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Global Agenda

The Digital Future of Brain Health

Global Agenda Council on Brain Research

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Contents

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Introduction

Despite the massive strides made over the past decades in medicine and science, understanding the workings of the human brain, the most complex organ in our body, remains one of our greatest challenges, as does finding solutions for brain disorders. To meet these challenges, major neuroscience research initiatives at a cost of billions of dollars have been launched around the globe recently. Their common goals are to develop frontier technologies for studying the brain and to accelerate collaboration with the hope of eventual insights for addressing brain health.

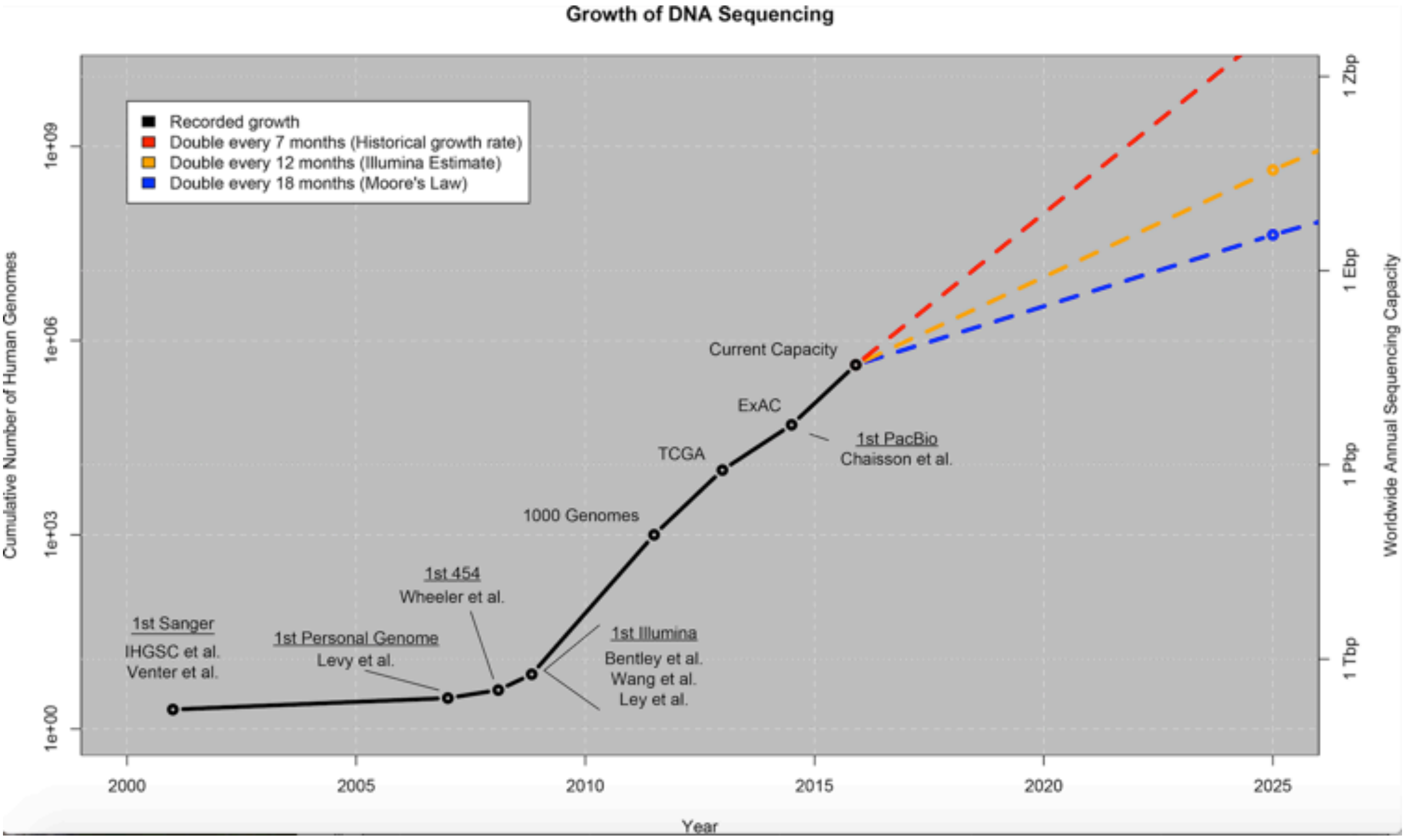
This surge in brain research comes at a time of accelerating advances in digital health technology, notably in the capacity to acquire and handle big biological data and the ability to mine it with computational tools. Technologies have grown exponentially in speed, capacity and adoption on multiple fronts over the last few years. Ten years ago, it cost $100 million to acquire a genome whereas today this can be achieved with just thousands of dollars[1]. We are increasingly able to collect more and more medical data about ourselves and store it using cloud computing (the remote storage of data and processing on demand). Anticipation is increasing that machine learning (a form of artificial intelligence for making predictions from data) can be applied to big health data to generate predictive analytics to deliver information for decisions about personalized health care.

Alongside these technical advances, healthcare is increasingly shifting from care of the sick to prevention of sickness and from volume-based care to value-based services. “Consumerization” of healthcare is on the rise, as patients take increasingly active roles in their care experience. Talk is growing of a “digital revolution” in which technology will enable healthcare anywhere and anytime, tailored to patients’ biology and life history, and in which patients will have unprecedented power to take control of their own health and their participation in research. Neuroscience and brain health are no exception to these developments; companies offering everything from tailored interventions to marketplaces for mental health services are proliferating. But what is the actual benefit of digital technology in healthcare for the brain? What is the likelihood the benefit will reach the people who need it most? In this report, we review five emerging themes in digital technology that may impact brain health.

[1] https://www.genome.gov/27565109/the-cost-of-sequencing-a-human-genome/

Big data

Scientists today are increasingly looking to genomics – the study of the function and structure of our genetic material – to better understand the causes of conditions such as autism, schizophrenia, mood disorders and Alzheimer's disease. Advances in technology have caused the cost to sequence a genome to plummet over the past decade, greatly out-pacing Moore's Law, and now researchers are faced with how best to acquire, store, analyze, and distribute this growing source of valuable data. Researchers estimate the computing resources needed to handle genome data will soon exceed those of Twitter and YouTube, posing a great technology challenge for researchers who are running larger and more comprehensive studies linking genetic variation to disease.



From: Stephens ZD, Lee SY, Faghri F, Campbell RH, Zhai C, Efron MJ, et al. (2015) Big Data: Astronomical or Genomical?. PLoS Biol 13(7): e1002195. doi:10.1371/journal.pbio.1002195

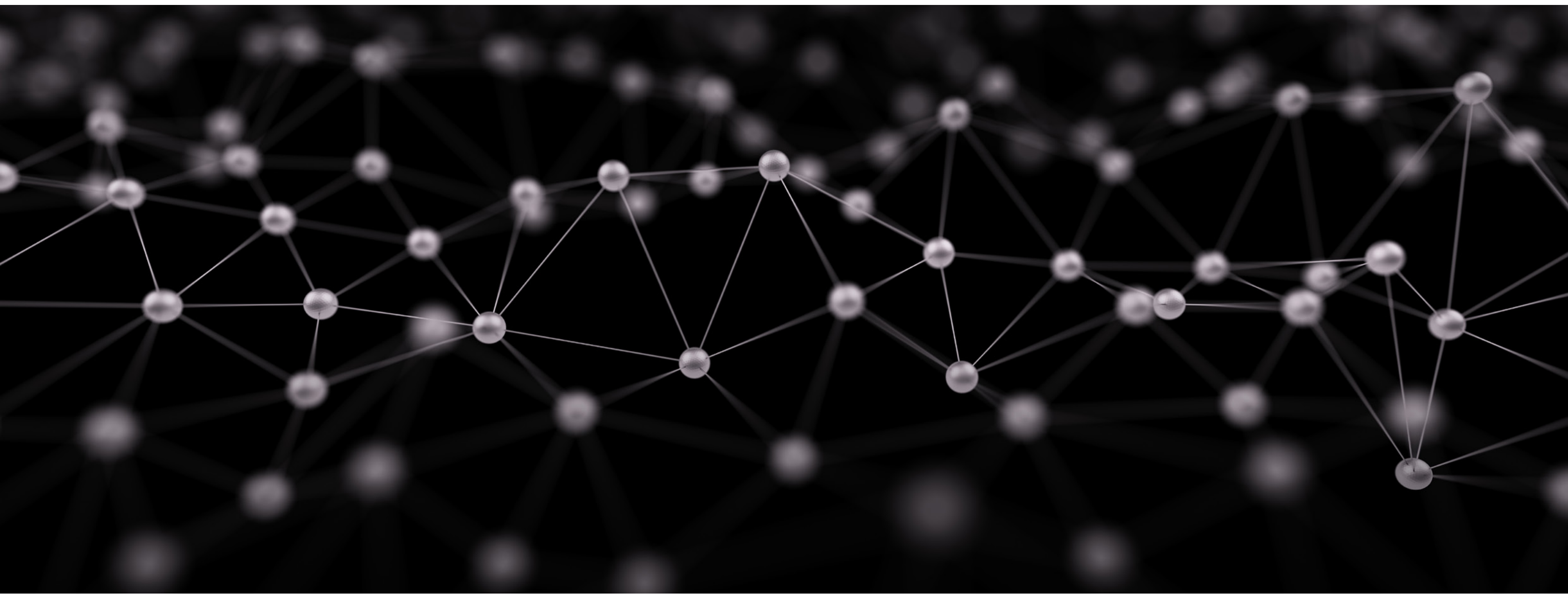
Machine learning

The challenges of finding signals for genetic risk in brain-related disorders are immense. In autism, for example, the combination of many, possibly hundreds, of genetic variations increases risk, and there is also a huge range of variation in the characteristics of people with the condition as well. Identifying genetic risk signals requires enormous amounts of data, made possible only relatively recently by technical advances in the acquisition and processing of genomic information, as well as by the collaboration of scientists around the world. Moving forward, to continue advancing our understanding of the relationship between genes and clinical traits, scientists also need more accurate descriptions of symptoms, treatment outcomes, physiology and behaviour. Initiatives in “deep phenotyping” are also growing, to collect such characteristics of individuals and their families with increasing resolution and quantity.

Past decades have also witnessed widespread interest in using imaging technology to visualize the brain, for Alzheimer’s disease, addiction, concussion, schizophrenia and other conditions, aiming to identify biomarkers that can accurately predict risk or diagnose brain disorders. As with genomics, the challenges are enormous to identifying meaningful signals that could indicate risk from the noise of normal variation of human brain development, function and ageing. For both genetics and imaging, cloud technology is easing the difficulty of storing and sharing the enormous amount of data needed to make sense of this biological complexity. Only a few years ago, it was a challenge to store and transfer just a few genomes, sometimes requiring physical delivery of hard drives. Now, cloud computing with on-demand IT delivery and pricing models make it routine for scientists to access huge datasets securely and collaboratively. In a recent HIMSS Analytics Survey, 83% of healthcare respondents reported actively using the Cloud, with many hosting sensitive clinical data[2].

The capabilities presented by machine learning – a branch of computer science in which programmes are designed to self-learn how to predict patterns from complex data – have multiplied in recent years with the advent of more powerful hardware such as graphics processing units (GPUs) and more publicly-available large data sets. The range of potential applications is expansive, both in application and sector; ranging from search engines, to weather prediction, to disease outbreak prediction, to fraud detection in financial transactions. In brain health research, there is excitement about the prospect of machine learning being used to identify signals of disease risk and treatment response from massive biological and behavioral patient data. Machine learning algorithms are also being developed for state monitoring, using behavioural data to detect early signs of when patients might deteriorate in conditions such as bipolar disorder, depression and psychosis. Other technologies enabled by the hardware and computational advances underlying machine learning include improved speech recognition software, which can support new methods for patient interaction, and enhanced visualization in medical imaging, enabling information from multiple imaging sources and techniques to be combined in real time.

Although the promise of artificial intelligence is great, some are uneasy about the prospect of machine-derived decisions replacing human expertise and judgement. These concerns must be addressed with respect if the real potential is to be realized – rather than “artificial intelligence”, the goal should be “augmented intelligence”, whereby technology serves to enhance human interpretation and decision-making.



[2] 2014 HIMSS Analytics Cloud Survey

Continuous monitoring

An estimated 50% of patients with chronic diseases in developed countries have less-than-optimal treatment outcomes because they fail to follow medical instructions given by their physicians, a significant public health consideration. Further, analysts have estimated that in the US, billions of dollars in avoidable healthcare costs each year are due to unnecessary escalation of treatment and recurrence of disease[1]. Remote wearable sensors - from fitness trackers to smartphones to physiological monitors to smart skin patches for monitoring body chemistry - are viewed as emerging developments that may improve and enhance patient health by enabling patients to collect their health and behavioral information automatically. These data may be transmitted to doctors, allowing better monitoring of patient condition and compliance with treatment, or potentially increasing access to care in remote locations, also allowing individuals to gain greater insight into their health and behaviour.

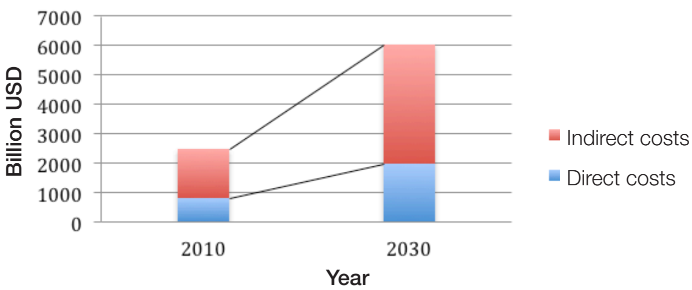
With respect to mental and neurological disorders, patient states often fluctuate significantly over time but their doctors are only able to assess conditions based on snapshot views during office visits. Continuous monitoring may help give a more complete and accurate picture of patient conditions, improving the effectiveness of care when patients need it, or even anticipating when they need it. Research and clinical trials might also be improved and facilitated by the use of remote sensors. Outside of the monitoring that occurs during clinical visits, data is often self-reported, and may be incomplete or biased. Remote sensors therefore present a potential for enhancing the quality and resolution of data, and reduced cost of clinical trials may be the first multibillion market opportunity for this technology. Before this promise can come to fruition, however, the onus is on sensor developers to ensure that devices deliver clinical-grade data that can be meaningfully and safely used in medical decision-making.

[1] http://www.ncbi.nlm.nih.gov/books/NBK53938/

Consumerization

Around the world, people suffering from depression, addiction and other mental illnesses cope in silence for fear of stigma or because they are unable to obtain care. Even in a high-income nation such as the United States, millions of people live in areas with severe shortages of mental health providers. The economic burden is significant – mental illness costs the US nearly $193 billion in lost earnings every year; worldwide, the cost of output lost to mental illness is estimated to be in the trillions.

Costs of mental illness worldwide, 2010 and projection



Source: Bloom, D.E., Cafiero, E.T., Jané-Llopis, E., Abrahams-Gessel, S., Bloom, L.R., Fathima, S., Feigl, A.B., Gaziano, T., Mowafi, M., Pandya, A., Prettner, K., Rosenberg, L., Seligman, B., Stein, A.Z., & Weinstein, C. (2011). The Global Economic Burden of Noncommunicable Diseases. Geneva: World Economic Forum

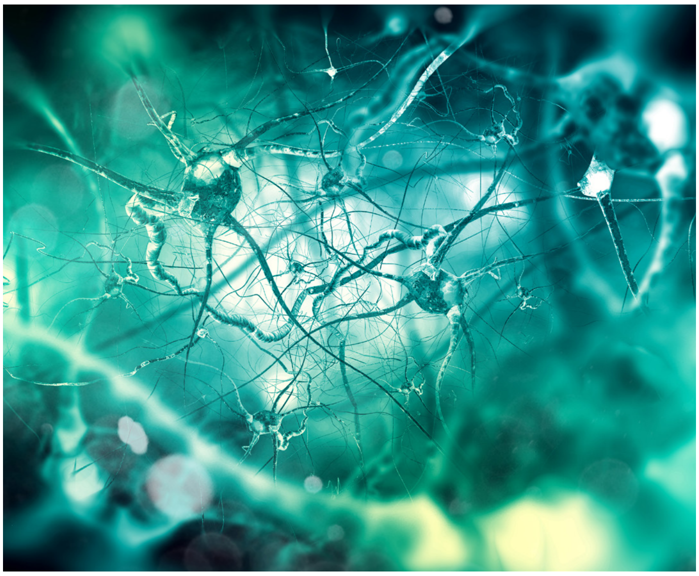
Digital platforms combining technology and the human touch may provide an affordable and accessible way for patients to receive care. Support may come in the form of help in navigating the mental health system to finding care providers or to obtain social support from peers or care providers when needed. Further, these digital tools are helping add an important level of transparency as to cost and quality of care, to aid consumers in making a more informed decision about their care. These added benefits of transparency, added reach and personalized experience are aiding the healthcare industry to move to a more patient-centric care model. Studies have shown that more engaged patients (and their caregivers) are more compliant patients, which, in turn helps reduce costs (unnecessary procedures, readmissions) and results in better clinical outcomes for patients.

Digital tools might also help patients manage their own behaviour. There is a proliferation of mobile-based mental health apps that provide patients with continuous, convenient access through their smartphones. Some interventions are being developed in the form of games, a powerful medium for intuitively engaging patients, with potentially greater chances that beneficial behaviours will be self-sustained compared to conventional clinical interventions. While the promise of gamified interventions is undeniable, to date there is little clinical-quality evidence. Going forward, patients, caregivers and families should demand rigorous scientific evidence to show that these apps can deliver effectively on their promise over a sustained period of time.

Open science

Containing hundreds of cell types with complex and dynamic wiring, the brain operates at multiple scales. Understanding, even at a basic level, how neural circuits underlie our subjective experience and behaviours remains an enormous challenge to neuroscience. One response has been the creation of community-wide knowledge, reflected in the steady growth of open repositories for data and technology. Private and public organizations around the world are investing in the creation of large, publicly-available repositories for brain research – from banks of human genomic data, to anatomical and molecular maps of mouse and human brains, to human imaging data showing function and connectivity in the brains. As these repositories proliferate, and the kinds of data being shared diversify, the challenges of standardization and curation become a major challenge that scientific bodies and other stakeholders must grapple with. In addition to open data, software, molecular tools and hardware designs are increasingly being shared as well, in the spirit of spreading knowledge and accelerating discovery.

As science becomes more open, numerous privacy and intellectual property questions remain regarding human data. Informed consent is a start, but often, patients may not understand what rights they are signing away or researchers may wish to use valuable data for an alternative use which they had not previously considered and are lacking the requisite level of consent to pursue potentially game-changing scientific research. Patients, researchers, and lawmakers should work together to highlight the benefits of open data and open science, yet, should put in place mechanisms that educate patients on their data rights and allow researchers to obtain the appropriate level of consent to cover a wider, yet contained, area to support their research.



Conclusion - Paving the road ahead

Digital technology presents the healthcare industry with an opportunity to leverage big data and new advances in data technology to aid in clinical decision-making, create new platforms/marketplaces for interacting with healthcare consumers and, most importantly, to open channels for fresh voices and minds to join with industry veterans to solve big challenges in healthcare.

But having access to large amounts of big data and state-of-the-art analytics alone is not a panacea to the challenges of scientific discovery and translation to clinical application. For digital technologies to transform healthcare, they must provide strong value-added capabilities and insights that can meaningfully guide treatment and diagnosis, and be easily incorporated into physician workflows. Scientific evidence needs to be captured and documented with the highest levels of rigour and regulatory requirements must be met. These demands can be daunting – entrepreneurs may be unfamiliar with how best to collect and demonstrate the kind of robust evidence that will persuade health systems to participate in proof of concept studies and support the process of obtaining approval from regulatory bodies. Scientists may be unfamiliar with how to navigate regulatory requirements when incorporating new digital technologies. Traditional healthcare players such as hospitals, pharmaceutical companies and medical device manufacturers may lack confidence in adopting applications created by new industry entrant startups.

Researchers, clinicians, entrepreneurs, investors and regulators need to be supported in a cooperative ecosystem that fosters collaboration and the sharing of ideas. We need a transparent, collaborative environment in which scientists, industry veterans, regulators, investors and entrepreneurs can share advances in technology, discuss trends in the industry and learn from successes in other industries. Mental and neurological disorders are global challenges and we need to encourage different sectors to join forces to power intelligent care, everywhere.

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