

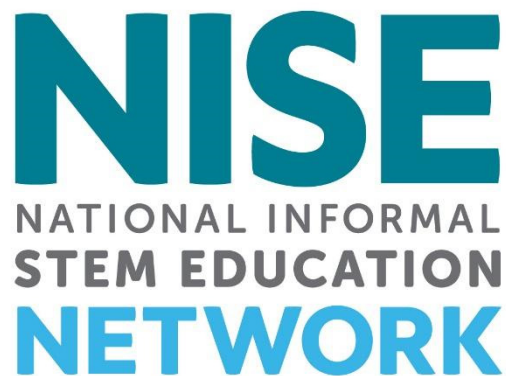


A Global Landscape of Neuroscience Public Engagement Efforts and the Potential Nexus of Neuroethics

August 2019

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NISE
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A Global Landscape of Neuroscience Public Engagement Efforts and the Potential Nexus of Neuroethics

Executive Summary

Neuroscience is rapidly advancing, presenting new frontiers for researchers, patients, and public audiences alike. A global community of international brain research projects has sought to embed neuroethics in both practical and theoretical aspects of scientific progress and technological development. Given the recognized need for public input on potential individual and societal implications of neuroscience, the (U.S.) National Informal STEM Education (NISE) Network, in partnership with The Kavli Foundation and the Neuroethics Working Group of the International Brain Initiative, conducted a series of interviews with neuroscientists, neuroethicists, patient advocates, and educators to characterize the landscape of neuroscience public engagement efforts around the world with possible connections to fundamental questions in neuroethics.

We focused our search by using an operational definition of public engagement as activities with the *potential* for two-way interaction between experts and public audiences. We also sought out programs that intentionally tackled societal and ethical impacts of neuroscience, but we did not filter for interaction formats and program goals. After almost 50 interviews, five categories of engagement styles emerged that are broadly representative of the current landscape of neuroscience public engagement connected with neuroethics.

1. Structured assessment of public opinions and attitudes
2. Interactive exhibits, public programs, and other informal STEM learning experiences
3. Inspirational media through partnerships with artists
4. Expert discussions for public audiences
5. Partnerships for clinical applications

Characteristic activities of each category shared similar implementation strategies, key features, and outcomes. Structured assessment covered deliberative dialogues, interviews and surveys, and online comment analysis with the goal of identifying community- or population-level attitudes. Exhibits and public programs stressed engaging, responsive, and social experiences, often leveraging free-choice learning and specialized physical environments. Inspirational media through artist partnerships resulted in popular and sometimes evocative experiences benefiting from extended dialogue opportunities. Expert discussions were the most common public engagement example found, with many flexible formats and diverse venues, occasionally featuring individuals with relevant lived experiences. Lastly, partnerships for clinical applications sought to shape treatment priorities, improve outcomes, or change attitudes often to reduce stigma or increase research participation.

As we look toward the future of neuroscience public engagement through neuroethics, and reflect on the lessons learned from previous interactions between experts and public audiences on other socio-scientific questions, we have observed several cross-cutting challenges and opportunities in our sample. Foremost of the challenges, we found pockets of innovation in neuroscience public engagement efforts connected with neuroethics, but these efforts are not consistent across geographic regions or institution types. International brain research projects, brain research centers, and neuroscientists have different goals around public engagement and different levels of access to or partnerships with neuroethicists. This variation in priorities also has led to uneven interest in the fundamental questions in neuroethics established by the Neuroethics Working Group, with topics around neurotechnologies, data privacy, and mental illness rising to the top. As with other STEM public engagement efforts, our interviews also revealed changes needed to academic culture for the continued growth of neuroscience public engagement, including more institutional recognition for faculty and students.

The opportunities we identified offer the outlines of a path forward for neuroscience public engagement. We observed a strong desire for more collaboration among neuroscientists, neuroethicists, and experts in other fields such as communications, survey methodology, public engagement, the arts, and evaluation and learning research. This enthusiasm for an interdisciplinary approach to public engagement can be the spark for a new, international network of practice that can effectively convene researchers and diverse audiences, with both public and professional impacts. A broad network could also leverage community and regional values to implement more culturally responsive public engagement.

Finally, almost all of the neuroscience public engagement programs we encountered could have benefited from open resources that directly support and build facilitation skills for one-on-one interactions between neuroscientists and public audiences. As we learned from some outstanding projects, dialogue about neuroethics results in meaningful conversations that can have tremendous impact on all participants. We discovered a wide range of practices and strategies used to trigger these rewarding interactions—from large-scale events with many partners to an intimate, compelling work of art. How can we scale up, share, and continually improve supporting resources to increase the capacity of scientists, ethicists, and educators to guide public engagement with neuroethics?

A Global Landscape of Neuroscience Public Engagement Efforts and the Potential Nexus of Neuroethics

I. Introduction

The field of neuroscience is at a crossroads, where high public interest and the increasing global scale of research do not match the level of public involvement. In January 2018 the (U.S.) National Informal STEM Education (NISE) Network, in partnership with The Kavli Foundation, held a strategic planning conference at The Franklin Institute in Philadelphia to conceptualize a new public initiative around brain science. The conference brought together a diverse group of education professionals, neuroscientists, and social scientists to discuss scientific trends and identify opportunities for greater public engagement. What emerged was a common belief among all participants that neuroscientists and educators should meet public audiences where they are, through an equitable exchange of values and ideas for the future (Das et al., 2018).

Concurrent with this refreshed direction for neuroscience public engagement, large-scale international brain research projects have increasingly recognized the need for systematic, ethical reflection and analysis of both individual and societal issues raised by neuroscience and emerging neurotechnologies—referred to as neuroethics. Given the unique role of the brain underlying our identity, privacy, and agency, neuroscience stands out among STEM disciplines for its immediate relevance to understanding our very nature. A September 2018 publication from the Neuroethics Working Group of the International Brain Initiative outlined the broad scope of neuroethics and its applications for guiding responsible research and innovation, including fundamental questions of philosophy, the integration of diverse cultural perspectives, and the importance of dialogue among ethicists, scientists, and public audiences (Global Neuroethics Summit Delegates et al., 2018). These wide-ranging issues were synthesized into a working framework of five Neuroethics Questions for Neuroscientists (NeQNs) based on likely research and development trajectories.

Neuroethics questions to guide ethical research in the International Brain Initiative

- Q1. What is the potential impact of a model or neuroscientific account of disease on individuals, communities, and society?
- Q2. What are the ethical standards of biological material and data collection and how do local standards compare to those of global collaborators?
- Q3. What is the moral significance of neural systems that are under development in neuroscience research laboratories?
- Q4. How could brain interventions impact or reduce autonomy?
- Q5. In which contexts might a neuroscientific technology/innovation be used or deployed?

Themes underlying these five neuroethics questions can motivate a diverse set of stakeholders to reflect on near-term to far-reaching—often unexpected—implications of new neurotechnologies, findings about the brain that result from neuroscience research, and the

implementation of emerging innovations (Global Neuroethics Summit Delegates et al., 2018). Can experiences fostering reflection, self-discovery, and conversation on neuroethical issues be at the core of a broad neuroscience public initiative essential for our times? And how can resulting interactions between neuroscientists and public audiences be guided by the multiple cultures and communities involved in the global scientific enterprise to understand the brain? As a first step towards answering these questions, we collected exemplars from around the world of neuroscience public engagement connected to neuroethics.

II. Operational definition of public engagement

In considering interactions between experts and public audiences, there are multiple dimensions that lead to different outcomes. The goal of the interaction; the specific topic or focus; the attitudes, behaviors, and expectations of public participants; and the attitudes, behaviors, and expectations of experts—all influence the nature of these interactions. These factors combine to create a spectrum within models that frame how scientists, educators, artists, policymakers, and diverse public audiences explore science, as well as its societal impacts (Appendix A). This spectrum stretches from a knowledge deficit model based on information in the **public understanding of science** to a mutually-informing dialogue model based on participation in the **public engagement of science** (Irwin & Wynne, 1996; McCallie et al., 2007).

Many current neuroscience outreach efforts fall under the umbrella of public understanding of science, where the goal may be to demonstrate a phenomenon, build excitement about science and its benefits, or inform about an issue—often a one-way dissemination of information with experts in control (Das et al., 2018). Meanwhile, many adults in the general population still have limited knowledge about the brain and applied brain technologies, as a result of the recent and rapid pace of change in neuroscience research, and widespread yet low quality brain science information from popular sources. Conversations with public audiences about neuroscience must consider how to bridge this knowledge gap, especially with respect to pervasive misconceptions or exaggerated claims.

Scientific information alone, however, cannot guide the choices we make about science and technology at an individual, community, or societal level. Ethics, cultural values, and impacts on future generations are among the factors that influence our understanding and applications of science. Although there are multiple definitions of public *engagement* with science, a common thread is a focus on dialogue between stakeholders that creates opportunities for an exchange of perspectives and mutual learning. An organized pivot towards public engagement with science started at the beginning of the 21st century, when governments, scientists and educators responded to a public crisis of confidence in science with a new emphasis on dialogue over dissemination (House of Lords, 1999-2000). The goals of public engagement interactions are diverse, and often intentionally integrate other domains of knowledge to tackle complex issues, promote responsible innovation, or facilitate participatory decision-making (McCallie et al., 2009).

For this landscape report focusing on neuroethics, we narrowed our search parameters to neuroscience public engagement projects with the *potential* for two-way interaction between experts and public audiences. We also sought out programs that intentionally tackled societal

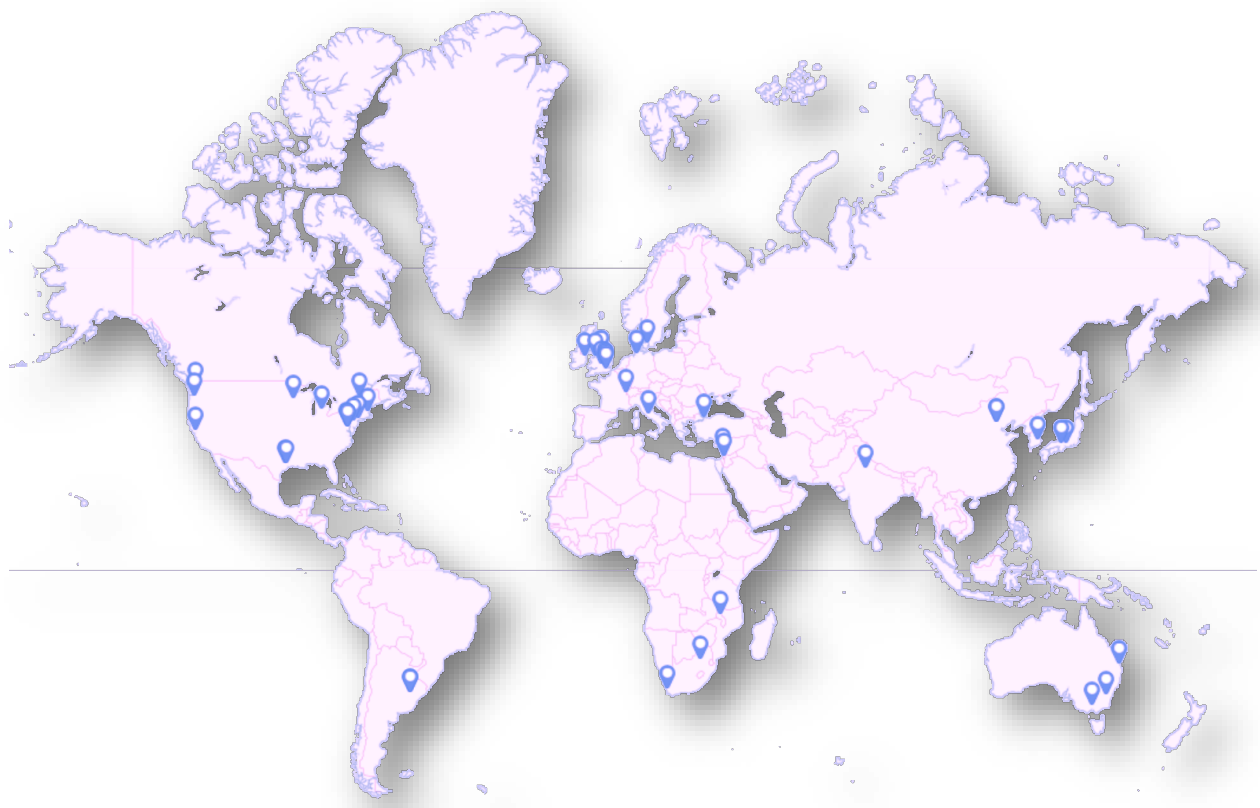
and ethical impacts of neuroscience, typically reflected in at least one of the NeQNs. In order to capture a full range of activities, we did not filter for interaction formats and program goals. Some activities we found were meant to spark public awareness of and interest in ethical issues, with minimal direct interaction between experts and the public audiences, while others were intended to shape the direction of research or policy through close collaboration between stakeholders. As described below, five categories of engagement styles emerged that are broadly representative of the current landscape of neuroscience public engagement connected with neuroethics.

III. Participant selection and interview methodology

To capture a wide range of public engagement projects around the world, we reached out to likely program facilitators and partnering neuroscientists through a variety of channels. Members of the Neuroethics Working Group connected us with potential leads in each of their countries as well as their broader networks. We also reached out to the science communication and informal STEM education communities, including the Association of Science-Technology Centers (ASTC) and Ecsite, for pertinent project suggestions. Professional neuroscience and neuroethics organizations, such as the Society for Neuroscience, the International Neuroethics Society, and the Federation of European Neuroscience Societies provided another network of contacts. Finally, we cast a wide net through literature and internet searches for potentially relevant projects.

Through this effort, we interviewed almost 50 participants between February and June 2019 (Appendix B). Participants represented expertise that roughly fell into one or more of five categories: academic neuroscience, academic neuroethics, patient advocacy, program administration, and informal STEM education. The map below shows the geographic distribution of the participants agreeing to be interviewed. Although some participants chose to respond by email, the majority of interviews were conducted via videoconference. We used a semi-structured interview protocol to generate 30- to 60-minute conversations. The starting questions were sufficiently standardized for comparison across participants, while also open-ended to allow further discussion of interesting topics that emerged. These questions focused broadly on: 1) describing neuroscience public engagement projects connected with neuroethics, that the participant was involved with or aware of; 2) general perceptions of the five NeQNs and their relevance to the participant's projects or community; and 3) recommendations for other potential contacts and projects for future interviews.

This report is by no means intended to be an exhaustive, worldwide list of neuroscience public engagement projects with neuroethics connections. Indeed, we expect the list will only continue to grow beyond the scope of this current report. There is likely to be utility in establishing a community resource that catalogs the breadth of this work more systematically. However, as participant responses converged into a set of similar engagement style categories, and common threads and names began to be suggested by different participants, we became confident that this report is a strong snapshot of the current state of relevant work.



Map of interviews showing location of home institution or organization. Refer to Appendix B for complete list.

IV. Trends in neuroscience public engagement with neuroethics

1. Structured assessment of public opinions and attitudes

A key motivation for public engagement with neuroethics is the desire for a generalizable understanding of community- or population-level attitudes about a particular issue. When captured through intentional, structured methods, this information helps to define broad cultural context and societal values that can then be applied to shaping research priorities, public policy, or communication strategies. The range of methodologies used to collect this data involve different levels of public participation and yield different types of information about public opinion. **As Lars Klüver of the Danish Board of Technology shared, it is necessary to separate “reflexive” answers from “reflective” answers—the latter may be more nuanced and informative, but sometimes it is useful to understand a gut reaction.**

Deliberative dialogue is a model of structured discussion that brings together diverse stakeholders to consider different points of view and come to a collective judgment—though not necessarily consensus—about an issue that synthesizes the thinking of the group (Nielsen et al., 2006). For dialogue about scientific issues, experts and public audiences are deeply engaged in a multidirectional conversation about a socio-scientific aspect of the topic, with shared background information on the topic and guidelines for discussion that ensure all participants are heard (Lowenthal, 2016). Discussions are framed with the explicit recognition that public participants have valuable expertise to contribute. While the format of deliberative dialogue necessarily limits the number of people involved in any given event, participants are often carefully recruited to be representative of the stakeholder population.

Interviews and surveys are considerably easier to administer at scale, allowing a larger reach. However, conclusions that can be drawn from interviews and survey results are highly dependent on methodology (Boynton & Greenhalgh, 2004). Valid, reliable survey instruments and interview protocols, ethically administered to a representative sample of the population, yield high quality, generalizable data. More informally designed instruments can be useful for formative evaluation for a particular project, but must be treated with caution when extrapolating to larger trends.

Online comment analysis is a third tool for assessing public opinion that, while not representative of a general population, leverages access to large communities of people who share a specific interest (Wright, 2005). An additional advantage of this method is that it easily allows comparisons of trends in public opinion at different periods of time.

FEATURED PUBLIC ENGAGEMENT: AI 360
Danish Board of Technology, Denmark

The Danish Board of Technology (DBT) is a leader in participatory programming that brings together citizens, experts, stakeholders, and decision makers towards positive societal development in Europe and beyond. [AI 360](#), an initiative within the Human Brain Project, is a new, two-stage experiment in public engagement, innovating on the classic, deliberative dialogue model DBT has previously applied to a variety of other topics in science and technology. Designed to evaluate the future implications of artificial intelligence and produce actionable solutions, the project first brought together a transdisciplinary group of experts in March 2019 to identify potential uses and societal impacts of artificial intelligence and machine learning. These insights will next inform a Europe-wide public engagement process in summer and autumn 2019 through self-organized citizen discussion groups, facilitated with online videos and text message-based discussion prompts.

Survey: American attitudes about biomedical enhancement - Pew Research Center, U.S.

- The Pew Research Center is a nonpartisan organization in the U.S. that conducts public opinion polling, demographic research, content analysis, and other data-driven social science research. In 2016, the Center conducted a public survey to examine Americans' attitudes about the potential use of [three emerging technologies](#) that could fundamentally improve human health, physical abilities, or cognitive abilities (Pew Research Center, 2016). One of the technologies was specifically neuroscience related— an implantable brain chip that would improve concentration and information processing. The sample of nearly 5,000 participants was drawn from a nationally representative panel of randomly selected adults, and weighted based on selection probability, likelihood of active participation, and demographics. The questions were developed through a series of formative focus groups, individual pilot tests, and expert consultation. Overall, a majority of U.S. adults said they were more concerned than excited about brain chip technology, predicted that the technology would become available before it was fully tested, and worried that inequality will increase since initially only the wealthy are likely to have access. In addition, respondents perceived that the stronger the potential enhancement effects of the technology, the less acceptable its use.

Interviews: Kenyan cultural models of early childhood development - FrameWorks Institute, U.S./Kenya

- The FrameWorks Institute is a U.S.-based nonprofit organization that designs and conducts social science research around the world to support social change. Among several studies relevant to neuroethics, including studies of addiction and mental health, FrameWorks explored attitudes and understanding of [early childhood development in Kenya](#) through interviews with a representative sample of public participants, decision makers, and experts. The public participants were recruited through community health networks, representing predetermined demographic criteria such as age, gender, language group, and educational background. These one-on-one, semi-structured interviews were supplemented with “on-the-street” interviews, where survey administrators intercepted participants in common public areas, making a general effort to recruit a broad range of demographic representation. For public audiences, the concept of “early childhood” as birth to three years of age was novel; once defined, participants recognized it as a period of developmental milestones when environmental factors—especially poverty—can have a major impact. This foundational understanding can support future public engagement about both the brain during early childhood development and the role of government and other systems in supporting children and their caregivers.

Survey: Community-guided ethical framework for research - Center for Neurotechnology, U.S.

- At the Center for Neurotechnology headquartered at the University of Washington, researchers Eran Klein and Sara Goering lead a [Neuroethics Thrust](#) to integrate ethics into the structure and practice of science. Among a variety of engagement efforts, the group is developing a public survey to inform development of a set of ethical principles to guide the field of neural engineering. As illustrated by this case and others we gathered, the involvement of a methodologist is not a common practice in public engagement research initiated by neuroscientists or neuroscience research centers.

Media analysis: Changing public perceptions of brain stimulation technology - University of British Columbia, Canada/U.S./U.K.

- Researcher Laura Cabrera (now at Michigan State University) studies the ethical and societal impacts of emerging neurotechnologies, focusing among other things on public perceptions and media coverage. With collaborator Peter Reiner she assessed public attitudes about [cognitive enhancement using transcranial direct current stimulation \(tDCS\)](#) through thematic analysis of online comments submitted to U.S. and U.K. popular media sources (Cabrera & Reiner, 2015). They analyzed comments from two time periods—before and after the first wide release of a commercially available tDCS product—to reveal a maturing public dialogue about an emerging technology. During the earlier period, tDCS was often confused with similar technologies, comments about enhancement were more polarized, and safety was of greater concern than ethical issues. In the later period, comments shifted to a tone of “cautionary realism,” with more understanding of the DIY (do-it-yourself) potential of tDCS, more distinction between tDCS and other stimulation techniques, and more frequent discussion of commercialization, therapeutic benefit, and policy. Cabrera’s research, both on tDCS as well as more recent work on new techniques of psychiatric neurosurgery, demonstrates how insights from online comments can inform communication strategies and public policy. While Cabrera focuses her work on public engagement with traditional media sources online, she shared that others are also working in the realm of social media.

Across these different types of structured assessment, a common thread that emerged was the challenge of finding the right level of contextual background to provide in order to elicit meaningful answers. Examples of scientific or societal context included short vignettes describing realistic scenarios for surveys and interviews, more extensive materials prepared for deliberative dialogue programs, and pairing online survey distribution with an in-person interaction. As illustrated in several examples above, determining this context is a critical part of the formative process of developing assessment tools as well. We also found that while public engagement practitioners recognize the need to separate fact from fiction, they often perceive an unfounded

prejudice among researchers—that public audiences must understand science before being able to engage in discussion of its societal and ethical impacts.

2. Interactive exhibits, public programs, and other informal STEM learning experiences

Exhibitions and public programs with strong interactive components have been a popular mainstay of science centers, children’s museums, community organizations, festivals, and other informal—or out-of-school—learning venues for decades. The resulting style of learning is fun, social, and shown to be critical in the lives of participants (Falk & Dierking, 2010). Informal learning opportunities are particularly effective for sparking interest and motivation to participate in STEM activities, and for helping learners develop an identity as someone who knows about and uses STEM (National Research Council, 2009). Furthermore, the development of successful exhibitions and public programs is supported by a strong professional community of practitioners who design, implement, and continually improve experiences for learners through evaluation and research (National Informal STEM Network, 2019).

Exhibitions frequently hold a special place in the memories of those visiting science centers. Modern science centers, and associated interactive exhibit experiences, emerged during the Cold War period of the 1960s with a handful of seminal institutions in the U.S. (such as the Exploratorium), sometimes taking inspiration from early museums of science and technology in Europe (Ogawa et al., 2009). Today, a variety of interactive exhibitions engage visitors inside and outside museums, and enable all ages to learn scientific principles, design and create, or simply wonder. Exhibitions come in small and blockbuster sizes, but often have common aspirations such as the use of immersive environments and the latest technologies. Social interaction, accessibility, and visitor flow also are important when splitting content across appropriate exhibit components.

Public programs in informal STEM education is an amorphous term covering a collection of experiences that bring people together to explore, learn, and discuss STEM topics. A public program could be a summer camp, an outdoor afterschool program, a science festival maker area, or many other supervised learning programs outside of school. These types of programs are rarely bound by education standards and lengthy curricula. Alternatively, they use free-choice or project-based learning, creating engaging environments with more opportunities for formative conversations with peers and facilitators. Hands-on activities, real science and technology tools, and increasingly STEM gaming are all frequent elements of these experiences.

FEATURED PUBLIC ENGAGEMENT: *Mind the Brain* Exhibition Bloomfield Science Museum, Israel

The Bloomfield Science Museum in Jerusalem is both a cultural and educational institution that promotes public interest in science and technology through interactive exhibits and associated activities. As a partner in the Human Brain Project (HBP) in Europe, the museum worked closely with neuroscientists and ethicists to create the *Mind the Brain* traveling exhibition that will visit science centers, community centers, and retail establishments in Israel and beyond. The main objective of the exhibition was to showcase fundamental brain anatomy, function, and research—especially when connected to HBP neuroscientists and findings. Neuroscience content was the primary messaging for the exhibition, but as a window into HBP, neuroethics also played a role in the development process and resulting components. **For example, Varda Gur Ben Shitrit, Deputy Director of Content Development at the museum, shared that her team learned while prototyping the exhibition that visitors “were very terrified to deal or speak about neurodegenerative diseases.”** Relatable questions were therefore used throughout exhibit labels to encourage parents to converse with their children on science and society topics. Prominently, a large pillar was added to the exhibition that allowed visitors to leave notes with “for,” “against,” or “not decided” opinions on six provocative statements (see below). Exhibit designers worked with the HBP lead on neuroethics to compose the final statements and will monitor their effectiveness during the summative evaluation of the exhibition.

The concept of mind

1. If we discover all of the biological mechanisms that control how the brain operates, we will understand what human awareness is.
2. Creating a copy of the human brain on a computer will challenge our understanding of what it means to be human.

Medicine

1. Personal medical information must be available to researchers so that science can advance.
2. If we were able to treat the process of aging in the brain, we would be closer to making eternal life a reality, and that is a good thing!

Society

1. I am scared that findings about the brain and how it works will be employed against humans.
2. People should be allowed to use technological means to obtain new traits and abilities, and thus improve their life.

Neuroethics also appeared in the planned facilitation for the exhibition. Museum guides use a group EEG demonstration with visitors, as an opportunity to have a short discussion on the different ways neurotechnologies can be used—steering away from a binary choice between good vs. bad. Another option to foster discussions with visitors may be guided tours of the exhibition conducted by neuroscience students and researchers. These neuroscientist volunteers would be trained by museum guides on how to engage public audiences by both using exhibit components and potentially sharing their own research connections with visitors.

Exhibition: Public space in a neuroscience research center - Wyss Center for Bio and Neuroengineering, Switzerland

- Many neuroscience research centers we talked with had some form of onsite public space that introduced their mission and related brain science content. The [Wyss Center](#) hosts a small exhibition primarily meant for school groups (ages 8 to 18) visiting their facilities at [Campus Biotech](#) in Geneva. The exhibition is one part of a larger public outreach strategy that separates neuroscience fact from fiction, especially around brain-machine interfaces and implantable neurotechnology. As part of a center focused on neurotechnology for human applications, the exhibition showcases implanted medical devices through several interactive platforms including augmented reality (AR). Visitors 'scan' QR codes on three mannequins to reveal the implanted devices. Jo Bowler and Tracy Laabs shared that presenters in the space sometimes attach the same QR codes to their clothing, giving the impression that they also have implanted devices. As brain-machine interfaces become more common—with the possibility to enhance the abilities of able-bodied people using neurotechnologies outside of medical supervision—many ethical and social challenges will likely become more urgent, including questions of autonomy, data privacy, and managing user expectations (Clausen et al., 2017). The research and development on implantable medical devices is highly regulated, so neuroenhancements are not directly addressed in the AR experience; only current and future clinical applications are represented in the exhibition. However, these topics come up during visitor conversations and as groups are adding their ideas to the "Draw your Future of Neurotechnologies" whiteboard at the conclusion of the exhibition. The Wyss Center has also created a basic [survey](#) to gauge public perceptions of neurotechnology and artificial intelligence, and encourages visitors to participate after they leave the exhibition. The survey questions allow participants to comment on the use of neurotechnology for both clinical patients and healthy people, but the survey was not created with a methodologist.

Public program: Mental health and youth - Neuro Champions program from Chanua, U.K.

- [Neuro Champions](#) is an innovative neuroscience youth program from [Chanua](#), a company in Liverpool addressing challenges in healthcare, mental health, and wellbeing. Breaking from a traditional symptoms-based perspective, Neuro Champions encourages youth to reflect on mental health with their peers through connections to their environment, technology, personal experiences, and emotional wellbeing. The program uses games, play and technology to support young people to become leaders of the future. This more transdiagnostic approach taken in workshops and activities helps the program reach neurodiverse communities and other populations in need (e.g. migrant families, underrepresented groups in STEM, etc.). Naomi Mwasambili shared that she co-created Neuro Champions to help students learn neuroscience and mental health content in a fun and engaging way, but also to understand the adolescent brain—

and view mental “illness” in the context of normal development. Trauma, low moods, and anxiety are all common issues for students participating in the program. She was also frustrated with how health content was delivered during her own professional background as a clinician and wanted to develop an outreach program that did not perpetuate the existing power dynamics in healthcare. Students in Neuro Champions often have the chance to engage directly with neuroscience research departments looking for youth input and gain research experience as young researchers. This interaction is part of a broader program goal of helping youth be creators, not just consumers, of their own digital futures. Neuro Champions stands out as a rare and intriguing example of a for-profit company receiving funding, in this case from the Wellcome Trust, for its public engagement work.

Public program: Student self-expression in neuroscience learning - Neuroscience/drawing workshop, University of Freiburg, Germany

- Researcher Oliver Müller shared a new type of program that asked young students to reflect on neuroscience content gained from expert presentations, laboratory visits, and group discussions, then develop graphic stories to go beyond the facts. Topics were based on the work of [BrainLinks-BrainTools](#) in Freiburg, which brings together university researchers and partners in a German Research Foundation-funded cluster of excellence to develop neurotechnologies. Parkinson's and epilepsy patients connected with students by discussing their lives in the context of their illness and treatments—including deep brain stimulation and other surgical interventions. Students also explored neuroethical questions through a role-playing game experience. The PlayDecide role-playing games, [Non therapeutic Neuro-Enhancement](#) and [Neuroscience - brain enhancements](#) both use structure and materials to engage people with different perspectives and backgrounds in informed conversations on complex issues (Duensing & Lorenzet, 2007). After learning more about creating graphic comics and working with a professional graphic artist, the students developed the concepts for their narratives. For one week, their completed [graphic stories](#) were exhibited in the museum and became part of a public science event.

The shared characteristics that stood out in the above examples, gathered from our interviews, perfectly mirrored the three major *Criteria for Identifying and Developing Productive STEM Out-of-School Programs* from a 2015 report from the National Research Council: **engaging, responsive, and make connections.**

Engaging: Engage young people intellectually, academically, socially, and emotionally

Responsive: Respond to young people's interests, experiences, and cultural practices

Make connections: Connect STEM learning in out-of-school, school, home, and other settings

Some highlights within these criteria shared by the examples were: *including first-hand experiences with phenomena and materials, positioning STEM as socially meaningful and culturally relevant, and leveraging community resources and partnerships* (National Research Council, 2015). Exhibitions and public programs featuring neuroethics—and addressing learners as individuals with emotions, experiences, and community—allow for stronger connections on societal-learning criteria than experiences driven solely by content. Neuro Champions, along with another informal neuroscience learning experience we heard about in our interviews—[Frontiers for Young Minds](#), a science journal edited by and for youth—particularly excelled at *supporting young people to collaborate and to take on leadership roles in STEM learning activities*.

Another common topic from our interviews in this category was a strong desire from those groups working on exhibitions to have more opportunities for peer learning and partnering to reach a wider audience. This sentiment was also repeated in interviews with the Korea Brain Research Institute and Japan’s RIKEN Center for Brain Science, with current and future public-access brain exhibitions, respectively, that so far do not plan to cover neuroethics. This finding supports the need for stronger inclusion of global brain research centers with exhibits at science-and-technology-center professional conferences, and reciprocal outreach from the museum community to interested brain research centers.

3. Inspirational media through partnerships with artists

Art and science have always shared bonds of creativity and innovation, but the connections with neuroscience can be argued to be fundamental. Beyond the incidental beauty of neurophysiology or neuroimaging, our senses, spirits, and selves are common threads of both brain research and artistic expression. More so than with many other STEM disciplines, artists have direct links with the mysteries that energize neuroscientists and public audiences alike. Artists channel imagination into expression and drive us to reach further into the unknown spaces of our consciousness. Our interviews identified several examples of artists acting as bridges between disparate communities surrounding neuroethical issues, by visualizing or verbalizing unspoken emotions and motivations through creative work. The two categories below attempt to characterize the major projects we learned about.

Artistic interpretation in neuroscience public engagement often begins with the unknown. How does it really feel inside the mind of an individual living with a mental illness? What does a self-selected neuroenhanced human look like? Can an AI system draw a self-portrait? Without the need for certainty and empirical knowledge, artists can help spark introspection and curiosity about neuroscience for public audiences. Neuroscientists can also partner with artists to generate a more human-centric lens for their research questions by adding back context, emotions, and aesthetics—which are often removed in a reductionist pursuit of scientific truth.

Theatre, film, and radio performance driven by narrative provide characters and situations to which viewers can relate. Theoretical neuroscience concepts and “faraway” ethical quandaries suddenly become critical when they concern someone with a face and name, whom we can begin to care about personally. Fictional stories are pathways to multiple futures for us to consider—allowing everyone, regardless of background or expertise, to discuss a hypothetical future they would like to help make a reality. Nonfiction documentaries hold a mirror up to our own lives, giving immediacy to issues or questions we can no longer avoid or ignore. Performance is powerful, and talented artists know how to reach an audience and make them walk away thinking in different and deeper ways.

FEATURED PUBLIC ENGAGEMENT: Picturing Parkinson’s University of Oxford, U.K.

Many factors including fear, prejudice, and dehumanization—among both scientists and public audiences—hinder the process of understanding how a neurological disease such as Parkinson’s impacts patients’ lives. Added to this, patients with Parkinson’s often struggle with communicating their own experience, due to both physical and psychological barriers. In the face of these challenges, patients’ perspectives are still fundamental to advancing objective scientific research on Parkinson’s, ethical discussions about new neurotechnology treatments, and informed societal views of the disease. [Picturing Parkinson’s](#) is a project that attempts to engage scientists and public audiences with patient stories through sometimes evocative interpretations by professional artists. Project leader Chrystalina Antoniades and other clinician scientists assist the artists in meeting and working with patients one-on-one either in the hospital or at the Ashmolean Museum, Oxford. In some cases, the artist has never seen or interacted with a Parkinson’s patient before, leading to an emotional journey with patients who attempt to be open and honest about their condition. The artists create an externalization of what patients are feeling. One artist, [Rebecca Ivatts](#), decided to depict the immediate effects of Deep Brain Stimulation on a patient’s tremors as a magician’s dove about to escape the brain. Another artist, Yejeong Mutter, interpreted a patient’s feeling of always being in a restrictive shell as sculpture using fragile wire around a fist, moving some viewers to tears. Each year, there is a public panel to discuss Parkinson’s in the context of the art resulting from patient stories. The audience for the first event included clinicians, scientists, students, artists, patients and families from all parts of the U.K. Antoniades shared her initial concern that a projected, interactive word cloud derived from audience reactions, starting with many words like “depression,” “sad,” and “no hope,” would only remain negative after the panel. After hearing the patient stories, the word cloud dynamically generated by the audience trended in the positive direction. **Antoniades added that she “sees this engagement giving patients their own voice, including some who have literally lost their own voice.”**

Theatre, film, and radio performance driven by narrative: Sense of self - Future Bodies and You Have Been Upgraded, Unlimited Theatre, U.K.

- [Unlimited Theatre](#) received funding from the Wellcome Trust to make and tour a new theatre show to investigate the ethical, political, and social impacts of cutting-edge biotechnology, including brain implants, cognitive enhancing drugs,

and advanced prosthetics. Unlimited Theatre created the show with the theatre company RashDash and a panel of scientific experts over a two-year period. [Future Bodies](#)—stemming from a 2015 interactive festival of human enhancement and biotechnology at Science Museum London—considers questions such as “What is our body’s relationship to our brain?” and “What is ‘human’ in a future of unprecedented enhancement possibilities?” A series of public engagement events involving the scientist partners and audience members accompanied the Future Bodies performances. Audience surveys showed 64% of respondents answered “A Great Deal” or “A Lot” as the extent to which “they had been provoked or challenged by the scientific ideas and messages.” The theatre performance was also followed up with a public event at the Manchester Science Festival. [You Have Been Upgraded](#) was a live conference session, in response to the themes introduced in Future Bodies. Through talks, interactions, and performances, You Have Been Upgraded explored how we choose to enhance our bodies and shared a positive, open approach to considering body enhancement. A [RFID/NFC chip](#)—used for wireless communications with electronic devices— was implanted live on stage, alongside a tattoo artist working with a volunteer participant throughout the sessions, to radically explore enhancement themes with attendees. The 300-person capacity event was sold out, with attendees queueing up afterwards to speak with partnering scientists about the technology being discussed.

Artistic interpretation: *Self Reflected* by Greg Dunn and Brian Edwards - The Franklin Institute, U.S.

- [Self Reflected](#), perhaps the most detailed artistic representation of the brain ever created, aims to inspire wonder, reflection, and discussion about the nature and complexity of consciousness. The work is currently on display in the [Your Brain](#) exhibition at The Franklin Institute science museum. The artists, Greg Dunn and Brian Edwards, invented a novel technique called reflective microetching to simulate the microscopic behavior of neurons in the viewer’s brain as they observe this work of art. Evaluation of the piece as a stand-alone work of art has shown that after viewing *Self Reflected*, visitors: make personal connections that change their perceptions of their own brain, appreciate the power of art to broaden modes of learning science and increase its accessibility, and reflect on how the experience helped them visualize the unseen (Das et al., 2017). The piece also serves as a focal point for facilitated conversations; for example, the artists have been invited to the museum’s evening events for adults to engage in deeper dialogue with guests. Among themes that have emerged from these conversations—elicited by the artists’ provocative statement that their work is the embodiment of human consciousness—are the very nature of consciousness, and the validity of scientific perspectives with respect to other modes of knowledge.

Theatre, film, and radio performance driven by narrative: Sense of self - *Elegy*, U.K.

- *Elegy* was a play by Nick Payne, supported by the Wellcome Trust. The premise of the play was that in the near future, an operation would exist to completely cure someone of a neurodegenerative disease, but the surgery would cause the patient to lose 30 years of their memories. The narrative explored the ethical implications of such a treatment through the lens of the patient and of the family relationship. What does it mean to be a person, and how do we define our sense of self through memories? The play also brought up questions about when and if scientists and clinicians should intervene in brain disorders when a patient's identity is in the balance. Anil Seth of the University of Sussex was one of the experts who served on the [science advisory panel](#) for the play. He shared that the advisors were brought in to discuss the play with the company after it had been written. He also added that there were public panel discussions with himself, the director, and religious leaders during the run of the play.

A consistent finding from our interviews of program leaders partnering with artists was the overwhelming public response to the final creations that leaders reported. Neuroscience-inspired drawings, full-body exhibit experiences (such as the colored mist installation of [Ann Veronica Janssens' yellowbluepink](#) in the States of Mind: Tracing the Edges of Consciousness exhibit of the Wellcome Collection), and music (like the [Sonic Tour of the Brain](#) by Guerilla Science) are readily accessible to public audiences and evoke strong emotions. Films, plays, and radio performances resulting from artist and neuroscientist collaborations are popular and win awards, like the 2016 BBC Best Drama-winning [The Sky is Wider](#); this radio program about a minimally conscious patient was first conceived at a Wellcome Trust "Experimental Stories" workshop bringing together scientists, writers, and radio producers. Collaborations with artists can even directly benefit neuroscience research; University of Houston researcher Jose Luis Contreras-Vidal has outfitted [artists with EEG caps as they work](#) in front of a public audience, allowing him to study the brain in action.

One clear regret we heard from interviews was when project partners did not follow up popular creations, missing the opportunity for public dialogues such as a panel with neuroscientists and artists who had been involved in the project, or other types of public or patient forums. Picturing Parkinson's, Future Bodies, *Elegy*, and other examples described above had post-production, public engagement strategies that took advantage of their potentially ephemeral media platforms. Discussing the creative process with public and professional audiences, setting up additional screenings with community partners, or providing online viewing access creates opportunities for extended ad hoc public engagement. Examples include a [University of California, San Francisco](#) forum with students, nurses, doctors, and medical providers, and a University of Washington Spinal Cord Injury forum with patients, that were both motivated by the documentary [FIXED: The Science/Fiction of Human Enhancement](#).

4. Expert discussions for public audiences

Because neuroethics brings together so many disciplines, the most common format for public engagement is literally to bring together experts representing the different perspectives of those disciplines, to discuss a particular topic in front of a public audience. Nearly half of the people we interviewed, across all geographic regions, referenced a public discussion event as part of their engagement portfolio.

A standard format for a public discussion is typically a 60- to 90-minute event, featuring one or more experts who make brief opening presentations and a moderator who then facilitates a conversation among the experts, using questions from the audience. Often there is a reception with light refreshments afterwards to encourage more unstructured conversation between experts and the audience.

Within this standard format, however, different production variables can have a major effect on the affective impact of the event. The venue in particular is critical in setting a tone—many event organizers choose to hold their events at public spaces like cafes, pubs, or art galleries. These venues create a more intimate setting for conversation than a university lecture hall; the choice may limit audience size, but helps to break down barriers and bring experts out of a lecture mindset. More recently, organizers have begun to broaden their definition of “expert,” recognizing that lived experience is a valuable and necessary type of expertise. Through our interviews we learned of several events where public stakeholders, such as caregivers, patients, or other end users (e.g. a former incarcerated individual as part of an event about the impact of solitary confinement), were involved to provide a real-world perspective to complement and challenge academic experts.

Below we describe several examples of how the basic public discussion format has been adapted by different practitioners to influence research culture, build new community connections, and broaden outreach to increase awareness of ethical and societal implications of neuroscience and technology.

FEATURED PUBLIC ENGAGEMENT: The Brain Dialogue Australian Research Council Centre of Excellence for Integrative Brain Function

[The Brain Dialogue](#) is a public engagement network made up of all the major brain research universities in Australia. It was modeled on a Responsible Research and Innovation (RRI) approach, that encourages mutual learning between scientists and public audiences through structured, issues-driven activities such as forums, panels, workshops and interviews (Nowak & Paton, 2017). The Australian version of RRI replaced ‘Responsible’ with ‘Responsive’ to reduce the appearance of judgment on existing brain research and to bring more attention to the greater alignment of the neuroscience community with societal needs. This approach was new for the neuroscience community in Australia, which was often characterized by those we interviewed as fragmented and focused on basic outreach before the Brain Dialogue. As they rolled out, the Brain Dialogue public panel debates and discussions began to address

important neuroethical issues, including neuroenhancements and brain-machine interfaces, self-administered brain stimulation, and how people with behavior or psychiatric disorders are treated in society. The launch of the program's website became an inflection point for all the neuroscience public engagement efforts in the country, by providing a public platform that encouraged further integration.

Rachel Nowak, former director of the Brain Dialogue, shared with us that one major accomplishment of the program was getting some senior neuroscientists in Australia to see the value of true public dialogue in their research—a significant change in culture. This work towards a mutual partnership between scientists and public engagement practitioners was a frequent topic of discussion in our interviews. Nowak referred to neuroscientists as “future makers” and stressed the importance of them sharing a platform with neuro-enthusiasts from the general public. She considered a Brain Dialogue public panel event where neuroscientists sat on stage with representatives from the sometimes scorned neuroenhancement community to be a great success.

Professional conference events: Public forums with the International Neuroethics Society (INS), U.S.

- The INS is an interdisciplinary professional organization that promotes the responsible development and application of neuroscience. As part of its annual conference, the INS hosts a public program for meeting attendees and the local community. Previous events have featured talks on the ethics of [emerging health technologies](#), [neurogaming](#), and [truth and lying](#). When feasible, forums are held in museums, libraries, or other public spaces, working with the venue to recruit the public audience. INS Executive Director Karen Graham described the 2018 conference public program, a forum titled “[My Brain Made Me Buy It: The Neuroethics of Advertising](#).” The featured speaker was a neuroscientist from a major marketing and consumer analytics company, with two researchers in neuroscience and decision-making as discussants. The event was held at the San Diego public library in partnership with the Center for Ethics in Science and Technology, which hosts a regular series of [public events about ethics and science](#). Like similar events, the discussion included time for audience questions, with a reception afterwards to encourage conversations between INS members and community participants.

Professional expertise and lived experiences: Human X Design, U.S.

- The format of the [Human X Design](#) conference held in New York in 2016 was unusual among panel discussion events, because it was sponsored by a commercial video game company, in conjunction with the launch of a new game set in a future world where augmented humans are discriminated against and separated from society. Researcher Anna Wexler, who moderated one of the sessions, described how the panels featured not only academic experts in technology and ethics but also people living with selective and therapeutic implants. Among them was Neil Harbisson, an artist born with a rare form of color blindness, whose brain is embedded with a chip that translates color into

sound. Harbisson became the first human to be recognized as a cyborg by a government body. According to Wexler, the mix of expertise among both the speakers and the invited public audience made the discussions and receptions especially lively.

Forums for extended discussion: Public courses at the University of Cape Town (UCT), South Africa

- The emergence of medical humanities in Africa as an interdisciplinary field with deep public relevance has created an opportunity for neuroethics to be infused into broader programs. Two examples of these programs include UCT's [Summer School](#) and [Medicine and the Arts online course](#). Summer School is a public education program for the local community with a number of courses in various disciplines, each consisting of 3- to 5-hour sessions. The 2019 Summer School featured several courses with themes relevant to neuroethics, including *Neuroscience*, *What Makes Us Human?*, and *Sleep and Dreaming*. UCT researcher Andrea Palk shared that *Neuroscience* was an especially popular course with the scientific discussions incorporating ethical questions. The Medicine and the Arts online course reaches a worldwide audience, with mental illness and medicine as one of its focal topics. Led by an anthropologist and a physician, the online course features discussions with scientists, social scientists, and artists to consider our tendency to separate the mind and body in medicine, our definition of humanity, and the connections between art and medicine. In online reviews, participants commented on the transdisciplinary content, the excellent participatory opportunities, the care and sensitivity of the instructors, and the global exchange of ideas. As one reviewer mentioned, "the topics were quite diverse, and it was fascinating to read other participants' views and experiences in their own countries."

Through our interviews we learned that this format is popular in large part because of its relative ease of implementation. Though the inherent one-to-many style of interaction limits the potential for meaningful dialogue, the transient nature of these events lends itself to addressing topical issues. As neuroscientist Diego Golombek shared, the current "neuroboom" is an excellent opportunity to talk about the impact of neuroscience in everyday life, through topics that attract public interest and connect to popular culture like perception, language, morals, money, and food. The format also provides opportunities to build professional connections across disciplines; for example, events and full-fledged programs in [Argentina](#), [Canada](#), and [Ireland](#) have featured neuroscientists, philosophers, physicians, ethicists, and journalists.

5. Partnerships for clinical applications

Understanding the mechanisms behind brain diseases and disorders and developing new therapies are critical aims of current neuroscience research. With a focus on new tools and technologies that can untangle these complex problems, the integration of ethical, legal, and societal considerations into research is essential to ensure that human wellbeing is prioritized (Greely et al., 2018). While some concerns of clinical neuroethics are shared with broader themes in bioethics in general, there are unique issues that emerge from the body-brain-mind relationship embedded in brain health and disease. Partnerships among researchers, hospitals, patients, and advocates have developed as an active area of public engagement to address these issues. In contrast to the four other types of public engagement described above, we found that partnership efforts are necessarily more outcome-driven. Through our interviews, we identified three key goals of these partnerships with multiple formats being used to support specific stakeholder needs.

Shaping research priorities. If scientific research is to meet the needs of patients and end users, then these stakeholders must be engaged at every phase of investigation. Researchers we interviewed reflected that in the past, stakeholder engagement has been limited because research stopped at proof-of-concept, or patients were recruited as subjects rather than partners. With the recent growth of transdisciplinary research collaborations like the International Brain Initiative, the explicit inclusion of ethical considerations has begun to create opportunities for patients and public audiences to participate on more equal footing with scientists. Key societal and ethical issues addressed through these efforts include shared development of research directions, usability of and access to novel therapies and technologies, and boundaries between treatment and enhancement. The format of these partnerships can include focus groups, public participation in research review boards, and even close collaborations among researchers, clinicians, and patients with rare genetic diseases to generate new hypotheses.

Improving participation and outcomes. Around the world, the historical—and in many areas, still persistent—cultural divide between biomedical researchers and patient groups has resulted in a legacy of systemic barriers and distrust that impedes public participation in new research (e.g. Coakley et al., 2012; Kong et al., 2017; Alemayehu et al., 2018). **Researcher Tzipi Horowitz-Kraus, head of the Educational Neuroimaging Center at the Technion, reflected on the challenge of getting approval for novel pediatric brain imaging research in Israel: “Nobody’s done that before, and [the perception is that] if nobody’s done that then maybe it’s risky.”** However, as both communities realize the value of diversity and broader inclusion for accelerating progress and improving health, shared incentives are facilitating new models of partnership. Among those we interviewed, partnership models included culturally sensitive frameworks to communicate the need for neurotypical study participants (subjects who have reached developmental milestones within the common range of the

general population), patient registries for data sharing, and innovative, patient-centered architectural design of study spaces. Key ethical issues faced include consent, privacy, dignity, and identity.

Changing public attitudes. Emerging neuroscience research has begun to develop stronger biological models of diseases and disorders, but cultural stigmas—especially with respect to mental illness—remain powerfully entrenched. A global study across 16 countries found that, while there is some cross-national variability due to local cultural traditions, the majority of people recognize the biological causes of mental illness but still harbor negative perceptions of those affected, especially in the context of intimate social situations or positions of authority (Pescosolido et al., 2013). Widespread societal efforts involving cross-sector partnerships are therefore necessary to build on general public understanding of the underlying neurobiology, and address issues of stigma and autonomy at the cultural level.

FEATURED PUBLIC ENGAGEMENT: Renaming schizophrenia in Japan
Japanese Society of Psychiatry and Neurology (JSPN) in collaboration with National Federation of Families with Mentally Ill in Japan (NFFMIJ)

In 1937, the JSPN introduced schizophrenia as a hereditary, untreatable disease with the term “Seishin-Bunretsu-Byo” (mind-split-disease). Inhumane treatments and legislation designed to exclude people with the diagnosis persisted throughout much of the 20th century, resulting in such severe stigma that many psychiatrists were not informing patients about their diagnosis (Sartorius et al., 2014). As research on the disease progressed to reveal a new understanding of treatment options and recovery, NFFMIJ requested a formal name change by JSPN in 1993. With input from NFFMIJ stakeholders, JSPN members, and public audiences, a new term, “Togo-Shitcho-Sho” (integration disorder), was approved by the Japanese government in 2002.

Within a year, the old term had largely been replaced in mental hospitals, dramatically increasing the willingness of psychiatrists to confer diagnosis using the new term (Sato, 2006). A study of newspaper articles mentioning schizophrenia showed that there was a significant decrease in the percentage of articles with negative or “danger” associations after the introduction of the new term (Aoki et al., 2016). The name change also catalyzed a series of sustained anti-stigma activities, including a new focus on community-based care, new guidelines for assessment and long-term treatment plans, and the inclusion of social workers in a new therapeutic alliance.

Shaping research priorities: Providing a strong voice for patients in research governance and trajectory - MULTI-ACT, Italy

- Modern healthcare has made progress in educating patients on recent discoveries and treatments, but there is no comprehensive strategy to engage patients as true stakeholders in health research. [MULTI-ACT](#) is a recent EU-funded, multi-stakeholder initiative coordinated by the Italian Multiple Sclerosis Society Foundation, which aims to improve the impact of research for patients

with brain diseases. In order to make research more effective and inclusive, MULTI-ACT is working towards broader patient engagement with executive and scientific governance of the research enterprise—pushing beyond traditional patient board input or one-sided involvement with clinical trials. By developing a new Collective Research Impact Framework, starting with multiple sclerosis and then expanding to wider brain and health research domains, MULTI-ACT hopes to elevate patient engagement and other patient-reported outcomes alongside metrics of scientific excellence, economic efficiency, and social impact. Similar to leaders of other projects whom we interviewed, MULTI-ACT leaders are highly motivated to learn about effective and scalable engagement strategies, especially in the digital space, that could prepare participants for public dialogue on brain research. The far-reaching goal of MULTI-ACT is a flexible digital toolbox for patients, researchers, and other stakeholders to facilitate closer cooperation and shared impact.

Improving participation and outcomes: Brain banks and traditional cultures - Korea Brain Research Institute (KBRI); China Organ Transplantation Development Foundation (COTDF)

- Rates of brain tissue donation in Asian countries, including Korea, China, and Japan, have historically been significantly lower than those in the West, impeding progress in brain research. This trend has often been ascribed to cultural traditions grounded in Confucian beliefs about bodily integrity after death. With emerging data suggesting that religious beliefs are no longer a primary barrier to donation in modern Asian society, brain research organizations like [KBRI](#) and COTDF are pursuing new public engagement strategies to raise awareness about the need for donors and increase brain bank registration. In China, a simple, [online donor registration process](#) administered through the mobile payment platform Alipay resulted in a dramatic spike in registration. In South Korea, researchers are partnering with public health facilities and developing community symposia to recruit participants (Kim et al., 2018). As neuroethical issues gain traction in the Asian scientific research community, these early efforts developed for brain donation will inform future public engagement on other issues.

Changing public attitudes: Continuing challenges for schizophrenia - National Alliance for Mental Illness (NAMI), U.S.

- NAMI is the largest mental health organization in the U.S. advocating for patients and families. While the Japanese example of changing nomenclature to change public perception is a positive example of how to address the stigma against mental illness, Andrew Sperling shared that the scientific complexity of understanding schizophrenia has led to continued challenges for NAMI's efforts in public engagement and policy. Despite decades of research, the absence of a coherent neurobiological model of the disease contributes to the difficulty of finding consensus on ethical issues as well. In the U.S., decisions on patient

autonomy and involuntary treatment remain in the realm of law, with individual cases judged in the courtroom based on different legal criteria in different states.

These examples highlight an emerging role for professional and advocacy organizations as a bridge between health research professionals and public audiences. Because both researcher and patient communities are often geographically dispersed, effective public engagement is more likely to be driven by shared interests and goals rather than physical proximity, while still accounting for cultural differences. As a result, there are a growing number of opportunities to leverage network-level partnerships. As professional organizations expand their scope beyond convening and communicating among researchers, to include public engagement, there may be long-lasting impacts on their own organizational and research cultures.

V. Case studies from other STEM disciplines

To understand how models of public engagement fit into broader applications of STEM-informed societal issues, we investigated the context and outcomes of public engagement programs in other STEM fields. We examined several case studies that demonstrate different formats and rationales for collecting and considering public input regarding a socio-scientific question.

1. Informing public policy: gene drives

The first example highlights the role of public engagement in making a specific policy decision initiated by a governmental agency. Since the debut of CRISPR-based gene editing in the mid-2010s, the prospect and relative ease of genetic modification of whole organisms has accelerated in the public consciousness from pure science fiction to real-world business models (National Academies, 2019). The gene drive technique promotes the likelihood that a deliberate genetic mutation will be propagated through reproduction, so that an entire population is affected with relative haste; for example, a CRISPR-aided gene drive has been suggested as a means of eradicating malaria by rendering mosquito populations infertile (National Academies, 2016). However, the ecological consequences of gene drives are unknown, and ethical discussions as to which “synthetic biology” methods should be considered acceptable are by no means resolved. As New Zealand seeks to eradicate invasive predators by 2050 (New Zealand Government, Department of Conservation, 2019), gene drive is one pest elimination method the government is considering including by assessment of public preferences. New Zealand’s constitution requires substantial public input for policy decisions, and the country has a precedent for national decisions on emergent technology: the “Nuclear Free Zone” policy action of 1987 (New Zealand Government, Parliamentary Counsel Office, 2013).

The government of New Zealand conducted **structured assessment of public opinions and attitudes** for pest control methods, through survey methodology with a large sample of citizens representative of the country's diverse population. Participants were asked to choose a preference between two predatory pest control scenarios—for example, poisoning vs. trapping rats—or choose neither. Researchers assessed attitudes toward four different culling methods: trapping, pesticide, “Trojan female” (selective breeding so any male offspring are infertile), or gene drive (genetic editing so only male offspring are produced). Four psychographic categories of respondents resulted. Researchers found that when given little information on the culling method, people in the group favoring life in all forms and in the group generally supporting scientific advice preferred gene drive; those in the group that had an extreme distrust of governmental institutions were least supportive of gene drive. These results suggest that personal values factored more heavily than scientific understanding in respondents' decisions and have implications for how to contextualize science in other fields, including neuroscience.

When framing and communicating capabilities and options, articulation of technological developments needs to prioritize community and personal values over just factual education.

Case Study 1: New Zealand Invasive Pest Control – Conventional vs Gene Drive

New Zealand (NZ) aims to eliminate invasive predators and seeks citizen input for the method of implementation: physical (trapping), chemical (pesticides), or biological (breeding or gene editing).

Program Description: In 2017, the Department of Conservation surveyed 8000+ citizens, across census categories, on preferences between hypothetical pest-control scenarios (current and eventual findings available [here](#)).

Results and Lessons Learned: NZ citizens cluster into four psychographic profiles: 1) high regard for life, mild distrust of organizations; 2) strong relationship to nature, extreme distrust of government; 3) economics-based deciders, least concerned for conservation; 4) scientific-based deciders, high trust in scientists. Greater support for gene drive: Group 1 as a humane method; Group 4 as trust in science.

Lower support: Group 2 possibly driven by a distrust of institutional approaches over conventional methods; Group 3 having difficulty with budgeting for unknowns. The government of NZ hopes to understand how to articulate and decide on STEM-informed policy. **“Just because a scientist can develop it, doesn't mean the public needs or wants it.”** (Edy MacDonald, Department of Conservation, Government of New Zealand).

2. Defining future research directions: geoengineering

The second example looks at a socio-scientific question being considered at a much earlier stage: how should solar geoengineering be governed? Geoengineering is defined

as the deliberate intervention to affect climate and/or weather patterns at the planetary scale. The concept of geoengineering—or “climate intervention”—has in some circles attracted a negative connotation as a reactionary approach, distracting from more proactive policies that would avoid its need. (National Academies, 2015). The goal of geoengineering is to change the input of solar radiation to mitigate the effects of increased greenhouse gases on Earth. Some methods include increasing the Earth's reflectivity (higher reflectance buildings or frothing the oceans with bubbles from ships), blocking solar input (cloud seeding or space-based sun shields), or removing greenhouse gases (encouraging photosynthesis blooms or filtering combustion exhaust for carbon sequestration). Such planet-scale technology deployment through conscious human activity has unprecedented geopolitical ramifications; arguably, only institutions created to consider military action have previously had similar, potential global impact. As no significant geoengineering deployments have occurred to date, even the framing of these ideas is untested, and there is little data on how a field test might scale.

Initiated by PlanetWorks, an academic initiative at Arizona State University that explores solutions to planetary problems, a partnership with the Expert & Citizen Assessment of Science & Technology (ECAST) program conducted **structured assessment of public opinions and attitudes** through deliberative dialogue format. Participants were provided with in-depth [background materials](#) to facilitate discussions about potential geoengineering research directions, who should fund the research, and how decisions should be made (Arizona State University, 2017). The success of this conversation model demonstrates a critical role for well-framed public input during formative phases of research that can shape emerging directions for neuroscience and technologies as well. **Informed non-experts can helpfully contribute to determining scientific research agendas before experts fully scope the options.**

Case Study 2: U.S. Geoengineering Non-Expert Deliberations on Policy

The [Expert & Citizen Assessment of Science & Technology](#) (ECAST) program, started in 2010, recruits demographically diverse non-experts on science and technology scenarios, to lend more voices to policy making. Topics have included asteroid protection, GMOs, driverless cars, and climate change intervention aka “geoengineering.”

Program Description: Several small, in-person groups are co-facilitated over one day via informal education activities to frame without bias; groups and individuals both provide policy recommendations (detailed methods available [here](#)).

Results and Lessons Learned: Often STEM policies concern existent research, with experts providing options for non-experts to consider. However, geoengineering is too new for scientific/technological consensus. Therefore, participants were given freedom to choose what to research, what technology to consider, and what governance system to employ, then tested their approach in a scenario. **“Geoengineering ... doesn’t exist yet ... [so we want to] capture narratives and stories that come out of the public thinking about where the science should go.”** (Mahmud Farooque, ECAST).

3. Shaping public perceptions of a new scientific field: nanotechnology

The third and final example looks at parallel public outreach during the substantial ramp-up of nanotechnology research funding by the U.S. federal government during the [National Nanotechnology Initiative](#) (NNI). Nanotechnology is the creation and use of materials and applications through the novel manipulation of matter on the nanoscale—or one billionth of a meter. With a projected budget in the billions (U.S. dollars) at its start in 1999, many prominent NNI stakeholders were concerned that a negative public reaction, similar to recent cases of genetically modified organisms or nuclear power, could jeopardize the ambitious goals of the strategic investment. The (U.S.) National Science and Technology Council produced a *Vision for Nanotechnology R&D in the Next Decade* (Rocco et al., 1999) that outlined considerable scientific opportunities while specifically calling for significant outreach activities to “*generate and maintain public support for nanostructure science and technology.*” The unprecedented inclusion of outreach at the early stages of a new scientific field faced immediate challenges of public awareness.

In the mid-2000s, as many commercial nanotech applications began to enter the market, polling data from the U.S. showed that most Americans had heard little or nothing about nanotechnology (Wilson Center, 2006). Actively misleading names of popular products like the iPod Nano (launched in 2005), and growing apprehension about the fantastical threat of “gray goo” featured in Michael Crichton’s novel *Prey* (2002), only led to further confusion. Researchers were calling for greater investment in public outreach to advance this “field of the future” at a time when public sentiment about nanotechnology remained largely neutral (Currall et al., 2006). In response, the (U.S.) National Science Foundation led early workshops to consider funding for an entirely new educational infrastructure to begin outreach efforts from the ground up (National Science Foundation, 2004). Eventually, networks with a national scope, focused on high school and undergraduate nanotechnology education (the National Centers for Learning and Teaching in Nanoscale Science and Engineering), nanotechnology in society (the Centers for Nanotechnology in Society), and informal nanotechnology science education (the Nanoscale Informal Science Education Network), were established through this federal funding (Roco, 2011).

Initially spearheaded by the Museum of Science, Boston, Science Museum of Minnesota, and the Exploratorium, the Nanoscale Informal Science Education Network grew to include over 600 partner institutions around the U.S. over a 12-year period from 2005 to 2017 (National Informal STEM Education Network, 2017). At its start, the network was primarily focused on creating hands-on learning experiences for the public to explore fundamental scientific concepts, tools, and applications related to nanotechnology, but the network also experimented with public forums on societal impact. Evaluation showed that public forums increased awareness and understanding of nanotechnology’s ethical and societal implications, while allowing for discussion to assess both the risks and benefits (Flagg & Knight-Williams, 2008). As the network

evolved, nanotechnology and society topics became more prominent in learning experiences, highlighted as one of the four main messages of the network's content map for educational products and program development (Ellenbogen et al., 2012). The network also partnered with social scientists from the Center for Nanotechnology in Society at Arizona State University, to grow beyond a consumer-driven viewpoint of risks vs. benefits towards a more nuanced strategy for engaging public audiences through ideas on values, relationships, and systems shown below (Wetmore et al., 2013).

Three big ideas in technology and society

Values: Values shape how technologies are both developed and adopted.

Relationships: Technologies affect social relationships.

Systems: Technologies work because they are part of larger systems.

This shift in public engagement allowed for new facilitator training and products to take advantage of more immediate personal relevance in the lives of learners. Conversations were supported through experiences that asked learners to reflect on their own values and take on diverse perspectives when considering ethical and societal implications. Embedding these techniques in hands-on activities for family audiences scaled up their use across a wider range of network partners, compared with resource-intensive public forums rarely conducted beyond large museums. After receiving training and products that supported facilitating dialogue about societal impacts, 83% of network partners reported they were offering learning opportunities related to nanotechnology and society by the end of the project (Goss et al., 2016). The lessons learned from nanotechnology public engagement contributed to eventual network projects on synthetic biology and chemistry, with more emphasis on embedded societal implications and strong partnerships with professional societies to tackle challenging topics. **Networks of informal science education and other cultural organizations can effectively convene researchers and diverse audiences, with both public and professional impacts.**

Case Study 3: U.S. Informal Science Education on Nanotechnology

The Nanoscale Informal Science Education Network created a national community of researchers and informal science educators dedicated to fostering public awareness, engagement, and understanding of nanoscale science, engineering, and technology.

Program Description: The network created a wide range of educational and professional development materials including a content map, hands-on activity kits, a small exhibition, professional development resources, deliberative dialogue-style forum programs, and educational media (links to products [here](#)). Network resources were disseminated to over 600 project partners.

Results and Lessons Learned: Collaboration among educational product developers, scientists, and social scientists overcame the challenges of nanotechnology as a topic for interactive learning experiences. The network approach enabled a broad reach to diverse public audiences, with partners empowered to adapt products for local relevance. Evaluation showed that the network's educational products and programs resulted in improved skills of educators and scientists, new knowledge related to informal learning, and lasting relationships among individuals and organizations (Goss et al., 2016). **"Informal science education has become such an important part...that we incorporated it into our mission. It's critical for scientists to get across their research and the value of it to the general public, so the public can be better decision-makers."** (Richard Souza, Materials Research Society)

VI. Conclusions

The breadth of examples of public engagement that we learned about through this study reflect the breadth of cognitive and affective goals of science communication and public engagement in general:

Goals for communicating science (National Academies, 2017; Besley et al., 2018)

- Share the findings and excitement of science
- Increase appreciation for science as a useful way of knowing
- Increase knowledge related to a specific issue
- Influence people's opinions, behavior, and policy preferences
- Engage with diverse groups to seek perspectives about science related to societal issues
- Demonstrate that the scientific community cares about society's wellbeing and shares community values

Effective science communication and public engagement require identifying the goals of any particular effort, determining the best strategy for achieving those goals, and acquiring the skills to execute the strategy (National Academies, 2017). As we look to the future of neuroscience public engagement connected with neuroethics, there are a

number of cross-cutting trends and opportunities we observed in our sample that can help define a successful way forward.

- **There are pockets of innovation in neuroscience public engagement efforts connected with neuroethics, but usage is not consistent across geographic regions or institution types.** The absence of neuroethics in public engagement can be due to many factors including: lack of in-house expertise to carry out more dialogue-centric programming, regional preferences in STEM education and discourse, or simply insufficient levels of funding. The highest proportion of interview participants incorporating neuroethics into their public engagement strategy were located in the U.K., U.S., or E.U.; this trend may indicate that existing expertise, developed from previous centralized efforts to address societal and ethical issues in STEM (e.g. genetically modified food or nanotechnology), is now being applied to a new field. In several other regions, we learned about strong public outreach networks that are currently focused either on communicating neuroscience content (e.g. in Korea), or on societal and ethical impacts of STEM topics of a more critical nature (e.g. medical humanities in Africa, especially with respect to infectious diseases). Based on our interviews, practitioners in these latter networks are likely to be enthusiastic partners with valuable local community perspectives for future efforts involving neuroethics.
- **There is also opportunity for more collaboration among scientists, ethicists, and experts in other fields such as communications, survey methodology, public engagement, the arts, and evaluation and learning research.** These collaborations can help identify the best tactics to achieve intended goals, incorporate those tactics into engaging programs, and evaluate those programs to assess their impact. One model of a cross-sector organization that supports these collaborations is the [Culture, Health, and Wellbeing Alliance](#) in the U.K. However, we heard many examples of programs where scientists or practitioners were enthusiastic about the idea of collaboration, but did not have funding or the right connections to develop and sustain such a partnership. Future efforts to coordinate high quality public engagement around neuroethics should encourage, facilitate, and support these interdisciplinary collaborations and networks.

As we consider who could be part of a larger network around public engagement with neuroethics, the value of lived experience is as critical as academic expertise. Individuals are experts on their own emotions, based on experiences with their own brains. A number of programs we learned about explored this approach to mutual learning, whether through having non-scientists share the stage with scientists or co-developing clinical research projects. Neuroscience has the potential to lead other STEM fields in developing new models of engagement that explicitly aim to build equitable views of “the other.” Many scientists reflected that although their research was intended to benefit patients

or end users, often public engagement programs were their only opportunity for personal interaction with those they aim to help.

- **Another trend that emerged is that the 5 NeQNs are not perceived equally by the neuroscience public engagement community.** Our interviews quickly showed preferences and priorities among the NeQNs based on institutional and regional characteristics. One example of this heterogeneity is due to the neurotechnology-focused research centers we talked with, including the Wyss Center and BrainLinks-BrainTools, that had a practical focus on NeQNs #4 and #5 (autonomy and neuroscientific technology/innovation). In contrast, NeQN #2 (data privacy) was of particular interest to multiple groups working in clinical partnerships, including the patient registry developed by the advocacy group Bridge the Gap. We also saw regional specificity with NeQN #1 (impact of a model or neuroscientific account of disease) being very prominent in interviews with neuroscience research centers in China, Japan, and Korea dealing with the severe social stigma surrounding mental illness—although this struggle with mental illness is not limited to Asia.

We encountered the fewest number of public engagement programs related to NeQN #3 (morality of laboratory neural systems). In fact, we heard from several participants that their communication efforts relevant to this question were more focused on presenting an accurate picture of the current state of research, as often news headlines suggest that these systems are far more advanced than they are in reality.

- **Several interviews touched on the following changes to academic culture that are needed for the continued growth of neuroscience public engagement:** (1) incentives such as additional funding or tenure credit for university level researchers working in public engagement, especially in early career; (2) recognition from journals and especially funders for research that incorporates public dialogue on ethical issues—as an example, our search for potential leads led us to a preponderance of U.K. programs participating in neuroscience public engagement all supported by the Wellcome Trust; (3) more funded and sustained public engagement training pathways for students to work with university neuroscience researchers and informal STEM educational partners.

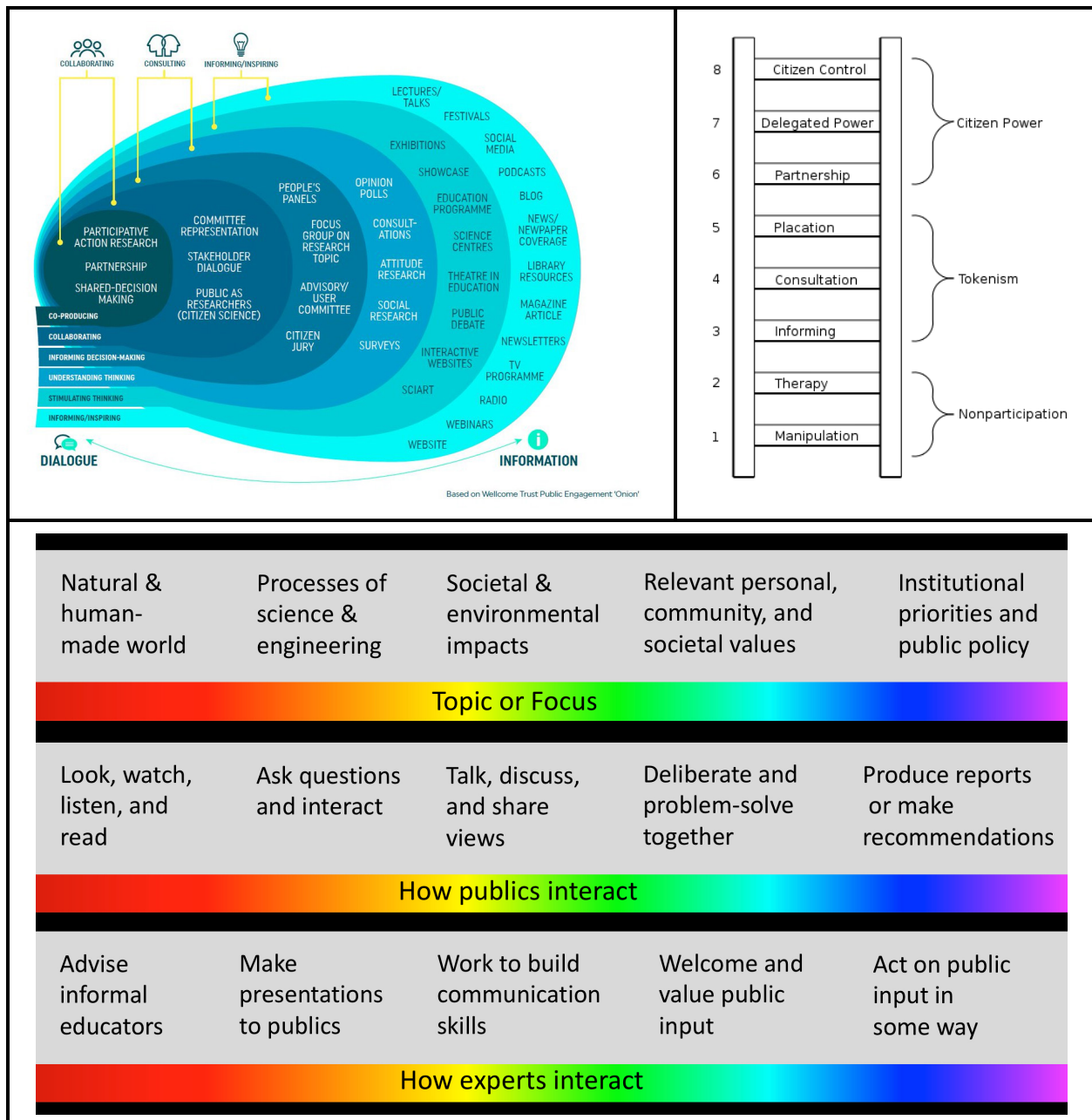
We talked to many researchers and to program leaders asking neuroscience students to act as expert guides in exhibitions and public programs. While not unique to neuroscience, this student-supported backbone of public engagement needs to be recognized and secured. We also learned through our interviews that more students are asking for this type of training, which could be an asset given the challenges surrounding the rapid rise in the number of neuroscience PhDs compared to every other biomedical research field in the U.S. (Akil et al. 2016). Encouragingly, in addition to the International Neuroethics Society, other professional societies have begun incorporating public events, such as the British Neuroscience Association's [Festival of Neuroscience](#) and the American

Academy of Neurology's [Brain Health Fair](#), into their regular conference gatherings, elevating the visibility of these public engagement efforts.

- **Almost all of the neuroscience public engagement programs we encountered could have benefited from open resources that directly support and build facilitation skills for one-on-one interactions between neuroscientists and public audiences.** The sparks of mutual understanding, contemplation, and empathy that come from a successful interaction lead to a high likelihood of public dialogue. As we learned from some outstanding projects, dialogue about neuroethics results in meaningful conversations that can have tremendous impact on all participants. We discovered a wide range of practices and strategies used to trigger these rewarding interactions—from large-scale events with many partners to an intimate, compelling work of art. How can we scale up, share, and continually improve supporting resources to increase the capacity of scientists, ethicists, and educators to guide public engagement with neuroethics? How could an international network of peers—initiated by this landscape report—and targeted professional development also support this work?

As the neuroethics community pivots toward a clear set of research questions as represented in the 5 NeQNs, now is the time to apply a lens of public engagement methodologies to ensure the underlying topics are responsive to societal and cultural values. Ideally, neuroethics and public engagement research can form a feedback loop, learning from and adapting to each other. As advancing technologies push the boundaries of our society, public audiences must play a role in making decisions about the implications of these technologies. As a coordinated research strategy in neuroethics evolves, a partnership with the public engagement field can propel both communities forward.

APPENDIX A



Public engagement schematics, clockwise from top left: from University College Dublin engagement strategy based on the Wellcome Trust Public Engagement model (Ní Shúilleabháin, 2018), A Ladder of Citizen Participation from Sherry R. Arnstein (Arnstein, 1969), and Spectrum of Public Engagement with Science from Larry Bell (Das et al., 2018)

APPENDIX B

The table below lists the people we interviewed for this report, as well as the types of public engagement projects related to neuroethics that these people are involved with or aware of. A few participants did not have any specific neuroethics projects to share, but were helpful in understanding the broader landscape of public engagement with science in their region or country. Abbreviations of categories: STRUC ASSMT = structured assessment of public opinions and attitudes; EXHIB PROGS = interactive exhibits, public programs, and other informal STEM learning experiences; MEDIA ART = inspirational media through partnerships with artists; EXPERT DISC = expert discussions for public audiences; CLIN PTP = partnerships for clinical applications.

Name	Institution	Region/ Country of Project	STRUC ASSMT	EXHIB PROGS	MEDIA ART	EXPERT DISC	CLIN PTP
Diego Golombek	National University of Quilmes	Argentina			X	X	
Paula Castelli	Universidad Torcuato Di Tella	Argentina				X	
Adrian Carter	Monash University	Australia				X	X
Joan Leach	Australian National University	Australia			X	X	
Rachel Nowak	University of Melbourne	Australia				X	
John Aspler	McGill University	Canada				X	
Pingping Li	China National Center for Biotechnology Development	China					X
Xiaomei Zhai	Chinese Academy of Medical Sciences	China					X
Lars Klüver/ Lise Bitsch	Danish Board of Technology	Denmark	X				
Oliver Müller	University of Freiburg	Germany		X	X	X	
Sarah Iqbal	India Alliance	India					
Kevin Mitchell	Trinity College Dublin	Ireland					X
Varda Gur Ben Shitrit	Bloomfield Science Center	Israel		X			
Tzipi Horowitz-Kraus	Technion	Israel/U.S.					X
Paola Zaratini/ Deborah Bertorello	Associazione Italiana Sclerosi Multipla A.I.S.M.	Italy					X
Norihiro Sadato	National Institute for Physiological Sciences	Japan	X				X
Osamu Sakura	University of Tokyo	Japan					

Name	Institution	Region/ Country of Project	STRUC ASSMT	EXHIB PROGS	MEDIA ART	EXPERT DISC	CLIN PTP
Tomomi Hida	Kyoto University	Japan				X	
Chisomo Kalinga	Edinburgh University	Malawi					
Andrea Palk	University of Cape Town	South Africa				X	
Marina Joubert	Stellenbosch University	South Africa				X	
Victoria Hume	University of the Witwatersrand	South Africa			X		
Amy Jung	Korean Brain Research Institute	South Korea		X		X	X
Jo Bowler/ Tracy Laabs	Wyss Center	Switzerland	X	X		X	
Yesim Isil Ulman	Acibadem University School of Medicine	Turkey					
Tuna Cakar	MEF University	Turkey					
Chrystalina Antoniadou	University of Oxford	U.K.		X	X		
Anil Seth	University of Sussex	U.K.			X	X	
Daniel Glaser	Fmr. Wellcome Trust, Science Gallery London	U.K.			X	X	
Elaine Snell	International Neuroethics Society (U.K.)	U.K.				X	
Naomi Mwasambili	Chanua	U.K.		X			
Tessa Gordziejko/ Jon Spooner	Unlimited Theatre	U.K.		X	X		
Andrew Sperling	National Alliance for Mental Illness	U.S.					X
Anna Wexler	University of Pennsylvania	U.S.	X		X	X	
David Sittenfeld	Museum of Science, Boston	U.S.	X				
Eran Klein	Oregon Health & Sciences University	U.S.	X			X	XS
Frances Jensen	Society for Neuroscience	U.S.					
Karen Graham	International Neuroethics Society (USA)	U.S.				X	
Katie Sale	American Brain Coalition	U.S.					X

Name	Institution	Region/ Country of Project	STRUC ASSMT	EXHIB PROGS	MEDIA ART	EXPERT DISC	CLIN PTP
Martha Farah	University of Pennsylvania	U.S.		X		X	
Monica Weldon	Bridge the Gap	U.S.					X
Sara Goering	University of Washington	U.S.				X	X
Silvia Bunge	University of California, Berkeley	U.S.					
Laura Cabrera	Michigan State University	U.S., U.K., Spain, Germany	X				
Alissa Ortman	Society for Neuroscience	U.S./ International				X	
Cristin Dorgelo	Association of Science-Technology Centers	U.S./ International					X
Pepe Contreras Vidal	University of Houston	U.S./Mexico		X			
Mark Rosin	Guerilla Science	U.S./U.K.		X	X		

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