant amount of time to annotate or detail the data to make it ready for

<sup>86</sup> Willem G. van Panhuis et al., A systematic review of barriers to data sharing in public health, 14 *BMC Pub. Health* (2014), [www.biomedcentral.com/content/pdf/1471-2458-14-1144.pdf](http://www.biomedcentral.com/content/pdf/1471-2458-14-1144.pdf)

<sup>87</sup> See, e.g., UK Minister of State for the Cabinet Office and Paymaster General, *White Paper on Open Data*, (June 2012), [https://data.gov.uk/sites/default/files/Open\\_data\\_White\\_Paper.pdf](https://data.gov.uk/sites/default/files/Open_data_White_Paper.pdf); What is Open Data? *Open Data Handbook*, <http://opendatahandbook.org/guide/en/what-is-open-data/> (last visited Nov. 22, 2015). See also OECD Policy Note, note 65, at 2 (“Obstacles to the reuse and sharing of data should be examined carefully with an eye to enhancing the benefits that can be reaped from data. Non-discriminatory access regimes, including data commons or open access regimes, should be explored, as a means to support the production of public and social goods without requiring governments or businesses to pick winners (either users or applications).”).

<sup>88</sup> Richard Y. Wang, A framework for analysis of data quality research, 7 *IEEE Trans. on Knowledge & Data Eng'g* 623, 629 (1995).

<sup>89</sup> *Ibid.* at 623. <sup>90</sup> Strandburg et al., note 20, at 196.

<sup>91</sup> Russell A. Poldrack and Krzysztof J. Gorgolewski, Making big data open: data sharing in neuroimaging, 17 *Nature Neurosci.* 1511 (2014).

<sup>92</sup> *Ibid.* <sup>93</sup> See App. (interview with Dana Bostrom).

someone else to use and access.<sup>94</sup> The need to address the computational and logistical difficulties involved in moving around and analyzing these large amounts of data is resulting in the rapid increase in the use of cloud computing and new resources such as data commons.<sup>95</sup>

### 8.2.2 Motivational

Open neuroscience advocates have noted that the reward system for neuroscientists is not conducive to participation in the neuroscience data commons. As observed by Choudhury and others, “individual researchers’ lack of motivation to share is considered a key obstacle to wider change in data sharing practices.”<sup>96</sup> Indeed, a primary factor blocking broad participation in the neuroscience data commons is the desire among neuroscientists to be the first to analyze their data, and to be recognized for findings from their data. This is such a widespread issue that it deserves to be termed the “first to analyze data” problem. Generally, when neuroscientists are conducting science, they are not necessarily thinking about making it accessible for the public good – they are thinking about working on their hypotheses and getting credit for their hard work: “In an academic context where funding is increasingly competitive, and data are relatively expensive to generate, anxieties about being ‘scooped,’ or undercut, by other data collectors constitute a very real challenge to the cultural reform envisaged by open neuroscience advocates.”<sup>97</sup>

Interviewee Hawrylycz stated that within the biological and medical sciences, organizations spend money to generate data, and this data is both precious and important to people’s careers.<sup>98</sup> Thus, neuroscience researchers may want to hold data back until the professional glory is fully extracted from it.<sup>99</sup> Others have noted a similar lack of motivation for researchers to cooperate and contribute to a common data pool, in the context of research on neglected diseases.<sup>100</sup>

Hawrylycz added that organizations do not want to squelch the innovative spirit of their scientists; since innovation strives for something new that stretches boundaries, the data that is collected in pursuit of the innovation might contain inaccuracies or be misinterpreted in the absence of context.<sup>101</sup> In addition to the race to be the first to present new results, “neuroscientists may also . . . fear being scrutinized publicly for inadequate paradigms or data collection methods, particularly after the very public forms of criticism of neuroimaging analysis . . . which initially used freely accessible online forums for criticism rather than peer-reviewed academic journals.”<sup>102</sup>

In many environments, individual neuroscientists “must meet tenure, promotion and grant criteria that fail to incent or reward sharing, but rather encourage

<sup>94</sup> Ibid. at 4; Chapter 3, this volume. <sup>95</sup> Green et al., note 30.

<sup>96</sup> Choudhury et al., note 4, at 4. See also Jean-Baptiste Poline et al., Data sharing in neuroimaging research, 6 *Frontiers in Neuroinformatics* 1 (2012).

<sup>97</sup> Ibid. <sup>98</sup> See App. (interview with Michael Hawrylycz). <sup>99</sup> Ibid.

<sup>100</sup> Strandburg et al., note 20, at 195. <sup>101</sup> See note 89. <sup>102</sup> Choudhury et al., note 4, at 4.



data retention as a basis for multiple publications.”<sup>103</sup> Scientists are rewarded for their publications but not for making their data openly available. To be successful, participating in data sharing must be legitimized as a form of scholarly work, similar to publishing a scientific article. Philip Bourne, former associate director of data science at the NIH, has discussed this imperative in his talks around the NIH’s commitment to data.<sup>104</sup>

And while putting neuroscience data into the neuroscience data commons might inform the scientific community about discoveries, accomplishments, and breakthroughs in research, data sharing presents challenges even in public research university settings. Interviewee Kathryn Partin stated that, while CSU has a strong culture for openness and transparency along with a taxpayer expectation for data to be shared for both ethical and financial reasons, its researchers may be hesitant to share raw data for no other reason outside of data integrity.<sup>105</sup> With raw data, uncertainty exists as to whether the data set contains inaccuracies. However, she noted that exclusion criteria are applied to published data, to ensure that the sample is what it says it is, thereby making it a shareable data set in which people can study the data without fear of misinterpretation.<sup>106</sup>

Unfortunately, no standard acknowledgment mechanisms exist for neuroscientists who practice team science; rather, the current knowledge ecosystem incentivizes individual accomplishments.<sup>107</sup> While the existing rewards may work fine for easy problems, the difficult questions that neuroscientists are trying to answer will not be answered without collaborative team science.<sup>108</sup> And even when there is collaboration and team science, there are tensions with being the first and last author on the publication.<sup>109</sup> Interesting differences among nonprofit organizations are apparent. For university-based researchers, the prevailing rules of academic scholarship, promotion, and tenure can reinforce the existing motivational barriers to sharing. On the other hand, 501(c)(3) organizations such as the Allen Institute are not bound as tightly to such imperatives. Many research scientists have migrated from prestigious research institutions such as CalTech, Harvard, and MIT, and some have given up tenure to participate in a nonprofit model of science that is not contingent upon the reward structures prevailing at academic institutions.

In addition to reputational and prestige motivations, economic motivations may militate against data sharing: “The process of data sharing requires human and technical resources for data preparation, annotation, communication with recipients, internet connectivity, etc.”<sup>110</sup> Open neuroscience is expensive if done right; it is also

<sup>103</sup> Accelerating Open Science, *One Mind 3rd Annual Summit White Paper 6* (May 2014), [www.onemind.org/ckfinder/userfiles/files/One%20Mind%202014%20Summit%20White%20Paper\\_FINAL\\_for%20website\\_2\\_05\\_15.pdf](http://www.onemind.org/ckfinder/userfiles/files/One%20Mind%202014%20Summit%20White%20Paper_FINAL_for%20website_2_05_15.pdf)

<sup>104</sup> Philip E. Bourne, Associate Director for Data Science, Nat’l Institutes of Health, Presentation at the University of Georgia: Data Science in Biomedicine – Where Are We Headed? (Oct. 12, 2015), [www.slideshare.net/pebourne/data-science-in-biomedicine-where-are-we-headed](http://www.slideshare.net/pebourne/data-science-in-biomedicine-where-are-we-headed).

<sup>105</sup> See App. (interview with Kathryn Partin). <sup>106</sup> *Ibid.* <sup>107</sup> *Ibid.* <sup>108</sup> *Ibid.* <sup>109</sup> *Ibid.*

<sup>110</sup> van Panhuis et al., note 86, at 5.

expensive to maintain. As stated earlier, the NIH requires a data-sharing plan for any research funded with more than \$5,000; however, future maintenance costs are not generally included in the funding. Additionally, at least part of any innovators' motivation is financial; for those neuroscientists who are entrepreneurial, there is an inherent conflict between financial benefit and providing one's innovations openly. Thus the incentives to hoard data can be as strong as the incentives to share it. Furthermore, the Bayh-Dole Act of 1980, which established a uniform policy for patent rights in inventions made with federally funded research, can affect the mission of research universities by making potential commercialization an important goal of scientific research.<sup>111</sup>

### 8.2.3 Legal

At least three kinds of rules-in-use<sup>112</sup> present themselves in the neuroscience research field with respect to intellectual property: (1) the absence of intellectual property, (2) intellectual property with offensive downstream licensing (to enforce exclusive rights), and (3) intellectual property with defensive downstream licensing (to ensure freedom to operate).<sup>113</sup> These approaches are not mutually exclusive, and their common long-term goal is the diffusion of knowledge.<sup>114</sup> For individual neuroscientists and neuroscience organizations alike, the need to protect intellectual property rights, which are exclusive rights to the individual or institution, can quash any desire or ability to participate in the neuroscience data commons. When launching One Mind's open science principles, for example, the interaction between openness and protection of intellectual property was one of the biggest issues impeding full participation in open data sharing, according to interviewee General Chiarelli.<sup>115</sup>

<sup>111</sup> See generally Arti K. Rai and Rebecca S. Eisenberg, Bayh-Dole Reform and the Progress of Biomedicine, 66 *Law & Contemp. Probs.* 289 (2003).

<sup>112</sup> Ostrom and Hess, note 8, at 52–53.

<sup>113</sup> Cf. De Beer, see note 7, at 57–60 (describing offensive and defensive IP management strategies in the context of open innovation); see also Colleen V. Chien, Opening up the Patent System: Exclusionary and Diffusionary Levers in Patent Law, 89 *Southern California L. Rev.* 4 (2016) (defining “Defensive patenting – holding patents in order to facilitate freedom to operate – is practiced by an estimated half or more of patent holders” and stating further that “[w]hile it often seems that there are only two approaches for supporting innovation with patents – to opt-in and exclude, or to opt-out and share, intellectual property, a widely-used approach between them is to acquire patents *in order to share*, or “defensive patenting.”).

<sup>114</sup> Chien, note 113 (“It is widely recognized that different industries use patents differently, and that patents support a diversity of business models. Allowing innovators to individually tailor patent rights, and in some cases, to change these options over the lifetime of the patent, would provide finer grained controls to those in the best position to know the right balance between exclusion and diffusion with respect to a particular invention.”)

<sup>115</sup> See App. (interview with General Chiarelli). This suggests that the neuroscience research area may be plagued with the “anti-commons” problem suggested by Heller and Eisenberg regarding the role of patents in biomedical research, a topic that is beyond the scope of this chapter. See Michael A. Heller and Rebecca S. Eisenberg, Can patents deter innovation? the anticommons in biomedical research, 280 *Science* 698 (1998).

Intellectual property rules are also relevant for NPOs participating in the neuroscience data commons. For example, in contrast to the Allen Institute, which, to date, is not focused on building a patent portfolio, the Broad Institute has a wide patent portfolio. Both the Allen Institute and the Broad Institute have common origins in the successes of the HGP, and both are committed to openness of research results. Nonetheless they currently have different intellectual property management positions in pursuing their respective missions. The Allen Institute's full range of knowledge resources includes not only data but also software, hardware, biological materials such as transgenic mice, methods, models, algorithms, publications, and other tools. While the Allen Institute does not have a fully developed program to license out (i.e., provide others with materials on a royalty basis), it does license in for some of its research in order to use materials provided by others. It also has developed terms of use for downstream use of its data and images found on its website, with three requirements: (1) attribution to the Allen Institute of the data and/or images used, (2) prohibition of repackaging the data and/or images for profit, and (3) respect for the Allen Institute's freedom to continue innovation.<sup>116</sup> Thus the downstream out-licensing approach of the Allen Institute for its data and images preserves freedom to operate, or defensive downstream licensing.<sup>117</sup> The Allen Institute and others affiliated with big philanthropy such as the Gates Foundation have been informal advocates for a less revenue-driven view of technology licensing within nonprofit-based technology transfer forums such as the Association of University Technology Managers (AUTM), which is an organization supporting the global academic technology transfer profession.

In the context of collaborative research, no actor is completely closed off from the licensing impacts of intellectual property ownership.<sup>118</sup> As Colleen Chien observed with respect to the patent system:

Declines in the cost of communication and computing, and increases in product complexity make it an opportune time for a pivot toward collaboration in the patent system. The patent system should pay more attention to supporting the rights of patentees to enable rather than to forbid, others from practicing patentable inventions, and to sell or waive certain patent rights or rights among certain populations. For example, if a patent holder wants to retain only rights to exclude larger competitors, or to waive all but defensive rights, enabling free use by green, humanitarian, educational, or start-up projects, for examples, it should be possible to do so. But presently, there are no easy ways to do so.<sup>119</sup>

<sup>116</sup> See Terms of Use, *Allen Institute*, <http://alleninstitute.org/terms-of-use/>. As Paul Allen put it, “[o]ur terms-of-use agreement is about 10% as long as the one governing iTunes.” Allen, note 72.

<sup>117</sup> Chien, note 113.

<sup>118</sup> Esther van Zimmeren et al., Patent pools and clearinghouses in the life sciences, 29 *Trends in Biotechnology* 569, 570 (2011).

<sup>119</sup> Colleen Chien, Why it's time to open up our patent system, *Wall St. J.* (June 30, 2015), [www.washingtonpost.com/news/innovations/wp/2015/06/30/why-its-time-to-open-up-our-patent-system/](http://www.washingtonpost.com/news/innovations/wp/2015/06/30/why-its-time-to-open-up-our-patent-system/); see also Chien, note 114; De Beer, see note 7, at 57-60.

Analogously, neuroscience research does not have large-scale mechanisms that would allow for a more efficient exchange or sharing of biological materials, tools and data used in neuroscience research.

In addition to intellectual property issues, privacy issues are significant: “Researchers’ willingness to share data can also be constrained by concerns for the privacy of the human research participants who are the data sources, and the data sharing permissions they have granted in consenting to participate.”<sup>120</sup> With genomic data, there is a concern of re-identifiability once the data is released.<sup>121</sup> While privacy considerations are very important, evidenced by current efforts allowing for presentation and anonymization of brain imaging data that will allow others to access and reanalyze these results,<sup>122</sup> it is beyond the scope of this chapter to investigate their impact in greater detail.

### 8.3 TOWARD THE FORMATION OF A NEUROSCIENCE DATA COMMONS

Data sharing is a common requirement of funding or publication, though this obligation may come as a surprise to some authors – and to their colleagues who have had trouble acquiring data from other laboratories. Many granting agencies, including the Wellcome Trust in the United Kingdom and the National Institutes of Health and the Howard Hughes Medical Institute in the United States, require grantees to share data whenever possible, so as to maximize the usefulness of the data whose collection they have funded.<sup>123</sup>

The previous sections summarize the importance of open neuroscience and some of the primary obstacles to participation. This part summarizes some possible solutions to these obstacles without attempting to assess or evaluate any efforts of the institutions discussed.

Open neuroscience advocates have welcomed more coordinated efforts among public and private organizations to advance more open data sharing in neuroscience. However, it is well documented that these types of partnerships were not as successful as had been hoped in the context of the HGP. The challenges faced by the public-private partnership model of the HGP caution the neuroscience research community that there may be some incompatibility in the goals of different types of institutions when they endeavor to share large-scale data.<sup>124</sup> That being said,

<sup>120</sup> Choudhury et al., note 4, at 4.   <sup>121</sup> Ibid.

<sup>122</sup> Russel A. Poldrack et al., Toward open sharing of task-based fMRI data: the Open fMRI Project, 7 *Front Neuroinform.* 12 (Jul. 8, 2013).

<sup>123</sup> Got Data?, 10 *Nature Neurosci.* 931 (2007).

<sup>124</sup> Choudhury et al., note 4, at 5 (“Recognizing significant interest from both public and private entities in achieving its goals, promoters of the HGP argued that sequencing the human genome would be greatly accelerated through collaboration and sharing of technological and financial resources. A coordinated public/private partnership involving the United States’ NIH and Department of Energy, The Wellcome Trust, and the private corporation of Celera was proposed to generate a draft

a number of public-private partnerships have emerged in the neuroscience research area, including Pistoia Alliance and Sage Bionetworks.<sup>125</sup>

Researchers have observed that “neuroscience does not at present have a central, general source for relevant data. Because there is no site that directly addresses their needs, neuroscientists by default make use of a variety of search engines (e.g., Google, Google Scholar, and PubMed) that are largely literature oriented.”<sup>126</sup> To address the lack of a framework or standards to properly archive open neuroscience data, as part of the Blueprint for Neuroscience Research, the NIH funded the Neuroscience Information Framework, which “presents neuroscientists with a single starting point for their searches, one that can be a portal that students start using at the dawn of their training and continue to utilize as their primary access to multiple and complex sets of data accessible from a growing number of neuroscience-specific databases.”<sup>127</sup> The NIH is also piloting projects enveloped under the commons framework<sup>128</sup> that, if fully implemented, would solve many of the technical issues addressed earlier. But, according to Philip Bourne, it will require more than the commitment from the NIH to be successful.<sup>129</sup>

Another more recent initiative aimed at working on ways to process and share big amounts of data is the Neurodata without Borders – Cellular Neurophysiology initiative,<sup>130</sup> in which researchers around the world can deposit their data, which would then be converted into a standardized format for use by other scientists. This pilot project, aimed at developing a common integrated data format for neurophysiology, was developed by private funding partners: the Kavli Foundation, the Howard Hughes Medical Institute (HHMI), and the Allen Institute.<sup>131</sup> The beta version of its Neurophysiology Data Format was released on June 9, 2016. Karel

sequence of the human genome using composites of 17 individuals. The hopes were that this partnership would reduce duplicative efforts and allow both private industry and public scientists to reap the rewards of efforts to sequence the genome with open access to data deposited in the GenBank public repository, though with some intellectual property rights in the data retained (Jasny, 2013). Despite a public face of coordinated effort, in reality the race to sequence the human genome was more like a competition between public and private interests in which neither side achieved their goals of a clean and complete publicly available sequence or a profitable private sequence in which all users would pay to view the results (Jasny, 2013).”

<sup>125</sup> Allen, note 72 (“Private nonprofits like the Pistoia Alliance and Sage Bionetworks are curating their own open-source repositories.”).

<sup>126</sup> Gardner et al., note 12, at 157. <sup>127</sup> Ibid.

<sup>128</sup> Philip E. Bourne, ADDS current vision statement, *PEBOURNE* (Oct. 31, 2014), <https://pebourne.wordpress.com/> (“[W]hile it will take much more than one person to change a deeply ingrained culture centered around specific diseases and organs; the complexity of disease and the value of sharing data across institutional boundaries, will drive us forward.”).

<sup>129</sup> Philip E. Bourne, The commons, *PEBOURNE* (Oct. 7, 2014), <https://pebourne.wordpress.com/2014/10/07/the-commons/>

<sup>130</sup> Neurodata Without Borders, [www.nwb.org/](http://www.nwb.org/) (last visited Dec. 28, 2015). The founding scientific partners include the Allen Institute, the Svoboda Lab at the Janelia Research Campus of HHMI, the Meister Lab at the California Institute of Technology, the Buzsáki Lab at New York University School of Medicine and the University of California.

<sup>131</sup> Ibid.

Svoboda, one of the original scientists in the initiative, has stated, “Some of these data are incredibly hard won and then just die . . . This is an effort to get ahead of the problem and solve it from the bottom up.”<sup>132</sup>

While the best motivations may come from agreement among significant actors that researchers will benefit from involvement in the neuroscience data commons, interviewee Hawrylycz noted a trade-off between individual credit, the need for funding, and doing good.<sup>133</sup> Therefore, the movement for openness is more likely to be realized with the increased acceptance and push from universities and funders, which are probably in the best position to strongly encourage participation in the neuroscience data commons. Even so, technical and incentive issues need to be addressed so that the funds that are provided are being used in the most efficient and effective way. And brute force by funders is not effective or sustainable given other institutional constraints.

Among the major commonly acknowledged hurdles to data sharing is the “crucial issue of academic credit, and [therefore the need to] devise methods that recognize and reward data sharing and encourage a culture of openness. This will include considerations about how best to reflect academic output and avenues for academic publication that encourage data acquisition and sharing as important contributions to the literature.”<sup>134</sup> Choudhury suggests a possible solution in the form of

“data papers,” which, while common to other fields such as genetics, robotics, and earth sciences, are lacking in neuroscience. These data papers, which would serve to detail the experimental protocol and data specification without covering analysis or interpretation, might provide a mechanism for citable professional credit to the data generators . . . [D]ata papers solve the problem of motivation for individuals to share data while “making it count” in the university system of merit, and at the same time allow different data users to draw on the same data sets for different interpretations, consistent with a central epistemological goal of open neuroscience.<sup>135</sup>

To address the “first to analyze data” problem within the scientific community, interviewee General Chiarelli suggested that the Nobel Prize for medicine be abolished because it causes people to work as individuals, does not force people into team science, and therefore reinforces the barriers faced by open neuroscience advocates.<sup>136</sup> He adamantly recommended that the incentive system must move away from individual accomplishment and toward team accomplishment. One suggestion is a change in the publication process such that authors are published in alphabetical order rather than the traditional last author/first author system.<sup>137</sup>

<sup>132</sup> Ibid. <sup>133</sup> See App. (interview with Michael Hawrylycz).

<sup>134</sup> Choudhury et al., note 4, at 7. (“It has been suggested that h-indices, metrics of publication citation, as measures of performance, are already a useful way to capture a result of data sharing, as long as a system is ensured for citing data from repositories that are used for analysis and re-analysis by authors other than the data generators.”)

<sup>135</sup> Ibid. <sup>136</sup> See App. (interview with General Peter Chiarelli). <sup>137</sup> Ibid.

Indeed, he went so far as to suggest that one year, the A's become Z's and the next year Z's become A's.<sup>138</sup>

In 2007, the editors of *Nature Neuroscience* wrote:

If data sharing is to become a routine part of academic life, universities and funding agencies will need to make further efforts to encourage it. One major step forward would be universities to give credit for good citizenship, as reflected in data sharing, during hiring and promotion decisions. This process would be facilitated by a system to track the downloading and use of shared data. Similarly, funding agencies may give preference in awarding grants to scientists who can demonstrate that they have provided easy access to their data collected in connection with previous grants.<sup>139</sup>

While the Allen Institute does not generally track unique visitors to its brain atlas data portal ([www.brain-map.org](http://www.brain-map.org)) individually, it measures impact in a number of ways to optimize the reach and impact of the Allen Institute resources. It tracks the number and IP address of its unique visitors in the aggregate and compares the visitor count against its public data releases and publications. It also tracks the number of primary publications citing Allen Institute data on the data portal – both published by Allen Institute scientists and by other scientists using Allen Institute data pulled from the data portal – as well as citations to these primary publications that are made as part of the Allen Institute's data portal terms of use. Additionally, it collects use-case scenarios on what people do with the data. Under its citation policy in the terms of use on the data portal, the Allen Institute asks users to give the organization credit with the appropriate citation. In this way, some interesting impact measures can be glimpsed. For example, starting with the problem that “neuroscience is data rich but theory poor,” two scientists developed an innovative model for generating hypotheses for proof-of-concept, based on a text/data mining of the neuroscience literature.<sup>140</sup> They counted word pairs that appeared most frequently together in neuroscience articles and integrated them with the Allen Institute brain atlas, to find brain regions that strongly express a neurotransmitter gene but are understudied. For example, they found that serotonin and striatum were found together in 4782 neuroscience articles, and serotonin and migraine in 2943 articles; however, striatum and migraine were found in only 16. They also checked and verified that these perceived and presumed relationships correlate significantly with areas of real gene expression, as indicated by the Allen Institute's atlas. This single example illustrates a broader principle. One fundamental driver for

<sup>138</sup> Ibid.

<sup>139</sup> Got Data?, note 123. Since this observation, these editors have begun an initiative called Scientific Data, [www.nature.com/sdata/](http://www.nature.com/sdata/), which is an open data publication resource, where authors in their other journals are encouraged to publish their data.

<sup>140</sup> Jessica B. Voytek and Bradley Voytek, Automated cognome construction and semi-automated hypothesis generation, 208 *J. Neurosci. Methods* 6 (2012).

open neuroscience is that the neuroscience literature is too vast for any one researcher to integrate.

From these examples, it appears that the limited commons in individual laboratories are giving way to a spectrum of larger commons pools described by Jorge Contreras and Jerome Reichman.<sup>141</sup> The NIH Neuroscience Information Framework could be viewed as a type of intermediate distributed commons (independent data pools integrated via a central access point or portal).<sup>142</sup> The Neurodata without Borders initiative is an effort to construct a fully distributed commons (maintained locally and integrated by a common legal and policy framework that authorizes users to access individual nodes under terms and conditions – or legal interoperability).<sup>143</sup> As more neuroscience researchers are drawn to Big Data questions such as the one illustrated by the follow-on research based upon the Allen Brain Atlas, momentum will be created to increase participation in data knowledge commons through both small and dramatic changes in institutional arrangements and collaborative agreements.

#### CONCLUSION

As with openness applied to resources, openness with regard to community describes an individual's capacity to relate to that community as a contributor, manager, or user of resources that comprise the knowledge commons.<sup>144</sup>

Several ambitious collaborative neuroscience initiatives have been announced recently,<sup>145</sup> indicating that it takes a global research village to make progress in neuroscience. Profound external as well as internal forces are pushing the neuroscience research community to come up with creative solutions and work-arounds to institutional dilemmas around sharing data. This chapter sets forth the context for encouraging participation in such a commons within an emergent open neuroscience movement. Its key observations include the following:

- The widespread desire in the neuroscience research community to engage more in collaborative data sharing to further the progress of science more efficiently.
- The identification of impediments, such as the existing reward structure for being first to analyze data rather than first to share.
- The convergence toward possible solutions, such as the formation of larger commons pools.

<sup>141</sup> Jorge L. Contreras and Jerome H. Reichman, Sharing by design: data and decentralized commons – overcoming legal and policy obstacles, 350 *Science* 1312 (2015); see also Jerome H. Reichman and Ruth Okediji, When Copyright Law and Science Collide: Empowering Digitally Integrated Research Methods on a Global Scale, 96 *Minnesota L. Rev.* 1362 (2012).

<sup>142</sup> *Ibid.* <sup>143</sup> *Ibid.* <sup>144</sup> Frischmann et al., note 13, at 29. <sup>145</sup> See note 3.



Arguably, every neuroscientist and neuroscience research organization could have greater impact by participating in the neuroscience data commons on some level. For example, the Allen Institute's "commitment to open science is rooted in [its] conviction to make an impact on science on a global scale."<sup>146</sup> To use the Ostrom and Hess terminology, the Allen Institute is an example of a relevant actor contributing toward action situation, with the goal of encouraging the formation of an open neuroscience ethos rather than participating uncritically in an ethos of individual competition. This chapter describes why many in this field believe the current level of data sharing is suboptimal, why this is an important moment to increase participation in a neuroscience data commons, and what some key actors intend to do about it.

#### APPENDIX: METHODOLOGY

With the assistance of Maria Therese Fujiye, the authors performed a literature search to identify the key questions in neuroscience research that related to open access, open data, and open science. Based upon the published literature, the authors formed a general outline for the research, followed by interviews with stakeholders, conducted by Maja Larson and Maria Fujiye. Interviewees were drawn from the following actors and action groups: individual scientists who both generate and use neuroscience data, representatives of institutions and companies that manage the dissemination of neuroscience research, research funders, and finally stakeholders representing the public who benefit from (and as taxpayers sometimes indirectly fund) the research.

##### Interviews Conducted for This Study:

- Telephone interview with General Peter Chiarelli, CEO, One Mind, August 20, 2015.
- Telephone interview with Michael Hawrylycz, PhD, Investigator, Allen Institute, August 14, 2015.
- Telephone interview with James Zanewicz, Chief Business Officer, Tulane University School of Medicine and Tulane National Primate Research Center & Instructor, Tulane University School of Medicine, July 29, 2015.
- Telephone interview with Richard Wilder, Associate General Counsel, Bill and Melinda Gates Foundation, July 30, 2015.
- Telephone interview with Kathryn Partin, PhD, Director of the federal Office of Research Integrity and former Assistant Vice President for Research and Professor, Department of Biomedical Sciences, Program of Molecular, Cellular and Integrative Neurosciences, Colorado State

<sup>146</sup> Global Impact, *Allen Institute*, <http://alleninstitute.org/about/global-impact/> (last visited Jan. 12, 2016).

University, Daniel Draper, Digital Services Librarian, Colorado State University, and Nicole Kaplin, Information Manager, Natural Resource Ecology Lab, July 31, 2015.

- Telephone interview with Craig D. Wegner, PhD, Executive Director, Head, Boston Emerging Innovations Unit, Scientific Partnering & Alliances, AstraZeneca IMED Biotech Unit, August 3, 2015.
- Telephone interview with Dana Bostrom, Executive Director, Orbis Cascade Alliance and former Executive Director, Data Commons LLC, August 7, 2015.