

Title: A Data Donors Scheme for Brain Researchers

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Summary: Understanding brain function in disease tends to be hampered by a lack of premorbid comparisons for the individual patient, yet a large amount of data exists in research institutions which could provide such information for at least some patients. I propose a voluntary Data Donors scheme, analogous to that which operates for organ donation, to address the issue of access to premorbid data.

Researchers in many fields of psychology and neuroscience frequently act as experimental control subjects for their colleagues. This generates a wealth of data, from psychometrics such as the Wechsler adult intelligence scales (WAIS)¹ to brain magnetic resonance imaging

(MRI) scans. Clinicians treating patients with brain illness or damage have also provided great insights into brain function. In most cases, however, they are hampered by the fact that they see the patient only after the illness or damage has taken hold, and must therefore estimate premorbid function.

To my knowledge, although the slogan "Use it or lose it" is widely applied to mental function, doing brain research does not itself immunize against brain damage or illness. Some researchers will develop brain-based disorders. If these individuals have in the past been subjects for colleagues then premorbid data may exist which could help clinicians to understand their disorders better. I therefore propose a voluntary "Data Donors" scheme, analogous to the organ donor card scheme currently operating in the UK and other countries. Such a scheme could be promoted on the Internet and in the biomedical literature. Participants would carry a card summarising what data are held on them by which institution. In the event of a brain-based disorder, their doctors could use the card to contact the institution and request the data. As our understanding of brain function in health and disease improves, the need for accurate pre- and postmorbidity comparisons will become more urgent, highlighting potential benefits of the scheme - especially if participation could be extended to a wider range of experimental subjects once the scheme were operational.

Of course, there are issues of data ownership and confidentiality, both academic and medical. However, in the basic scheme proposed above data would only be requested by doctors responsible for investigating and treating a patient, so given the will to do so, it should be possible to overcome problems with medical confidentiality. As for ownership and academic confidentiality, these tend to have a shorter effective time-span than medical confidentiality, because the findings based on the data are rapidly placed in the public domain (by contrast,

brain illness or damage may take years to manifest). In addition, data useful to the clinician are often not central to the findings of the publications which use them, but are required as background= for example psychometric assessments.

In an ideal world, participating researchers, and other subjects, would volunteer to undergo a standardised test battery. The resultant data would be archived either on a specialist Internet site or by participating institutions, in a database format with appropriate data protection built in. As a first step, a data donors=scheme could, if sufficiently well-supported, help to provide at least some clinicians with a more accurate view of the premorbid function of their patients. That can only be beneficial for the long-term understanding and treatment of brain disorders.

1. Wechsler D. Wechsler adult intelligence scales (revised). San Antonio, TX: Psychological Corp., Harcourt Brace Jovanovich, 1981.