

Shadows over data sharing

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In a paper about to be published in *EPJ Data Science*, Barbara Jasny, deputy editor for commentary at Science magazine in Washington, DC, USA, looks at the history of the debates surrounding data access during and after the human genome "war". In this context, she outlines current challenges in accessing information affecting research, particularly with regard to the social sciences, personalised medicine and sustainability.

The trouble is that most researchers do not currently share their data. This is due both to <u>research practices</u> and research culture. Scientists withholding data put forward various <u>justifications</u>. These include the prohibitive amount of work involved, the need to withhold data prior to publication to retain a competitive advantage, or constraints associated with the <u>raw data</u> itself when received under confidentiality agreements.

The author focused particularly on data sharing during the human genome sequencing race. The competition to present the first complete sequence of a human genome was then perceived as a battle. It set free genome data access advocates—within the public research initiative funded primarily by the NIH and the UK Wellcome Trust—at odds with proponents of proprietary information—namely the US company Celera, which intended to exploit the data commercially. However, the situation became increasingly complex.

Further <u>data access</u> battles intensified after the publication of the draft genome in 2000. Although the public research initiative made data available, there were conditions on publishing research results based on the data. The data thus only became truly free to use after some delay.



Jasny concludes that two forces are currently impacting the research community: first, the need to protect individual privacy regarding information; and second, the push towards open access to data, which is increasingly being mandated by public funding agencies.

More information: B.R. Jasny (2013), Realities of data sharing using the genome wars as case study - an historical perspective and commentary, *EPJ Data Science*, 2:1, <u>DOI: 10.1140/epids13</u>

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