A novel, web-based approach to public participation in neuromodulation research

Christopher A. Harris[1] & Laura L. Kilarski[2]

1. University of Sussex, UK; 2. Cardiff University, UK

Introduction

Rapid advances in science and medicine have led to calls for increased public participation in deciding the direction of research (European Commission, 2005; Bucchi & Nerresini, 2004). But while scientists generally value public understanding of science, few accept the need for public participation in the scientific decision-making process (Royal Society, 2006), especially since such participation may involve simplifying and dramatizing complex scientific issues (Maeseele, 2007), and speculating on future research findings, technical applications and their societal impact (Colingridge, 1980). Public participation in science, when it does occur, is often narrowly focused on risk and does not constitute a genuine discussion between citizens and scientists about the values and vision of scientific progress (Maeseele, 2007). Many research institutions also fail to take advantage of the extraordinary interactive opportunities of the internet, and instead use the net merely as a presentation tool (Massoli, 2007). This is particularly troubling at a time when news organizations are drastically reducing their science coverage and citizens are moving to the net as their primary source of information (Nesbit, 2008 lecture).

These problems are clearly present in neuromodulation research. Experts in the field seldom engage in open discussion about future applications and long-term societal impacts of new neuromodulation technologies. Rather, they simply insist on proceeding with care (Bubnoff, 2009; Kringelbach & Aziz, 2008) and "hope we never get too good at this" (Blomstedt, 2008 radio). To promote public participation in neuromodulation research we have created an atypical web-resource that describes in detail a single, hypothetical development in deep brain stimulation research (conditional rewarding brain stimulation for human use, see right-hand column), and invites the public to discuss, criticise, and develop the details and the cultural framing of this technology. The web-resource also provides information about monoamine neuroscience, deep brain stimulation and other information necessary for effective participation in the discussion. Several new information ('web 2.0') technologies, such as social networks, video channels, blogs, microblogs, web-crawlers, polls and forums, were used for communication. Comments and discussions that developed on these platforms were continually incorporated into the information presented on the main website and in our video clips. Coinage and use of the term 'iPlant' as a noun to refer to the hypothetical implant under consideration allowed rapid ('viral') spread of information and discussion, and was key to effective use of web 2.0 technologies.

Methods and results

Website. We used Microsoft Sharepoint Designer to create a HTML/JavaScript website. The site went online in November of 2007 at http://www.iplant.eu, hosted by Spray (Stockholm, Sweden). It is currently hosted by Ballou (Stockholm, Sweden). The site has a header (100% width, 104px height), a text area (70% width) and a sidebar (30% width). The header and sidebar are identical for all pages, whereas the text area contains information relevant to the topic of each page (table 1). The site consists of eleven pages. Presented here are site traffic statistics for June and July 2009. No changes to the content of the web-resource were made during this period. In June and July, the site received 1625 page views by 866 visitors, 522 of which were unique visitors. The average time spent on the site was 3.22 minutes. A breakdown of traffic for individual pages is presented in table 1. Traffic sources are presented in figure 1.

Table 1. Website word count and traffic for June - July 2009

Page name	Page content	Word count	Page views	Avg. time on page
Home	Introduction/overview (5 languages) and news/recent developments	672	831	00:02:20
Fiction	Dramatized account of conditional rewarding brain stimulation for personal use (chapter 1) and for research (chapter 2)	3860	52	00:04:39
Monoamines	Information about monoamine neurobiology (particularly dopamine) as it pertains to cognitive function	703	127	00:03:37
Rewarding brain stimulation	Information about historical and current use of intracranial self-stimulation in rodents	374	54	00:01:39
Programming	Speculative discussion about how conditional rewarding brain stimulation could be used to help human patients	1693	67	00:03:38
Implant technology	Information about deep brain stimulation, particularly as applied to the ventral striatum	273	80	00:03:05
Magnetic technology	Very brief discussion about transcranial magnetic stimulation as an alternative to deep brain stimulation	103	34	00:01:52
Ethics and philosophy	Discussion of concerns raised by members of the public	1274	60	00:04:50
FAQ	Responses to common questions	293	49	n/a
Site administrators	Contact information, blogs, Twitter and FriendFeed accounts and CVs of the authors	442	45	00:03:27
References	List of relevant references	2385	20	00:02:09
Site overall	---	**12072**	**1625**	**00:03:22**

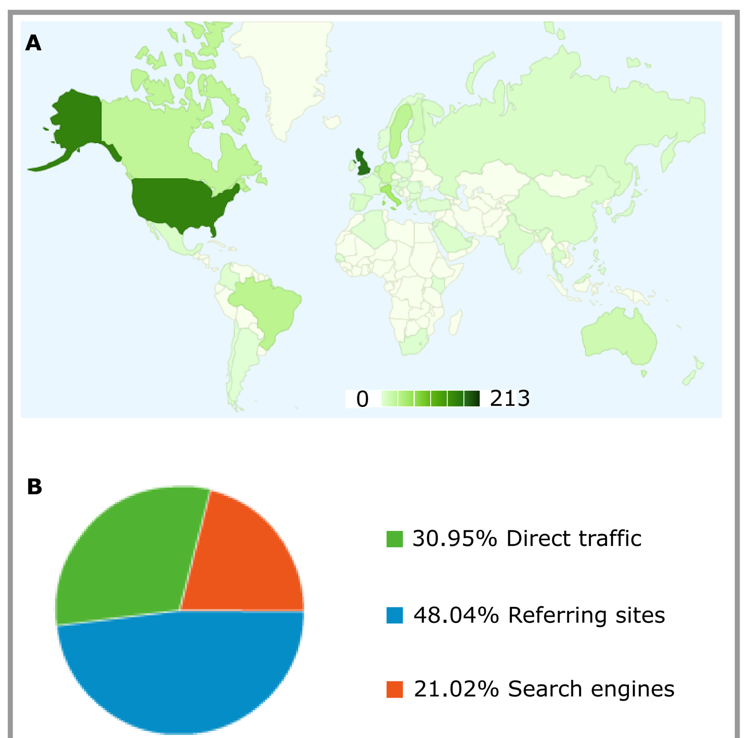


Figure 1. Website traffic sources for June - July 2009. A. Traffic by country. B. Traffic by source. Note: 44% of search engine visits came from searches on the word 'iplant'. Top referring sites: brainimplant.blogspot.com 10.28%, youtube.com 9.93%, psiqueii.blogspot.com 5.66%.

Video. Eight short videos (~2-5 min) and a longer (30 min) seminar were scripted, recorded and distributed on YouTube (http://www.youtube.com/iPlantChannel) and Facebook (http://www.facebook.com/video/?id=10521196166) (table 2). Videos were filmed using a JVC Everio HDD camera provided by the University of Sussex, a Logitech QuickCam Pro, and a Sony ECM-MS907 microphone, and were assembled in Windows Movie Maker. On YouTube, videos were viewed a total of 6152 times during June and July 2009. 4178 of those views were by unique viewers. A breakdown of viewer statistics for individual videos is presented in table 2. Viewer location and demographics are presented in figure 2.

Table 2. YouTube video viewer statistics for June - July 2009

Video name	Video content	% of total views	Watched to end
What is an iPlant?	Introduction to conditional rewarding brain stimulation for human use	5.2%	45%
iPlant seminar (pts 1-4)	Extended introduction to conditional rewarding brain stimulation for human use	n/a	n/a
Deep brain stimulation for depression	Comments on a research paper	5.5%	15%
Program yourself (pts 1-2)	Reading of iPlant-fiction	3.1%	n/a
What is dopamine? *	Introduction to the role of dopamine in human cognition	53.0%	85%
Dopamine and the frontal lobes	Introduction to the functional relation between the dopamine and the frontal lobes	18.0%	80%
What is rewarding brain stimulation?	Introduction to intracranial self-stimulation	1.4%	n/a
Dopamine, attention, working memory, neuronal groups and the prefrontal cortex	Introduction to the prefrontal cortex and the role of dopamine in working memory	8.0%	50%
iPlant 101	Introduction to conditional rewarding brain stimulation for human use	3.1%	n/a

* *Viewer sources: 43% YouTube search (keyword 'dopamine': 28%); 31% Google search (keyword 'dopamine': 25%)*

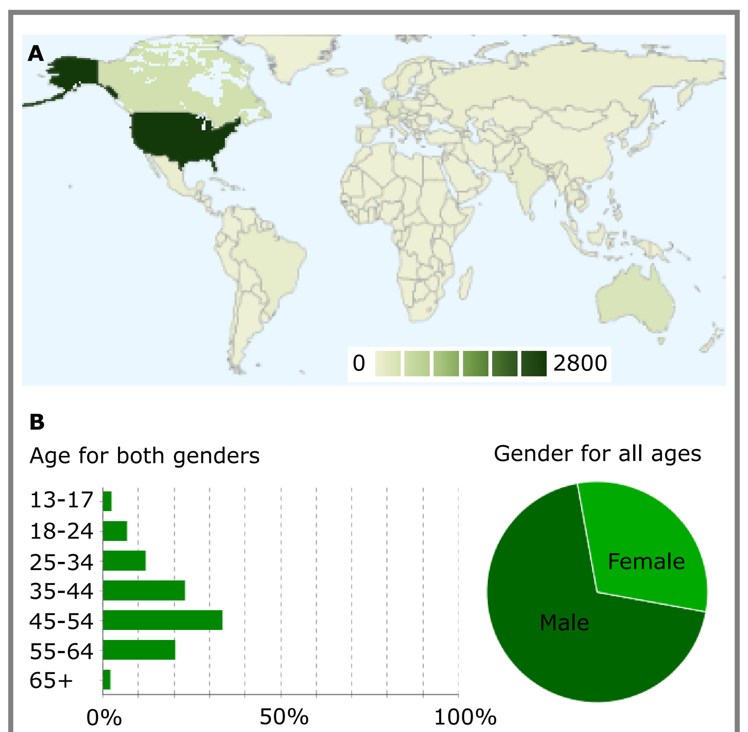


Figure 2. YouTube video viewer location and demographics for June - July 2009. A Viewers by country. B. Viewers by age and gender.

Web 2.0 technologies. 'Web 2.0' technologies are internet platforms that grow through user contribution and allow for rich social interaction. YouTube and Facebook are such platforms. In addition to these, we used a variety of other web 2.0 platforms and related technologies to attract visitors to the web-resource, to spread information about new developments and changes, to provide additional channels for communications, and to build and maintain a community of people interested in the development of iPlants. Using 'iPlant' as name and logo, were able to create an easily identifiable presence across a large number of platforms (table 3).

Public participation. We continue to receive communications from the public on a daily basis. Currently, most of these are in the form of comments on YouTube or on blogs and forums. Many commentors express strong positive or negative sentiment about some aspect of the development of iPlants (figure 3), while others request additional information, particularly about dopamine function. We use concerns raised by the public to develop our presentation of the iPlant, particularly the ethics and FAQ sections of the website (see *Concerns and policy suggestions* in the right-hand column). Discussion among the members of the Google Group forum contributed substantially to the initial development of policy guidelines to answer common concerns but the forum has since been inactive. Members of the forum also contributed translations of the website starting page, which is currently available in five languages. Some members distributed printed material at local universities. Comments on the development of iPlants that occur outside of the web-resource, e.g. on private blogs, are picked up by our Google Alerts web-crawler, which regularly scans the net for use of the term 'iPlant': new texts that include the term are found within 24 hrs and are often linked to in the sidebar of the website. Many of these external comments generate extensive discussions of their own.

Table 3. Web 2.0 technologies

Application name	Application function	Members/ subscribers
Google Groups (groups.google.com/group/iplant)	Forum and mailing list that was critical to early, in-depth discussion of societal impacts and other aspects of human use	19
Twitter (twitter.com/iplant)	Popular microblog service that sends real-time updates (e.g. regarding new videos or discussions) to subscribers	26
Facebook (facebook.com/group.php?gid=20810906248) (facebook.com/pages/iPlant/10521196166) (facebook.com/pages/Dopamine/18682073247)	Extremely popular social network, which also provides video hosting	40 40 740
FriendFeed (friendfeed.com/groups/iplant)	Real-time aggregator	8
Blogspot (brainimplant.blogspot.com)	Blog service used develop new content	41
IEET, FutureBlogger	Popular futurist sites/blog networks for targeted communication	n/a
Google Alerts	Web-crawler collecting texts mentioning the term 'iPlant'	n/a
Polldaddy	Poll and survey service (see figure 4)	71

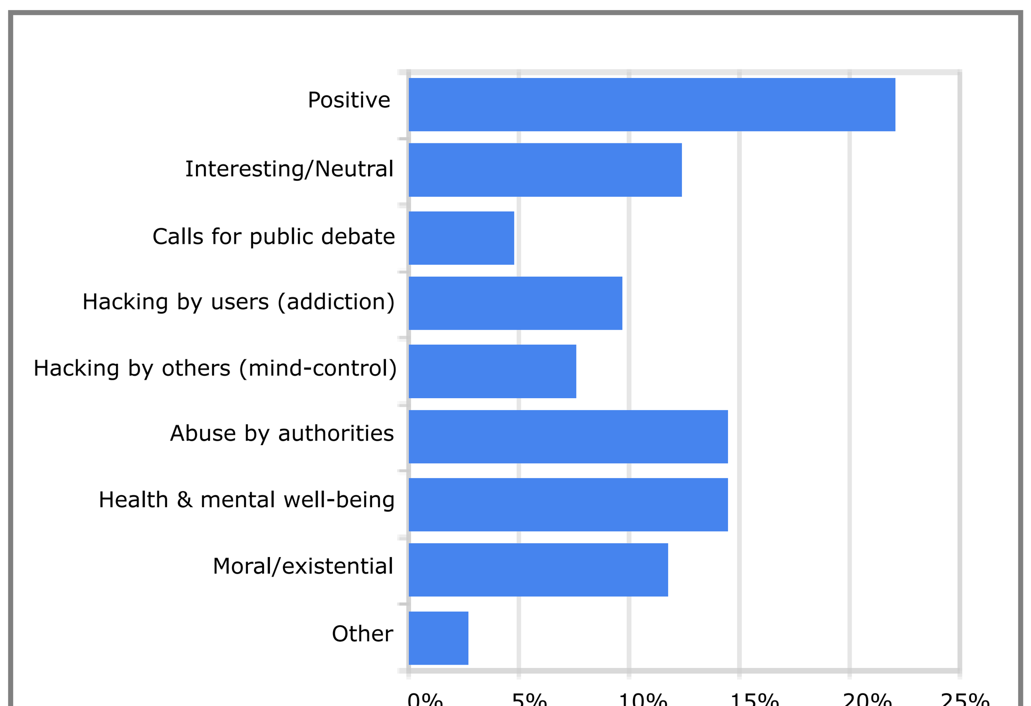
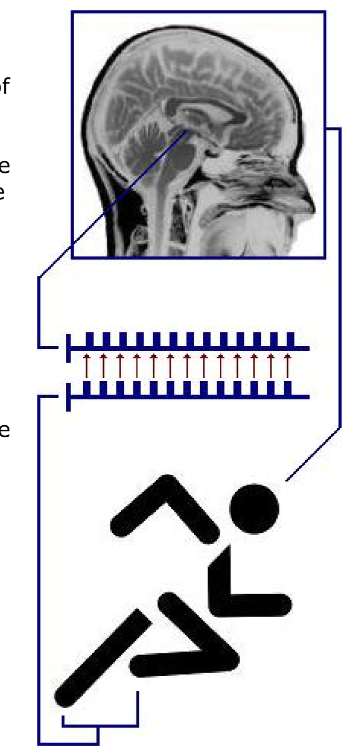


Figure 3.
Classification of 145 comments recieved on website, videos and other platforms.

The iPlant

We use the term 'iPlant' to refer to a deep brain stimulation (DBS) system that would be used to generate conditional rewarding brain stimulation (RBS) in a human patient for the purpose of motivating demanding tasks. Conditional RBS has been used to motivate rats to engage in behaviours such as heavy physical exercise (Burgess et al., 1991; Garner et al., 1991) and problem solving (Hermer-Vasquez et al., 2005) but has not yet been used to help human patients. In rats, the technique involves placing electrodes in brain regions associated with reward processing and allowing the animals to activate the electrodes by performing some operant behaviour, such as pressing a lever, running on a treadmill, lifting weights, or solving a problem.

The nucleus accumbens (NAc) is one region in which RBS can be induced (Prado-Alcalá & Wise, 1984; Wise, 1996). Conditional RBS for human use has therefore been feasible, with existing technology and procedures, ever since DBS electrodes began being placed in the NAc to treat obsessive compulsive disorder and, recently, major depression (Schlaepfer et al., 2008; Malone et al., 2009). The difference is one of stimulation parameter settings: DBS to the NAc involves constant application of high-frequency current (e.g. 145 Hz, 90 ms pulse width) whereas RBS to the region involves brief bursts of current (e.g. 60 Hz, 500 ms pulse width).



Our web-resource invites the public to study, discuss, criticize and develop the details of how conditional RBS could be used to help human patients motivate themselves to perform various challenging behaviours. Several applications have been proposed and developed; these include:

RBS-driven exercise. RBS would be delivered when the user pulls a stroke on a rowing machine, when his/her pressure-sensitive running shoe hits the ground (see figure next to text), for each basket ball through a net, for pushing the pedals of an exercise bike, etc. RBS-driven exercise might be applicable to a wide range of patients who require but fail to engage in physical exercise. It should be noted that DBS has already been applied to the human hypothalamus to treat obesity (Hamani et al., 2008) and that RBS-driven exercise might have a more reliable effect given the many health benefits of rigorous exercise.

RBS-driven learning. RBS would be delivered when the user successfully finishes a given exercise or provides correct answers to questions posed by computer tutorial software designed to teach (e.g. algebra, foreign languages).

RBS-driven research. Many (especially molecular biology) laboratory techniques involve simple, repetitive behaviours. RBS would delivered when the user has classified a blot, collected samples from the freezer, pipetted samples onto microarrays, etc.

Concerns and policy suggestions

A number of theoretical, practical, ethical and societal concerns have been raised about the development of iPlants (see also *Results: Public participation*). Roughly, these concerns can be divided into three categories:

Hacking (abuse by the user or by others). iPlants depend fundamentally on rewarding brain stimulation being delivered if and only if the user performs some pre-specified, beneficial behaviour or task. Concerns have been raised that users might find ways to circumvent such restrictions and self-stimulate unconditionally and endlessly. Similarly, concerns have been raised that malicious individuals would find ways to circumvent restrictions and control the behaviour of the iPlant user. Successful use of iPlants may therefore require that users have limited access to the settings of their implants; that such limitations are subject to sophisticated encryption and enforcement; and that an accountable implant manufacturer/hospital/doctor is able to maintain access control without abusing the trust of the user.

Abuse by governments or cultures. iPlants could, if widely adopted, produce significant changes in society. Concerns have been raised that authorities might abuse iPlants by artificially motivating citizens to engage in demeaning or dangerous behaviour. Concerns have also been raised that cultures could abuse iPlants by pressuring individuals to conform, e.g. to unreasonable standards of productivity. These concerns indicate that the development of iPlants, if it is to take place, must occur in the context of transparency, public participation and debate, and under rigorous oversight by civil rights groups such as Amnesty, the CCLE, and the UNESCO bioethics council.

Damage to natural self-discipline. Concerns that iPlants would have a negative impact on users have been expressed. Some report fear that users would become excessively dependent on their iPlant, possibly to the detriment of their own self-discipline. For instance, a person who exercised 1 hr per week before being fitted with an iPlant might able to exercise 1 hr per day with the aid of the implant, but would be tempted to always use the implant for motivation when exercising. Removal of that 1 hr per week of iPlant-free exercise might be psychologically damaging, since exertion of effort is necessary for the maintenance and growth of self-discipline. This indicates that iPlant-driven behaviour should only be engaged in when the user would normally be idle (or engaged in destructive behaviour). Again, the need for a manufacturer/hospital/doctor capable of enforcing proper use of the technology without abusing the trust of the user appears crucial.

Poll: When will iPlants enter clinical trials?

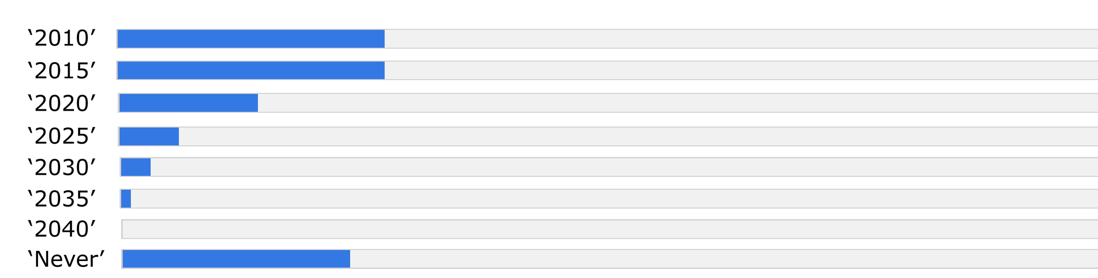


Figure 4. Results of an ongoing poll, prominently displayed on the website and on brainimplant.blogspot.com. Number of respondents = 71.

Conclusion and future directions

We have created a web-resource that that aims to engage the public in the development of conditional rewarding brain stimulation for human use. Our website received 866 visitors in a two month period and our YouTube videos were viewed 6152 times in the same period. Videos about dopamine were particularly popular, indicating a shortage of videos describing dopamine function on the net.

Web 2.0 platforms allowed for public commenting and discussion about the proposed neuromodulation technology. Google Alerts proved very useful for identifying discussions occurring outside of our web-resource. Comments were typically positive or expressed one of several recurring concerns. These concerns were addressed on the main website and discussed further on our forum.

While discussions regarding concerns are rich and ongoing, future development of this project should encourage participants to address, through comments or surveys, a broader range of topics relating to the development of iPlants, such as sociocultural complexities, new applications of the technology, and interactions with other emerging technologies.

Other plans for the future include: increased transparency, interviews with researchers in relevant fields, better/clearer textual information, and more videos about applications and concerns regarding iPlants, and about relevant aspects of neuromodulation research.

Acknowledgements

This project was conducted separately from the PhD studies of the authors. However, we thank the University of Sussex for help with equipment and logistics. All proceeds from the iPlant Zazzle store are used to pay Ballou (Stockholm, Sweden) for hosting the website.

References

Blomstedt P (DBS neurosurgeon at Umeå University Hospital, Sweden) speaking on Vetandets Värld 18 July 2008 on Swedish Radio (our translation from Swedish).

Bubnoff A von (2009) With deep brain stimulation, experts want to tread carefully. Los Angeles Times.

Bucchi M & Neresini F (2004) Why are People Hostile to Biotechnologies? Science 304(5678):1749.

Burgess ML, Davis MJ, Borg TK & Buggy J (1991) Intracranial self-stimulation motivates treadmill running in rats. Journal of Applied Physiology 71:1593-1597.

Collingridge D (1980) The Social Control of Technology.

European Commission (2005) Europeans, Science and Technology.

Garner RP, Terracio L, Borg TK & Buggy J (1991) Intracranial self-stimulation motivates weight-lifting exercise in rats. Journal of Applied Physiology 71:1627-1631.

Hamani C, McAndrews MP, Cohn M, Oh M, Zumsteg D, Shapiro CM, Wennberg RA, Lozano AM (2008) Memory enhancement induced by hypothalamic/fornix deep brain stimulation. Annals of Neurology 63(1):119-23.

Hermer-Vazquez L, Hermer-Vazquez R, Rybinnik I, Greebel G, Keller R, Xu S (2005) Rapid learning and flexible memory in "habit" tasks in rats trained with brain stimulation reward. Physiology & Behavior 84: 753-9.

Kringelbach ML & Aziz TZ (2008) Deep brain stimulation - avoiding the errors of psychosurgery

Maeseele PA (2007) Science and Technology in a Mediatized and Democratized Society. Journal of Science Communication 6 (1):1-10.

Malone DA Jr, Dougherty DD, Rezai AR, Carpenter LL, Friehs GM, Eskandar EN, Rauch SL, Rasmussen SA, Machado AG, Kubu CS, Tyrka AR, Price LH, Stypulkowski PH, Giftakis JE, Rise MT, Malloy PF, Salloway SP, Greenberg BD (2009) Deep Brain Stimulation of the Ventral Capsule Ventral Striatum for Treatment-Resistant Depression. Biological Psychiatry 65(4):267-75.

Massoli L (2007) Science on the net: an analysis of the websites of the European publich research institutions. JCom 6.

Nesbit J giving a keynote at Cornell University in 2008.

Prado-Alcalá R & Wise RA (1984) Brain stimulation reward and dopamine terminal fields. I. Caudate-putamen, nucleus accumbens and amygdala. Brain Research. 297(2):265-73.

Royal Society (2006) Survey of factors affecting science communication by scientists and engineers.

Schlaepfer TE, Cohen MX, Frick C, Kosel M, Brodesser D, Axmacher N, Joe AY, Kreft M, Lenartz D, Sturm V (2008) Deep Brain Stimulation to Reward Circuitry Alleviates Anhedonia in Refractory Major Depression. Neuropsychopharmacology 33(2):368-77.

Wise RA (1996) Addictive drugs and brain stimulation reward. Annual Reviews Neuroscience 19:319-40.

www.iPlant.eu