
Volume 14 - Issue 4, 2014 - Cover Story

Big Data and The Brain

Key Points

- The brain itself is “big data”: coordinated systems, which continually process and produce voluminous information.
- Alzheimer’s Disease and other forms of dementia disrupt neural systems with devastating consequences. Fortunately, big data can offer preventive, diagnostic and therapeutic healthcare solutions.
- A number of projects around the world are being coordinated for dementia research.
- Open data that can be safely shared across borders will facilitate research success.
- New models are needed for new insights.



A big opportunity exists to meet the big challenge of Alzheimer’s Disease: big data. With hundreds of organisations involved in dementia research around the world, vast amounts of information already exist which, if optimally organised and linked, will provide a better understanding of the condition, its causes and paths of progression. So-called “deep” data from academic and clinical research is now being combined with “broad” data from health records (Ontario Brain Institute 2014).

Strategies for prevention and interventions are urgently needed as the global population ages, with associated costs fast outpacing each devastating diagnosis. Current estimates starkly state that 35 million people are affected by dementia, with estimated annual costs exceeding US\$604 billion (€478 billion) (OECD 2013a). Socio-economic costs for affected families are more difficult to calculate, since many caregivers are relatives who must limit or stop working to provide care.

In many ways, Alzheimer’s Disease is an ideal candidate for capitalising on the powers of big data. At a June 2013 expert consultation organised by the Organisation for Economic Cooperation and Development (OECD), Lefkos Middleton, a professor of Neurology, Neuroepidemiology and Ageing at Imperial College London’s School of Public Health elegantly described the case: “The aetiology and pathophysiology of AD are neither linear nor additive but like a ballet choreographed interactively over time, involving genetic, gene expression, epigenetic and multitude of environmental factors” (OECD 2014).



Data Organisation: The Brain is Big Data

One of the most important discoveries in neuroscience is that brain functions, which were once thought to have localised correlates, actually depend upon functional networks. A stroke or other brain injury in the “language area” of the left hemisphere can cause predictable problems with speech and language comprehension, for example, but focal brain damage seldom results in a single functional deficiency. The brain itself is big data; only powerful with networks intact. The complexity of the brain and its disorders makes it essential that numerous sets of heterogeneous data can be combined.

Thus, the importance of networks extends to big data and its potential for advancing the understanding of Alzheimer's Disease and other forms of dementia. Bigger volumes of data, even if quality keeps pace with quantity, are worthless to AD researchers and patients until coordinated efforts can improve efficient analysis. Disconnected systems must be organised so that data can be shared and interpreted with innovative methods and results. Biomedical advances can aid in the prevention and diagnosis of dementia, and in the pharmaceutical treatment and care delivery for those who live with the disease. But existing research and development processes are disconnected, expensive and not always efficient. New models are needed to generate new insights (OECD 2014).

Data Sharing: Connectivity and Creativity

There are two levels of data sharing in dementia research. Participants or patients must consent to share their personal, private data before it can be collected for specific projects. Academic, clinical, commercial and government organisations must also collaborate to share their findings across the borders of companies and countries. Of course, it is not a simple matter involving the mutual agreement of patients and scientists that data sharing is a valuable endeavour. There are big challenges in big data sets, stemming less from their size than from the heterogeneity of records. Variation in formats and structure across entities complicate the task of data sharing.

The blending and sharing of data must take place on at a global level, which entails additional practical and legal concerns. Just as discussions of big data often refer to the "V"s (volume, velocity, variety, veracity, value) the OECD's work on the information economy examines three "C"s: connectivity, creativity and confidence. Regional, national and international calls for access and sharing of data should be synchronised/ integrated to ensure open access, while also protecting patient privacy and safety as well as data security. Without compatible frameworks for data governance, it is not possible to verify the value of data for sharing (OECD 2013b).

Projects are gaining momentum around the globe.

OECD

In September 2014, an international meeting convened in Toronto for a discussion of how big data can bring value to dementia research. The workshop provided a platform for the perspectives of more than 50 doctors, data experts, patient advocates and politicians to share their diverse concerns and ideas for new approaches. It was held by the OECD in partnership with the not-for-profit Ontario Brain Institute (OBI) and the University of Toronto's Institute of Health Policy, Management and Evaluation (IHPE). The purpose of the event was to identify ways in which government, industry and scientific entities could streamline goals, optimise investment efforts, and ultimately link data resources to advance dementia research (Grant 2014).

The OECD continues to bring together the perspectives of government and non-government viewpoints to address the dementia challenge. It aims to inform healthcare systems about the adaptations required to address the crisis, and to recommend ways to use big data and information technology as tools for innovative dementia prevention and treatment. In a 2013 paper, "Unlocking Global Collaboration to Accelerate Innovation for Alzheimer's Disease and Dementia", the OECD identified five areas of urgent coordination among stakeholders in policy development for data governance:

- Ensure functional and financial sustainability of large, linked research networks;
- Facilitate timely data exchange and access, compliant with risk assessment standards;
- Link complementary datasets at regional, national and international levels;
- Identify the tech and management tools that make databases efficient;
- Incentivise education and training to extend expertise and build capacity (OECD 2013b).

Big Data for Advancing Dementia Research

Between July 2014 and March 2015, a project commissioned by the OECD and coordinated by the University of Oxford's Oxford Internet Institute (OII) will evaluate best practices in data sharing, based on the following four case studies. Each of the "Big Data for Advancing Dementia Research" studies will firstly provide an analysis of records comprising documentation, websites, policies, consent and other legal forms. Such data will be supplemented by interviews with key decision makers and users. The aim of the project is to advance dementia research by recommending best practices, with results due to be reported to an OECD advisory board and the World Dementia Council next year.

- AddNeuroMed is a data repository funded by the EU and pharmaceutical partners, designed to detect biomarkers for AD.
- The Kungsholmen/Swedish National Study on Ageing and Care (SNAC) links multiple longitudinal studies; datasets include care information.
- The UK Biobank, while not focused exclusively on dementia research, comprises data from 500,000 people. It is a model for patient/ participant consent of private data.
- World Wide Alzheimer's Disease Neuroimaging Initiative (WWADNI) is an umbrella organisation for regional and national partners focused on neuroimaging in AD (Oxford Internet Institute 2014).



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The VPH Dare@IT Project

Within the European Virtual Physiological Human (VPH) Initiative, the VPH Dare@IT project acknowledges that dementia is far from a “one size fits all” disease. Its models of the human body and its disorders take into account individual risk profiles and clinical presentations, stratifying patients in a way that will optimise preventive and therapeutic interventions. The “in silico” modelling platform of the program permits data from diverse sets of medical and biological information to be integrated. The advantage of such integration is that the human body’s complex physiological systems are considered, rather than their isolated components. The links between heterogeneous data sets, in turn, allows for investigation of speculated links between disease causes and outcomes. The project runs from 2013 to 2017 with a budget of €18 million. More details about the project can be found in “Fighting the Rising Tide of Dementias” in this issue of Health Management.

UK Dementia Research Platform

In June 2014, the Medical Research Council (MRC) launched the UK Dementias Research Platform (UKDP). The program was announced at the Global Dementia Legacy Event in London, where Prime Minister David Cameron affirmed his country’s pledge to dementia drug discoveries and development. The platform is a partnership between public and private entities, including pharmaceutical companies and leaders in biotechnology. The UKDP is uniquely positioned to benefit from a number of research initiatives in the UK, with 22 studies amassing a total research population of almost two million people. (Davenport 2014) The combination of smaller and larger studies will permit researchers to explore the significance of smaller studies in bigger populations, or conversely to take a finding from a large sample size and zoom in on specific data that can only be found in more targeted projects. If structured to promote open access and sharing, the data will allow scientists to ask and answer big questions, according to Dr. Craig Ritchie of Imperial College London (ICL)’s Department of Medicine, a member of the UKDP steering committee. “It will enable the research community to move seamlessly between different levels of data, which simply could not happen if we worked in our own separate research groups and areas” (Davenport 2014).

UK Biobank

By far the biggest project contributing data to the UKDP is the UK Biobank, which is amassing health data on 500,000 people in the UK. The vast and varied collection of open-access data, and the longitudinal nature of the project, will be valuable not only for dementia research but for population health in general. Its Imaging Working Group is chaired by Professor Paul Matthews, head of the Division of Brain Sciences in ICL’s Department of Medicine. In May, the group began to collect imaging data from participants at one of its centres, with the goal of performing 18 full sets of brain, heart, bone and blood vessel scans per day for up to 100,000 study participants. The imaging information will powerfully supplement observational data within the Biobank. The team includes experts whose responsibility it is to ensure that the variety of scans comply with protocols and can be stored and shared appropriately.

Neuroimaging in AD is of critical importance. With structural evidence of dementia most apparent in later stages of the disease, single MRI scans are not the most helpful tool on the table. Functional MRI measures changes in blood flow over time, giving analysts greater insight into neural activity and anomalies. However, it is data-intensive: a patient’s 20-minute scanning session involves approximately 15,000 voxels per 3D scan, and each voxel examining hundreds of thousands of neurons. It is also time-intensive, requiring manual processing of the scans. An innovative solution for automating fMRI-based methods would improve early detection (OECD 2013a).

Additional value will come from being able to identify which types of markers coincide with dementia onset. The expression of cognitive decline can be indicative of damage already done in the brain, prohibiting the impact of late-stage interventions. Perhaps because the causes and correlates of Alzheimer’s Disease are not yet well understood, stubbornly mired in mystery by the neurobiological complexity of the human brain itself, pharmaceutical trials have thus far yielded disappointing results. Based on studies which compare brain imaging and biomarker profiles of people at high risk for developing the disease, some estimates indicate that slow, continuous neuronal deterioration may begin a decade before clinical symptoms appear. Thus, the real potential in opening data sets for sharing and innovation lies in learning how to prevent dementia in the first place.

Opportunities and Optimism

Despite the daunting task ahead, there is reason to be hopeful. G8 ministers have agreed that international cooperation can lead to innovative solutions to the multifaceted challenge of AD. With collaboration between countries increasing and new relationships developing between private and public partnerships, data sharing will reduce the risks and expenses of the dementia epidemic.

Professor Paul Matthews, who leads the Division of Brain Sciences at ICL, expressed optimism at the opportunities ahead for dementia research based on the capacity of scientists to capitalise on shared knowledge. "We are committed to this new scientific environment where open data creates a space for greater innovation and faster translation into treatment," Prof. Matthews said. In addition to its involvement with the UKDP, ICL recently launched the Imperial Data Science Institute, and hosts the Parkinson's Disease Society brain bank and the MRC-NIHR National Phenome Centre, all of which investigate aspects of dementia (Davenport 2014).

George Vradenburg of the Global CEO Initiative on Alzheimer's Disease addressed the public ahead of the OECD's Toronto event, noting that research funding for dementia lags behind that for other diseases such as cancer, heart disease and HIVAIDS. One possible reason, he said, is that victims cannot speak for themselves and those who care for them are too exhausted to speak on their behalf. Nonetheless, Mr. Vradenburg is hopeful that a cure or treatment can come from continued and coordinated efforts, reminding the audience, "There wasn't any hope for an HIVAIDS cure. There wasn't any hope for polio for a long period of time. There wasn't any hope for a lot of these diseases. But at some point people got sufficiently angry that there wasn't anything done that anger turned into mobilisation" (Grant 2014).

Published on : Sat, 8 Nov 2014