# WikiTweaks: The Encyclopaedia that Anyone (Who is a Skeptic) Can Edit

# Abstract

This article documents recent attempts to update the Acupuncture page on Wikipedia with current scientific knowledge, and describes how such pages are presently controlled by self-styled skeptics, who prevent anyone else from editing them, thus ensuring the information conforms to their own biased and skeptical beliefs. The author provides key research papers and mainstream medical guidelines from around the world in order to provide acupuncture practitioners with robust evidence that can be used to counter biased and unfounded claims about acupuncture.

It is an interesting time to be practising a foreign, several thousand-year-old medical therapy in the West. The easy flow of information available to patients means that an unprecedented opportunity exists to inform the public about what practitioners of acupuncture and Chinese medicine have to offer. The growing realisation by the public that the reliance on pharmaceuticals and invasive interventions for complex chronic health conditions is often ineffective and carries significant risk (Null et al., 2005) means that patients are researching alternative solutions for their health problems rather than passively relying on the expert opinion of conventional health care providers. This presents practitioners of acupuncture and Chinese medicine with a welcome opportunity to educate the public.

# Medical information on the internet

In 2011, the UN Human Rights Council declared the right to access information on the internet to be one of the most basic human rights of global citizens (Park et al., 2016) partly because more than half of all patients use the internet as a first port of call for specific health information (Hesse et al., 2010). This makes the quality and accuracy of this information an important public health issue. The internet being what it is, there is a huge quantity and spectrum of quality available to the seeker of health-related information. But what does research tell us about where people tend to go when they ask the internet a question about their health?

Websites considered to be generally reliable and high-quality sources of information include those of national health services, such as NHS Direct and the National Institutes of Health, those of disease-specific patient advocacy organisations, and doctor- and research-led resources such as WebMD. However, the site most frequently consulted as a source of medical information falls into none of these categories. The most frequently consulted source of medical information, not only by patients, but also those medically qualified and licensed individuals with whom they entrust their care, their health and their life, is Wikipedia.

Wikipedia, launched in 2001, is a free online encyclopedia that, according to its slogan, 'anyone can edit,' and is developed and maintained by a global community of volunteers. This model creates a situation that may seem positive or disastrous depending on your worldview. Free access to the world's knowledge can be empowering, but this access is only as helpful as the accuracy of the information contained therein. Be that as it may, out of all medical online search queries, a Wikipedia article is the number one hit more often than any other website, including MedlinePlus, Medscape, WebMD.com, NHS Direct Online or the BBC (Laurent & Vickers, 2009).

In this context, the information conveyed in the Wikipedia article on acupuncture plays an important role in educating the public about this modality; for a significant proportion of people, this article constitutes their first contact with information on its potential benefits and the evidence for its use. Thus the article provides an opportunity to share research into its effectiveness and official recommendations for its use, as well as its well-established modes of action. While in theory anyone can edit the article

# By: Mel Hopper Koppelman

Keywords: Acupuncture, Wikipedia, research, bias. regardless of their opinions on the subject, Wikipedia's editing guidelines specifically prohibit 'editorialising' or sharing the opinion of an editor as if it were factual. Which is why it is somewhat perplexing that the article is decidedly anti-acupuncture. In the introductory paragraph, we are informed that 'acupuncture is a pseudoscience,' a controversial and derogatory designation, while the sidebar informs us that the only benefit of acupuncture is 'placebo.' Any of the positive research and recommendations that have been allowed to remain appears to have been done so grudgingly, with a negative spin taken at every possible turn.

The bullying and banning of Wikipedia editors is not new and is not restricted to the acupuncture page.

#### Bullying and banning

Now, you may be thinking, 'It's too bad that the article is giving acupuncture such negative and biased press. But, didn't you say that anyone can edit Wikipedia articles? Why don't you just change it?' And therein lies the rub. Ostensibly, Wikipedia is the 'free encyclopedia that anyone can edit,' but in practice things are a bit more complicated. Last month I joined Wikipedia as an editor to find out just how easy it is to bring the acupuncture in line with the published evidence. Shortly after joining in with the discussion and presenting respectful and referenced arguments as to why acupuncture should not be classed as pseudoscience, I was indefinitely banned from editing Wikipedia. I would later find out that I was the most recent in a (very) long line of editors who were bullied and then banned for disagreeing with the established Wiki-'consensus' that acupuncture is 'pre-scientific gobbledygook.'

The bullying and banning of Wikipedia editors is not new and is not restricted to the acupuncture page. After writing about my (brief) experience as a Wikipedia editor on my blog, I was contacted by Rome Viharo, creator of a website called *Wikipedia*, *We Have a Problem* (coincidentally, the title of my blog post), who has been documenting skeptic bullying on Wikipedia for years. Writing of his experience:

My first two studies on platform abuse focused specifically on a group of Wikipedia editors who edit through the Fringe Noticeboards on Wikipedia. Many of them focus specifically on articles of a 'skeptic' interest and edit to the voice of the 'skeptical points of view'. Many of them are self disclosed skeptics, but their behaviors and attitudes reminded more of 'privileged white male anger', with bullying, personal attacks on character, incredible circular logic, and mob type mindset. Discovering that they govern a wide section of articles including integrative and alternative medicines informed me of the drastic impact that bias can hold sway on Wikipedia without much recourse.

But how do a bunch of self-styled Skeptics 'govern' articles? Noting that many of the administrators and editors that I came up against have been involved with Wikipedia editing for many years, some over a decade (which is remarkable when you consider that Wikipedia has not even celebrated its sixteenth birthday), my suspicion is that as early adopters they were able to gain legitimacy to be 'admins' by default. In addition to their longevity, the Skeptic editors' position is aided by support from Jimmy 'Jimbo' Wales, co-founder of Wikipedia. In 2014, the Association for Comprehensive Energy Psychology launched a petition in response to the censorship, bullying and banning of dissenting editors on Wikipedia. Here is Jimmy's response:

Every single person who signed this petition needs to go back to check their premises and think harder about what it means to be honest, factual, truthful.

Wikipedia's policies around this kind of thing are spot-on and correct. If you can get your work published in respectable scientific journals - that is to say, if you can produce evidence through replicable scientific experiments, then Wikipedia will cover it appropriately.

What we won't do is pretend that the work of lunatic charlatans is the equivalent of "true scientific discourse". It isn't. (Wales, 2014)

A look at the Skeptic Fringe Theories Noticeboard confirms that acupuncturists, too, are considered to be 'lunatic charlatans.'

#### Acupuncture? Fringe?

While I suspected that the Wiki-Skeptics would not be open to true scientific discourse, the only point I attempted to argue in the Acupuncture page discussion forum (before getting promptly banned) was that as Fringe theories do not enjoy mainstream scientific or medical support, but acupuncture does, acupuncture does not qualify as a Fringe theory. To support this point, I made reference to a dozen mainstream medical guidelines from highly respected medical institutions located in Canada, the US, the UK, Scotland, Australia and New Zealand. Medical guidelines are considered by Wikipedia to be high-quality medical references. At the very least, these sources demonstrated ongoing controversy necessitating changing of the article's wording. These sources were shot down by the Skeptic admins in favour of two sources that describe acupuncture as 'pseudoscience': the first is an introductory undergraduate textbook for non-science majors (Baran et al., 2014). The second is a primer on science in education (Good, 2011). Neither of these sources is peer-reviewed, referenced or bills itself as a representation of scientific or medical consensus. Amusingly, one of the most vocal Skeptic admins had this to say about the medical guidelines recommending acupuncture: 'These are irrelevant. All (most especially the WHO) are the result of True Believers advocating within the bodies concerned.' A conspiracy theory from a Skeptic? Oh, the irony.

### Key evidence for your arsenal

In my experience, Skeptics do not update their beliefs based on new evidence. However, given the reach of Wikipedia, it is helpful to be aware of key acupuncture research papers in order to provide balance when speaking with those who may be influenced by the article.

#### Systematic reviews and meta-analyses

The evidence from large-scale reviews falls roughly into two categories – sham-controlled research and real-world pragmatic studies that compare acupuncture to usual care:

- In 2012, The Acupuncture Trialists Collaboration published a meta-analysis on acupuncture for pain, which included nearly 18,000 patients (Vickers et al., 2012). This review found that acupuncture was more effective than sham and much more effective than usual care. A follow-up study due to be published in the journal *Pain* has found that these positive effects were sustained at 12-month follow up (MacPherson et al., 2016).
- The Cochrane Collaboration publishes high quality, independent systematic reviews and is considered to be a source of strong evidence. In 2016, it published updates to both the tension-type headache (Linde et al., 2016a) and migraine (Linde et al., 2016b) reviews, which found that acupuncture was more effective than sham and much more effective than usual care.
- In 2014, The American Veterans Association created an Evidence Map of Acupuncture that included 183 systematic reviews of acupuncture for all clinical conditions. It found evidence of a positive effect for headache, chronic pain and migraine, as well as a potential positive effect for a further 20 conditions (Hempel et al., 2014). Since publication, this review has now been updated by the Australian Acupuncture and Chinese Medicine Association (AACMA), which includes more than 100 additional systematic reviews published in the intervening three-year period, and has found further evidence of a positive or potential

positive effect for many additional conditions. This review is due to be published shortly.

# Skeptics do not update their beliefs based on new evidence ...

#### Recommendations

To make the case that acupuncture is recommended far and wide by respected, mainstream medical guidelines, I presented the following list of recommendations:<sup>1</sup>

- The Joint Commission, which accredits more than 21,000 hospitals, health care organisations and programmes in the United States and globally recommends acupuncture as a first-line treatment in the management of pain
- The Agency for Healthcare Research and Quality (AHRQ) guideline on non-invasive treatments for low back pain found acupuncture to be amongst the most effective treatments
- The Joint Clinical Practice Guideline from the American College of Physicians and the American Pain Society on the Diagnosis and Treatment of Low Back Pain recommends acupuncture
- The American Academy of Family Physicians recommends acupuncture for a variety of pain conditions
- The American college of occupational and environmental medicine's practice guidelines recommend acupuncture
- The U.S. Department of Health and Human Services
  National Institutes of Health Guidance on Low Back Pain recommend acupuncture
- The State of Colorado Division of Workers' Compensation Medical Treatment Guidelines for Low Back Pain recommends acupuncture
- The Institute for Health Economics Evidence-Informed Primary Care Management of Low Back Pain Alberta, Canada recommend a course of acupuncture for chronic low back pain
- Scotland's National Clinical Guideline for the Management of chronic pain recommends acupuncture for low back pain and osteoarthritis, characterising the strength of the evidence as Grade A (the highest support available)
- The National Institute for Health and Care Excellence (NICE) recommends a course of acupuncture for the prevention of migraines and tension-type headaches. In fact, acupuncture is the only treatment recommended for the prevention of tension-type headaches

- The 4th Edition of *Acute Pain Management: Scientific Evidence,* Produced by the Australian and New Zealand College of Anaesthetists and Faculty of Pain Medicine, found Level I evidence for acupuncture for five different clinical indications
- The World Health Organisation has developed a list of 27 conditions for which it recommends acupuncture after its evidence review

[Weblinks for these recommendations can be found at http://www.abetterwaytohealth.com/wikipedia-we-have-aproblem/]

Subsequently, it was brought to my attention that Stephen Birch has been conducting ongoing research into recommendations of acupuncture in guidelines:

[B]y November 2015 we had found over 870 recommendations for over 100 conditions from multiple international groups and over 30 countries. The following are examples of the extent of these recommendations. The National German Gynaecologic Oncology Association...recently recommended acupuncture for twelve problems in breast cancer. The Ministry of Health of Rwanda recommended acupuncture for 8 problems. The US Department of Veterans Affairs and Department of Defense have recommended acupuncture for 9 different problems.

Stephen is due to publish an update to this search that will include more than twice as many recommendations (Birch et al., 2016).

#### Ways to get involved

- Sign and share the petition to Jimbo Wales asking him to enforce Wikipedia's policies, which would allow a significant rewrite of the acupuncture page: https:// www.change.org/p/jimmy-wales-clean-up-thewikipedia-acupuncture-page-to-reflect-medical-andscientific-consensus?source\_location=minibar
- 2) Contact me if you have any media contacts that would allow the Acupuncture Now Foundation (ANF) to spread the word about acupuncture's evidence base and mechanisms of action, and how it is being used by top institutions globally.
- 3) Consider donating to the ANF's film project Getting to the Point. We have teamed up with Doug Dearth, creator of the award-winning documentary 9,000 *Needles*, which chronicled his brother's treatment with acupuncture in a Chinese hospital after suffering a stroke. The film will showcase some impressive clinical uses of acupuncture as well as its scientific basis, paving the way for greater mainstream acceptance.

#### In closing

It can seem frustrating that such ignorant and ill-informed people as the Skeptic Wikipedia admins are in a position to mis-educate the public on this effective and safe treatment modality. That said, this challenge is having the effect of stimulating professional acupuncturists to organise our thoughts and message and to coordinate and collaborate so that we can better inform and serve the public. For that I am grateful.

**Mel Hopper Koppelman** is a British-American acupuncturist, functional medicine practitioner and blogger. She holds two healthcare-focused MScs and is Vice President of the Acupuncture Now Foundation, an international charity focused on elevating acupuncture through education to help it reach its full potential in easing and preventing human suffering. She can be reached at mel@ abetterwaytohealth.com.

#### References

- Baran, G. R., Kiani, M. F., & Samuel, S. P. (2014). Healthcare and Biomedical Technology in the 21st Century. Springer: New York.
- Birch, S., Alraek, T., & Lee, M. S. (2016). "Challenges for clinical practice guidelines in traditional medicines: The example of acupuncture," *European Journal of Integrative Medicine*, 8(4)
- Good, R. (2011). "Why the Study of Pseudoscience Should Be Included in Nature of Science Studies." In Khine, M. S. (Ed.), Advances in Nature of Science Research (pp. 97–106), Springer: New York
- Hempel, S., Taylor, S. L., Solloway, M. R., et al. (2014). "Evidence Map of Acupuncture." Available at <http://www.hsrd.research. va.gov/publications/esp/ acupuncture.pdf>[Accessed: 18 January 2017]
- Hesse, B. W., Moser, R. P., & Rutten, L. J. (2010). "Surveys of physicians and electronic

health information," *New England Journal of Medicine*, 362(9), 859–860.

- Laurent, M. R., & Vickers, T. J. (2009). "Seeking health information online: does Wikipedia matter?" Journal of the American Medical Informatics Association : JAMIA, 16(4), 471–479.
- Linde, K., Allais, G., Brinkhaus, B., et al. (2016a). "Acupuncture for the prevention of tensiontype headache." *Cochrane Database of Systematic Reviews*, Issue 4, Art. No.: CD007587, DOI: 10.1002 / 14651858. CD007587.pub2
- Linde, K., Allais, G., Brinkhaus, B., et al. (2016b). Acupuncture for the prevention of episodic migraine. Cochrane Database of Systematic Reviews, Issue 6, Art. No.:CD001218. DOI: 10.1002/14651858.CD001218. pub3.
- MacPherson, H., Vertosick, E. A., Foster, N. E., et al. (2016). "The persistence of the effects of acupuncture after a course of treatment."

Pain, 1–22, DOI: 10.1097/j. pain.0000000000000747

- Null, G., Dean, C., Feldman, M., et al. (2005). "Death by Medicine." *Journal of Orthomolecular Medicine*, 20(1), 21–34.
- Park, E., Masupe, T., Joseph, J., et al. (2016). "Information needs of Botswana health care workers and perceptions of Wikipedia." *International Journal of Medical Informatics*, 95, 8–16.
- Vickers, A. J., Cronin, A. M., Maschino, A. C., et al. (2012). "Acupuncture for Chronic Pain." Archives of Internal Medicine, 172(19), 1444.
- Wales, J. (2014). "Jimmy Wales' Response," Change.org petition.Availableat:<http:// www.change.org/p/jimmywales-founder-of-wikipediacreate-and-enforce-newpolicies-that-allow-for-truescientific-discourse-aboutholistic-approaches-tohealing/responses/11054> [Accessed: 18 January 2017]