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WikiProject Medicine: Creating Credibility in Consumer Health

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Introduction

Wikipedia needs little introduction. But after 15 years of operation and growth, it still finds itself appearing to need a great deal of justification. Wikipedia, the crowd-sourced, communally written encyclopedia of all things, has been a giant of the Internet from soon after its inception. For some years, it has been one of the most heavily trafficked websites in existence, with hundreds of millions of monthly visitors avidly reading millions of encyclopedic articles in hundreds of languages (1).

Among thousands of articles on Pokemon, the roster of Chelsea Football Club, different varieties of coffee pots, historical figures both incredibly well known and almost completely obscure, Wikipedia includes a huge number of articles on medical topics. This popular content dwarfs most, if not the entire standard, understood to be credible, and held-to-be-authoritative sources of health information. In 2013, Wikipedia’s medical content was viewed more than 6 billion times. This was not only a greater number of page views than the NIH website, but a figure outstripping WebMD, the Mayo Clinic, and the World Health Organization websites combined. See Figure 1 for the single most used website for health information (2).

Wikipedia’s audiences

It may be unsurprising that because of its comprehensive scope and immense reach, Wikipedia has become one of the most significant sources of health information for multiple audiences; however, medical librarians may be surprised to discover that physicians, pharmacists, and other health professionals are amongst its users, along with medical and nursing students. A small, survey-based 2009 study revealed that 70% of junior doctors used Wikipedia as a resource, citing its convenience and access to information that was considered to be better and more up-to-date that what might be available in handbooks and textbooks (3). Surveys on social media use by clinicians have shown...
consistently high use of Wikipedia as a reference and study tool by medical students, early-career physicians, and pharmacists (4,5).

High school teachers, information literacy specialists, and librarians of almost all stripes have been discussing and evaluating the quality of information on Wikipedia since the dawn of Web 2.0. There’s a considerable corpus of research literature, blog postings, and listserv debates relating to the objective quality of content, the ethics of authoritativeness, and the reliability of the resource. To a large extent though, the debate over Wikipedia’s overall authority has been settled, with naysayers in retreat since 2005, when Nature pointed out that the website’s error rate was comparable to the Encyclopedia Britannica’s (6).

**Wikipedia is more important than you thought**

Wikipedia casts a long shadow over the information landscape. It is one of the largest, most trafficked websites in existence, attracting a lay and professional audience, which includes physicians that are as likely to consult Wikipedia as Up-to-Date. It is hardly worth pointing out that special circumstances apply when discussing medical reference and consumer health resources. Professional collections and public libraries alike have a tremendous obligation to ensure that their collections reflect the best available knowledge of STEM disciplines (7). This being the case, librarians’ caution over Wikipedia is not entirely unreasonable; unlike many other areas of the field, it could indeed be a matter of life and death. However, it’s not tenable to hand-wave away Wikipedia’s significant influence in access to medical reference and consumer health, and experience has shown that librarians are ill-advised to try ignoring *satisficient* resources is a recipe for marginalization.
Wikipedia is more reliable than you might have expected

Although the traditional image of Wikipedia is of a sort of informational anarchy, where credentials and experience have little sway, and vandals and e-demagogues run unchecked, it is in fact now considerably less of a free-for-all than it was in its initial vision. Since 2005, the administrators of the site have authorized a variety of policies to address some of the more Wild West aspects of being an editor. Particularly on controversial or newsworthy topics, it’s not always possible for a novice user or an anonymous vandal or troll to edit an article at all. These protections are typically instituted at the request of users in response to non-constructive activity on a page.

In the context of the entire encyclopedia, medical topics have never been the most subject to spur-of-the-moment, poorly sourced revisions. That dubious honor goes to almost any article related to WWE wrestling and a current snapshot of pages in protected status certainly shows some anatomical topics, but nothing that can clearly be defined as a medical topic.

An in-depth analysis of controversial topics on Wikipedia, published in ArXiv, lists circumcision as the only medically-related article among a list that is predominantly of race, religion, and political topics. In this paper, controversy was defined as the number of ‘reversions’ in an article over time, that is, the number of time editors completely removed content made by another (8). Other studies have shown that most malicious or misleading edits to articles tend to be identified and removed very swiftly, by either human editors or 'bots' created to automatically review recent edits and identify vandalism (9). In short, readers are unlikely to find a plausible and persistent claim that the Zodiac Killer was a Texan senator, or that Abraham Lincoln was a vampire hunter.

As a community, Wikipedians are pedantic in the extreme and prone to sometimes absurdist interpretations of the various principles of the site, particularly around sourcing of information. In one dramatic example, the American novelist Philip Roth was outraged that his word regarding the inspiration for one of his novels was held to be insufficient evidence to correct the article about it, since it fell under the long-standing “No Original Research” rule, which prohibits claims that are not found in secondary sources (10).

Wikipedia project medicine: A community of experts

Wikipedia is a community of experts as well as enthusiasts, and with the emerging realization that the site was becoming increasingly significant for the delivery of health and medical information, a consensus began to grow that improving the quality of that information in a systematic manner was important. A community of editors came together in 2004 to propose
WikiProject Medicine (WPM), an initiative to identify the most important biomedical articles on the site, evaluate them for accuracy and timeliness, and improve them as necessary. Over the next few years, Project members created a style guide, promulgated guidance on standards for article outlines and the selection of references, and established back-end coding to convert PMID codes into external links (11).

As of June 2016 there were more than 600 members of the Project, although most were considered to be inactive, having made no edits within the scope of the project in the past 6 months or more. The project also includes task forces on Emergency Medicine, Cardiology, Nephrology, Pulmonology, and Pathology. Project participants have included physicians in many fields, such as emergency medical technicians, nurses, bench scientists, informationists, and more. Of the three hundred ‘core’ members in 2014, 85% were college educated and about 50% were currently or studying to be health care professionals.

To support the work of the Project, the Wiki Project Med Foundation was established in 2012 and has developed partnerships with a number of international health promotion institutions including the World Health Organization, NLM/NIH, Cancer Research UK and others. These relationships have led to the establishment of “Wikipedians in Residence” (WiR) at Cochrane, the Wellcome Institute, and NLM.

The WiR programs seek to leverage the content and expertise of the host institution to improve related content on Wikipedia through integration of unique resources, to research how consumers use the information provided by the host, and to train host institution staff members and the public in the use of Wikipedia. WiRs engage with the public and professional audiences through such events as “edit-a-thons,” where groups are trained in the fundamentals of wiki editing and style, and then work together to improve a specified group of pages within a particular topic, based on the expertise of the group or the focus of the institution.

Wikipedia’s GLAM community (Galleries, Libraries, Archives, and Museums) led the way in establishing this type of community-based, low cost, high impact event through partnerships with special collections and other cultural content institutions to digitize and distribute locally held content with the goal of improving the encyclopedia. A 2013 edit-a-thon at the National Library of Medicine was introduced by NCBI Director, David Lippman, MD, with the following remarks:

Wikipedia really is a miracle...I go to Wikipedia, and I find something useful. At the very least, it’s always the beginning of finding useful information (12).

After a decade of patient work, Dr. Lippman’s remarkable statement is a testimony to the reach and impact of this unique encyclopedia. That a representative of an organization whose commitment to evidence-based
science, data, and documented scholarship would vouch for this site suggests that there are yet-unrealized opportunities for medical librarians and professionals to create valuable new services through this platform.

**Accomplishments of the Wikiproject medicine**

The current goals of the WPM are to improve the quality of a selected list of biomedical articles, to have 80 articles promoted to ‘featured’ status. Featured articles are less than 0.1% of the total number of articles in existence articles and considered to be the very best on the site after being evaluated according to stringent criteria. WPM also plans to have 300 articles promoted to ‘good’ status. As of June 2016, editors had achieved 60% of the goal to improve the quality of the selected list of biomedical articles and 80% of the goals to increase featured and good articles (13).

The list of articles that have been given featured status includes Alzheimer Disease, Parkinson’s, Multiple Sclerosis, and Dengue suggesting that some of the most significant medical issues are discussed in articles that are considered to be amongst the best written, comprehensive, and well-sourced articles within the encyclopedia. The directed and organized efforts of a community of topic experts were largely responsible for that.

As of June 2016, the Wikipedia article on Dengue fever included 74 citations with 3 from 2016, from *Lancet Infectious Diseases*, the World Health Organization, and *Scientific American*. Other citations were from Cochrane, the *New England Journal of Medicine*, and *Nature*. As further evidence of its quality, the article on Dengue was formatted for publication in the now-defunct peer-reviewed journal *Open Medicine* and published in 2014 as *Dengue Fever, a Wikipedia Clinical Review* (13).

WPM has also been adopted into the curriculum of some medical schools, as part of new media based initiatives to improve medical students’ ability in communicating information to non-peer or consumer audiences, or to provide a practical experience in selecting and verifying evidence-based resources. In a collaborative initiative with the WPM, fourth-year medical students at University of California San Francisco have been able to take an elective class on editing Wikipedia, in which they select an article from WPM’s list of most important articles, verify, improve, and update the content with the goal of gaining ‘good article’ or better status (14). A secondary goal is to improve the accessibility and ease-of-reading of articles, which is a useful practicum on avoiding jargon and learning how to communicate with consumers.

Other researchers have appealed for broader inclusion of Wikipedia into the medical school curriculum in order to advance student skills and to improve, in real time, the quality of information to be found on this significant resource (15). Carol Haigh argued that while nurse educators...
should exercise critical discernment in their use of the resource, the overall
general reliability of information found there and the quality of citations used
suggested Wikipedia could have a useful role in teaching concepts about
critical thinking and literature searching (16).

**Disappointments of Wikiproject medicine**

Participation continues to be a challenge for Wikiproject Medicine. As noted
above, the majority of editors who have listed themselves as being part of this
community are not active, and the majority of new content and improvements
are created by a diminishing cadre of power users. This, to some extent, is a
problem that the entire Wikipedia project faces, and has been variously ascribed
to a number of different causes such as perceived intimidation by experienced
authors, high technical hurdles to becoming an editor, and the sense that
Wikipedia is a difficult institutional environment with a counter intuitively
high organizational complexity for such an aggressively open concept (17).

The readability of Wikipedia articles has continued to be unsatisfactory
according to the yardstick of consumer health best practices. This may in some
part be due to the competing priorities of producing the best, most compre-
hensive article possible and having it be accessible to the widest possible
audience. WPM editors are highly informed and highly educated, as noted
above, and active editors have considerable experience and authority.

The article on Parkinson’s Disease can be considered to be the epitome of
what the project seeks to accomplish; to be a vital article of tremendous
interest to a broad community about a devastating disease, which was
improved by the community to the point where it reached the coveted
*featured article* status in 2011, and which receives multiple substantial edits
on a monthly basis. However, according to a recent assessment of the
reading level of this article, a high *narrative complexity* had the potential
to alienate readers and make them refer to substandard, simplified sources.

The reading level of this particular article was calculated to substantially
exceed the NIH’s recommended 7th grade readability level with almost any
assessment tool that was used. A number of other studies have the same
findings both for particular disciplines and for the encyclopedia as a whole.
Nora Hutchinson’s article is fairly representative of this research in its finding
that Wikipedia’s reading level was significantly higher than that of WebMD,
the Mayo Clinic’s website, and a number of other diagnosis-specific sites (19).

Editors have responded to this issue by improving content on Simple English
Wikipedia (https://simple.wikipedia.org/). This site is geared for people with
different needs, such as students, children, adults with learning difficulties, and
people who are trying to learn English., the main site, nor its comprehensiveness.
Also, there is no consistent cross-referencing of main encyclopedia sites with their
corresponding simplified versions.
Conclusion

In part, this issue’s column is as much a piece of advocacy as information. This editor has long believed that Wikipedia is an important research tool for K–12, higher education, and professional audiences as well as a website that increasing audiences and interest groups depend on and increasingly assume to be reliable. Because of its reach and familiarity, and the unique affordances of the platform, there are fascinating pedagogical applications suitable for all manner of students including nursing, medical and dental in initial training and continuing education. It is a bonus that there is an organized community of experts who are committed to the initiative.

Should you join them? This editor would argue yes. Librarians in general, and particularly those in healthcare settings have unique insight into making communication suit a variety of audiences. That is something that clearly needs improvement in Wikipedia’s medical content to have well-practiced skills in navigating the information landscape and selecting high-quality resources.

Wikipedia has long reached out to librarians for various improvement and engagement projects, most recently with #1lib1ref, in which librarians across the English-speaking world were encouraged via Twitter to add one reference to an article of their choice. Health Sciences Librarians are ideal advocates for the Wikiproject Medicine Project because they sit at the hub of the information nexus of their institutions, with engaged relationships with students and professionals of all stripes alike. Also, Health Science Librarians share the Project Mission’s of improving access to high quality medical information.

Imagine a world in which every single person is given free access to the sum of all medical knowledge. That’s what we’re doing (13).

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References


