

The unintended consequences of open access: How non-scientists are using scientific papers to zap their brains

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Abstract

People who use electrical brain-stimulation devices at home have told us that they use scientific research papers for inspiration and guidance on how to use their devices. However, these scientific papers are written for scientists, and it is unclear how useful the information they contain is to non-specialists. What we do know is that scientific papers are becoming increasingly easy to access online. This is in large part due to the global trend towards 'open access' scientific publishing, in which articles are made freely available online. We are exploring the consequences of this partial access in which scientific papers are physically available to a diverse range of readers, but still written in a language and style intended for a highly trained scientific audience. As a first case study, we have surveyed home users of electrical brain-stimulation devices; the preliminary results of this study are shared in this article. The survey included questions to determine how the home users' use of scientific research publications compared with other knowledge sources; the extent to which research publications played a role in their decision-making; and the ways in which current scientific publishing standards and norms influenced how they understood and used those papers. We will follow up with case studies on other groups of non-scientists who use scientific literature, including medicinal marijuana users, stem cell technology health tourists (travelling overseas for unproven therapies not available within Australia) and people making a decision about vaccination. Our findings will help improve the way scientific knowledge is shared by identifying ways in which the scholarly publishing industry can adapt its products to meet the needs of this new audience, as well as informing policy and practical responses for the scientific research sector.

Keywords: brain stimulation; open access; science publishing; scientific literature

In July 2016, neuroscientists published 'An Open Letter Concerning Do-it-yourself Users of Transcranial Direct Current Stimulation' in the *Annals of Neurology* (Wurzman et al., 2016). The four authors of the letter, which was endorsed by a further 39 researchers, warned about the unknown effects of brain stimulation in both the short

and long term, and the risk of affecting more of the brain than intended, enhancing cognitive abilities at the cost of others, together with other unintended consequences.

The letter and reactions to it in the media and online (for example Loria, 2016; Nowak, 2016; Velocci, 2016; Wexler, 2016) highlighted several key points regarding safe home use: first, home users appear to be using the research literature to make decisions about how they use brain-stimulation devices at home; second, home users may significantly alter the brain-stimulation techniques they see in research papers – for example, by increasing the duration, frequency and intensity of the stimulation, which are carefully controlled in the lab setting; and third, research literature is not currently designed for use by non-scientists, and is not fit for this purpose – for example, non-scientists may not be aware of the phenomenon of ‘publication bias’ (also called the ‘file drawer problem’), which means that the scientific literature on brain stimulation is likely to be biased towards studies that showed an effect; failed studies or those that had negative consequences are more likely to be relegated to the ‘file drawer’.

Overwhelmingly, scientific literature is written for scientists, and it is unclear how useful the information it contains is to non-specialists – or indeed whether it may inadvertently mislead them. What is clear is that scientific papers are increasingly easy to access online, due in part to the global trends towards open access (OA) scientific publishing, in which articles are made freely available online rather than kept locked behind subscriber paywalls, and use of file-sharing sites such as Research Gate and pirating sites such as SciHub. Non-scientists are interested in science, as evidenced by the recent crashing of the servers of the journal *Physical Reviews Letters* after the publication and media coverage of Abbott and colleagues’ (2016) paper on gravitational waves and black hole mergers (Straumsheim, 2016). Now these individuals have almost unfettered access to it.

We are currently exploring the consequences of this access in which scientific papers are available to a diverse range of readers, but still written in a language and style intended for a highly trained scientific audience. As a first case study, we conducted a survey of home users of electrical brain-stimulation devices, the results of which are shared in this article. The survey included questions to determine how the home users’ use of scientific research publications compared with other knowledge sources; the extent to which research publications played a role in their decision-making; and the ways in which current scientific publishing standards and norms influenced how they understood and used those papers.

Open access literature

The research on OA scientific literature ranges from early discussions on the technical aspects of freely sharing information within library and information technology disciplines, and the economics of shifting to a ‘free’ model within the publishing industry and business sphere, to discussions of broader, more global effects from within science, social science and arts disciplines (Bernius, 2010; Dimchev & Stefanov, 2015; Hochschild, 2016; Nwagwu, 2016; Parker, 2013; Tennant et al., 2016; Worlock, 2016). Overwhelmingly, the discussions stemming from this last area focus on open access

publishing as a way to stimulate innovation and discovery generally, although there is a tendency to focus on benefits to academics, publishers and research itself. Somewhat secondarily, it also espouses open access as a societal good.

Open access to the scholarly literature does not just benefit academics, but also has wider impacts on other domains in society. It makes research available to anyone with an internet connection who has the ability to search and read the material. Therefore, it transcends academic affiliation and supports sustainable lifelong learning. Examples of groups who might benefit most from OA include citizen scientists, medical patients and their supporting networks, health advocates, NGOs and those who work in linguistics and translation. In theory, OA affects anyone who uses information and opens up possibilities for knowledge to be used in unexpected, creative and innovative ways beyond mainstream professional research (Tennant et al., 2016, p. 12).

For these reasons, many science funding organisations – including the Australian Research Council (ARC), Australia’s National Health and Medical Research Council (NHMRC), the Wellcome Trust in the United Kingdom and the US National Institutes of Health – request that the research they support be published in an OA form. The following text is on both the ARC and NHMRC websites:

The Australian Government makes a major investment in research to support its essential role in improving the wellbeing of our society. To maximise the benefits from research, publications resulting from research activities must be disseminated as broadly as possible to allow access by other researchers and the wider community. (NHMRC, 2014)

Beyond this general benefit to society, there are four major themes in the literature on open access that relate to possible effects on the public, two positive and two negative:

- 1 scientific literacy, where open access may play a role in cultivating scientific literacy, although concerns are raised regarding the ‘cognitive accessibility’ (Zuccala, 2010)
- 2 open or citizen science, where open access encourages greater participation in science, either as traditional research participants or as quasi- or amateur researchers themselves (Kelty, 2010), with the potential to ‘introduce new ways of knowledge creation’ (Tennant et al., 2016, p. 13)
- 3 national security and public safety, where open access would give a blueprint for the creation of dangerous substances (such as viruses or toxins) or technologies (such as nuclear processes), and lead to an increase in terror threats (Landrain et al., 2013; WHO, 2005)¹
- 4 medical decision-making and cyber-chondria, where open access may lead to positive or negative changes in health care decisions and an expansion of the Dr Google/cyberchondria phenomena that shows increased access to medical information increases anxiety surrounding symptoms (Davis & Walters, 2011).

Further to these ideas on effects of access to scientific papers, there have been discussions on public understanding of science and the complex interconnections between science and the societies it ostensibly serves, focusing particularly on public

interactions and engagements as primary elements of responsible research and innovation (Grove-White, Macnaghten & Wynne, 2000); Macnaghten et al., 2014; Nowak & Paton, 2017; Stilgoe, Owen & Macnaghten, 2013; Wynne, 2008). From this perspective, science is strengthened by connecting researchers and their various end-users, including industry and the lay public, in two-way or multi-directional communication. Problematically, much science communication remains unidirectional, with little opportunity for non-scientists to 'speak back' to the research literature, even where open access publishing exists. It is also rare for self-reflexive research to occur in these areas. While one study exists on the public perception of open access publishing (Zuccala, 2010), for instance, there are no general studies that ask non-scientists about their use of scientific papers (Davis & Walters, 2011). The limited number of studies found to have focused specifically on non-scientists' use of brain stimulation literature to self-experiment with cognitive enhancements or to self-treat mental illness is discussed at the end of the following section.

Brain stimulation

Transcranial direct current stimulation (tDCS) uses low intensity electrical currents to excite or inhibit the nerve cells in the brain (Heinrichs, 2012; Wexler, 2015). This form of stimulation is non-invasive, with the small currents (typically 1-2 milliamps) passing through the cortex between two electrodes placed on the scalp. The part of the brain stimulated and possible effects depend on the size, polarity and placement of those electrodes (Heinrichs, 2012) as well as the duration and repetition of stimulation (Kadosh et al., 2012). tDCS is seen to be easy to administer, painless and safe (if used according to the manufacturer's instructions). Devices are portable, legal and relatively cheap to buy online and import to Australia. They are largely unregulated, and marketed as gaming rather than therapeutic or medical devices. Access is not a major hurdle:

Since a tDCS device is essentially a 9 V battery with two wires that rest atop the head, a crude, but functional, device can be soldered together with parts from a hardware store and a bit of electrical know-how. (Wexler, 2015, p. 2)

Unlike the relative ease of accessing a device, gaining a clear picture of the safety and efficacy of tDCS (especially when used outside of lab conditions) from the scientific literature is much more difficult. A 2015 survey of neuroscientists using tDCS in their research (Riggall et al., 2015) showed that researchers were cautiously optimistic in their evaluations of its efficacy across cognition and motor function research as well as in neurological and psychiatric clinical applications. The researchers surveyed were much less optimistic about the efficacy of tDCS to enhance normal function:

Overall ratings were substantially lower than for use in research and clinical contexts. In addition, a relatively high percentage of researchers perceived tDCS as 'ineffective' in this context and only four comments directly supported its efficacy. (Riggall et al. 2015, p. 8)

Overall, there is some limited evidence for the effectiveness of tDCS in the treatment of a range of conditions including Parkinson's disease, depression, anxiety and chronic pain, as well as in the rehabilitation of or recovery from events such as stroke (de Aguiar, Paolazzi & Micele, 2015; Doruk et al., 2014; Kuo, Paulus & Nitsche, 2014; Lefaucheur et al. 2017; Shin, Foerster & Nitsche, 2015). However, these effects are generated in strictly controlled lab or clinical settings with medical guidance and individual consultation, and are difficult to reproduce even within those settings. Researchers are wary of using tDCS in healthy populations, emphasising its importance as a tool for understanding the functions of the brain rather than as a means of short- or long-term enhancement (Duecker, de Graaf & Sack, 2014). Tellingly, the researchers would not use tDCS on themselves for neuro-enhancement because of a lack of evidence and insufficient benefits (Shirota, Hewitt & Paulus, 2014; Horvath, Forte & Carter, 2015).

Despite this conflicting or cautious evidence provided in the scientific literature, the number of home users of DIY or commercial brain-stimulation devices is growing. Jwa (2015) estimates an online tDCS community of up to 10000 users with a core group of dedicated subscribers to the most popular forums and YouTube channels of approximately 2700. Relatively little is known about these home users, their motivations or the ways they are using brain-stimulation devices. Only a handful of research papers are available on the subject, although many more discuss the issues associated with the proliferation of commercial tDCS devices and call for regulatory frameworks for their use in non-research or non-clinical settings (Cabrera & Reiner, 2015; Carter & Forte, 2016; Fitz & Reiner, 2015; Maslen et al., 2015; Wurzman et al., 2016).

What the minimal literature in this area *does* tell us about DIY and home users of tDCS is they are predominantly men in their twenties and thirties, and university graduates, although a range of other demographics were present in a survey of home-users (Jwa, 2015) and the bulk of users in the online communities interact there anonymously (Wexler, 2015). Jwa (2015) and Wexler (2015) both found the reason for practising tDCS at home was primarily for cognitive enhancements, but also for the treatment of medical conditions – particularly psychiatric disorders such as depression.

To date, there has only been one study attempting to evaluate how these home users utilise the scientific literature to take up or modify brain stimulation practices. In this preliminary and exploratory study, Wexler (2015) attempted to understand the DIY tDCS community in order to better understand the nature of its practices, individually and communally, 'with a focus on knowledge that is formed, shared and appropriated within it' (2015, p. 1). This occurs at two levels: first, with the community's use of scientific literature; and second, with the generation of their own data and knowledge collateral. This includes discussion of the ways in which the community attempts to replicate or adapt research based on their reading of the scientific literature. Wexler, however, sees this preliminary study as an 'impressionistic sketch', and points to the need for further, more in-depth research on how the DIY tDCS community uses and understands the scientific literature:

Knowledge that DIYers will likely use scientific papers to conduct self-experiments may be something for neuroscientists to keep in mind when reporting the results, if not in designing the experiments themselves. (2015, p. 5)

The following discussion stems from the first case study of our research into these gaps in the open access and brain stimulation literature, investigating in greater depth how non-scientists use scientific papers.

Methods

The initial results from our research stem from an online survey (hosted by Survey Monkey). The participant information sheet appeared as the first and second page of the survey. After providing consent to participate in the study, participants completed a 29-question survey, including questions to determine how the home users' use of scientific papers compared with other knowledge sources; the extent to which scientific papers played a role in their decision-making; and the ways in which current scientific publishing standards and norms influenced how they understood and used those papers. The survey also included demographic questions (including science training or employment). Questions relating to the users' motivations for experimentation and experiences with brain stimulation were not within the scope of this survey, which focused on scientific paper use, but would be included in future, in-depth interviews with respondents.

Responses to closed questions were analysed using descriptive statistics or mean comparisons, while responses to the open questions were analysed using a basic open or grounded coding process to look for the categories of response or themes coming out of the response data. Responses that contained multiple themes were coded as separate entries for each theme (consequently, some total numbers or *n* figures for qualitative results may be greater than the number of respondents). We present the qualitative data in concert with the quantitative analysis of survey responses in order to better depict the views of respondents.

Respondent demographics

There were 109 total respondents to the survey (not including fourteen incompletes). Twenty-seven respondents (24.7 per cent) had used a brain-stimulation device (e.g. tDCS devices such as Thync, Halo), whether purchased or homemade. Respondents who had not used a brain-stimulation device were disqualified from answering further questions. This correlates with other studies that discuss having difficulties accessing this population. One reason for this may be that self-experimentation, particularly around brain stimulation, is somewhat stigmatised. In a media article, for instance, people within this population were referred to as 'battery lickers' (Mannix, 2015).

In terms of respondent demographics, more men than women responded to the survey (69.2 per cent), although a greater percentage of women responded to this survey than in other research (31.8 per cent compared with 4 per cent in Jwa, 2015). The largest group represented in the survey were 36- to 45-year-olds (26.9%), followed

by 46- to 55-year-olds (23.1 per cent) and 56 to 65-year-olds (19.2 per cent). The oldest were 66- to 75-year-olds (7.7 per cent), the youngest 18- to 25-year-olds (11.5 per cent). Respondents to this English-language survey came predominantly from the United States (47 per cent) and Australia (41 per cent). In terms of their education level, fifteen of 27 respondents (57.7%) had a university degree, with five of those holding a doctorate (19.2 per cent). Several respondents held a school leaving qualification (7.7 per cent) or some form of post-secondary qualification (30.8 per cent). Only one respondent had no qualification. The majority of survey respondents had undertaken some form of training as a scientist (66.4 per cent). Those with scientific training tended to have trained across multiple fields, predominantly in engineering (44.4 per cent), followed by mathematical sciences (27.8 per cent), biological sciences (27.8 per cent), information and computer sciences (27.8 per cent) and neuroscience (27.8 per cent). Only 19.2 per cent were currently employed as scientists.

Results

Of the 27 respondents who indicated they had used tDCS devices at home, 24 (88.9 per cent) had read scientific papers on brain stimulation. This corresponds with formal and informal observations of the online DIY community, who are often engaged in discussing or sharing this material in online forums and websites (Jwa, 2015; Wexler, 2015). The tDCS subreddit forum, for instance, can be seen as a combination of links to scientific papers, discussions of scientific papers, technical discussions, seeking advice to facilitate use and anecdotes on user experience. Home users rated (on average) scientific papers as the most important source of information for their use of brain stimulation (4.23/7), followed by online forums (3.53/7) and websites (3.48/7). Media were rated (on average) as the least important source of information on brain stimulation (2.14/7).

In addition to the value they place on scientific papers, survey respondents were also asked questions about trust. For the respondents, trustworthiness was a question of quality in specific research processes, particularly surrounding research methods, as well as an over-arching trust in the general scientific process (n=23).

Some are clearly bullshit (small N, no control condition, wild exaggerations, unclear outcome measures), some are more even-handed.

Their methods may be wrong, even if they have passed peer review. Some journals are noted for publishing sensational novel 'positive' studies as opposed to replicated studies or studies that do not provide evidence for predicted hypotheses.

Science is the most effective known method for gaining quantitative knowledge of the Universe and its physical laws.

Scientific papers are a lot more reliable than the ramblings of some random (and unidentifiable) person on the internet

While the open-ended responses show a large degree of scepticism about the publishing process, the respondents felt the resulting papers were mostly trustworthy

(54.2 per cent) or somewhat trustworthy (33.3%). Only one respondent felt they were never trustworthy (4.2 per cent).

At-home users placed a high value on science in general and scientific papers specifically, and believed they were essential for using brain-stimulation devices at home. At the same time, however, these home users disagreed that the science literature could provide them with all they needed to know to use brain-stimulation devices at home (29.1 per cent somewhat disagree; 29.1 per cent completely disagree; 12.5 per cent neutral), and were divided on whether following the same methods and techniques used in the research would keep them safe (29.1 per cent somewhat agree; 29.1 per cent somewhat disagree; 25 per cent neutral). Rather than relying solely on scientific papers, they sought information from a variety of sources, including friends, forums or other sources. This use of multiple sources also appeared in responses to the open-ended question on the kind or type of information they found most useful (n=24):

Meta analysis reviews and personal stories.

Lectures, other people's (the seemingly intelligent ones) experiences with tDCS, and documentaries that feature tDCS. I also like to read about various disorders that I think would benefit and eventually become a part of the discussion regarding the efficacy of using tDCS as a treatment.

Feedback on results, usage and equipment info.

A mix of research papers and home user anecdotal evidence.

When they did seek out scientific papers, the respondents used them primarily to find out what these devices could do (80.8 per cent) – for instance, their application to treatment of particular diseases or disorders, or to cognitive functions such as learning or memory. They also used papers to find information electrode placement (61.5 per cent) and stimulation session duration (61.5 per cent), both of which were likely to go beyond the specifications provided by the device manufacturer. Survey respondents were least likely to use the papers to help them decide which device to purchase (3.8 per cent).

Respondents were also asked about their methods for reading and evaluating the papers they had read, giving some insight into how easy or difficult it may be for lay readers to take away useful information from a scientific literature that is designed for a professional and highly specific audience. How did these home users, for instance, evaluate research when presented with papers that contradicted one another? Responses here (n=31) indicate that respondents were inclined to review elements of the research or to research beyond the papers:

Continue to investigate and look at things such as size of study.

Look at the different methods used to come to different conclusions. Look to see if apples to apples were really compared.

I pry deeper and locate other papers to tip the data scale towards proof of validity of one of the perspectives represented in the literature.

Look for more information.

In some cases, respondents used the reputation of the authors to help judge the quality of the research, while others attempted to replicate results themselves through self-experimentation:

Seek advice in forums. Worst case just use both and note/share any info or data I collect.

That would depend if either had an outcome I wanted to apply the same technique to myself. I would test at low time/intensity first.

Looking deeper into how the respondents used the scientific literature, respondents were asked to consider the last scientific paper they had used. Only 30.8 per cent of respondents said they had read all of the last scientific paper they had used. The most read sections of the scientific papers used were the results section (57.7 per cent); this corresponds to earlier discussion of trust, with respondents feeling the data itself was trustworthy, but the publishing process and format less so:

I think the papers report the data correctly even if their interpretations might be a bit flakey.

After the results section, the abstract (50 per cent) and conclusion (50 per cent) were the most read sections of the scientific literature on brain stimulation. The least often read were the discussion (26.9 per cent) and key points section (26.9 per cent).

Perhaps more concerning for neuroscientists and scientific publishers, given the tendency for home users of brain-stimulation devices to attempt to replicate the results they have read about in these papers, is that only 16 per cent of respondents felt they understood all of the last scientific paper they had used. The majority felt they had understood most of it (56 per cent) or some of it (28 per cent). No one indicated that they felt they had understood none of it.

Linking into the question of understanding, all but two of the open-ended responses indicated that scientific papers need to be easier to read (n=27). The respondents believed improving the language used in scientific papers would make them easier to understand. This includes using plainer language in summaries as well as the main body of the text and using less jargon:

I never read the results sections because I don't really understand stats. I rely on the other sections to interpret them, so making sure the other sections are clear and not full of jargon is helpful.

Summaries in plain language.

Less scientific language (jargon). It is possible to look up terms and phrases but that can introduce confusion or further misunderstanding.

Some felt more detailed methods sections would make scientific articles easier to read:

More detail in methods.

How-to tips. Also revealing the exact ingredients or conditions being utilized in the research.

More technical details about waveforms used, intensity, and hardware.

Define ALL abbreviations used. Be clearer on exact placement of the electrodes. Specify where cathode is placed in the ABSTRACT (most times left out). If a brain test or motor test was done, be clearer if the result was positive or negative. Sometimes the author thinks the audience is VERY familiar with a test and assumes they know by looking at a graph or something if the outcome was good or bad. Not TRUE.

With these responses in particular, it is possible to see that the respondents felt they would like the scientific papers available to them to be easier to not only understand but also to translate into practice.

Discussion

The preliminary results of this survey show that home users of brain-stimulation devices across a range of ages and education levels are attempting to induce effects in their brains, whether to treat or 'cure' disorders or diseases or to improve their normal cognitive functions. The majority of these home users are also using the scientific literature produced by neuroscientists and other professional researchers to guide these practices. While they generally consider scientific papers valuable and trusted sources, they supplement these with other information found on user-generated websites and online forums. The information they find most useful for their practice of DIY brain stimulation is not just the methods and technical details outlined in the scientific literature, but also anecdotal evidence of other home users' experiences, particularly where these experiences push the boundaries of the current research's methods and results and manufacturers' recommendations. While a large proportion of the respondent group held a university degree or some training in a scientific field, relatively few home users of brain stimulation read all of the last scientific paper they had accessed. Even fewer felt they understood it all. Respondents suggested how to make these papers easier to understand, focusing primarily on greater clarity of language, but also on clearer descriptions of pathways to self-experimentation and replication of results.

It is clear from the survey that home users are using the output from scientists and other researcher professionals in unintended ways, pushing beyond the boundaries of existing research in their search for information and their self-experimentation. It is also clear that warnings such as the open letter from neuroscientists (Wurzman et al., 2016) or calls for stricter regulations of commercial brain-stimulation devices (Fitz & Reiner, 2015; Maslen et al., 2015) are not enough to deter home users from these practices. Instead, numbers of home users have steadily increased over the past six years (Wexler, 2015), and will only rise as research in the area discovers and confirms new areas of efficacy in either treatment or enhancement, as media coverage of these new technologies continues, and as individuals grow ever more curious or concerned about their own brain functioning.

Questions remain, however, about what responsibilities the scientific community has to these unintended audiences, and what role it and the publishing industry can

play in generating better, safer outcomes for home users. Is it, for instance, necessary, practical or ethical to restrict access to particular scientific results? And if so, which topics would best be restricted? Will improving readability or the level of technical detail for non-scientists lower rates of improper usage? Should the scientific community, including scholarly publishers, at the same time be advocating for greater scientific literacy?

While answers to these questions are beyond the scope of the current survey, it is hoped that further research into the unintended uses of scientific literature will address them. We will follow up with in-depth interviews with respondents of the current survey who agreed to be contacted, as well as further case studies on other groups of non-scientists who use scientific literature, including medicinal marijuana users, stem cell technology health tourists, and those making decisions about vaccination. This would give us scope to analyse how scientific papers are used across user groups as well as across national contexts. It is hoped that our findings will help improve the way scientific knowledge is shared by identifying ways in which the scholarly publishing industry can adapt its products to meet the needs of this new audience, as well as informing policy and practical responses for the scientific research sector.

Notes

- ¹ In the WHO report *Life Science Research: Opportunities and Risks for Public Health* (2005), the authors note that access to potentially dangerous research is currently controlled by research institutions and editors of research journals in a self-governing and self-policing fashion rather than through regulation and legislation. Three major scientific journals, *Nature*, the *New England Journal of Medicine* and *Science*, for example, currently have a case-by-case approach where ‘editors will deal “responsibly and effectively” with papers that raise “safety and security issues” and that “on occasions an editor may conclude that the potential harm of publication outweighs the potential societal benefits. Under such circumstances, the paper should be modified, or not be published.”’ (WHO, 2005, p. 17). The report notes significant opposition to this and any form of censorship of scientific research.

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