Developing Oncopedia: Creating and Editing an Online Collaborative Educational Resource for a Global Audience

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This article describes the development and editing of Oncopedia, a source of information on pediatric oncology that combines interactive collaborative e-publication with traditional peer-reviewed models. Oncopedia is a product of the International Outreach Program at St Jude Children's Research Hospital in Memphis, Tennessee. The mission of the International Outreach Program is to improve the survival rates worldwide of children with catastrophic diseases through the transfer of knowledge, technology, and organizational skills.

Oncopedia is part of one of the program's key strategic initiatives, Cure4Kids.org, an online educational resource that provides free and easy access to current clinical information and educational materials to those caring for children with cancer and other catastrophic diseases. At the end of 2008, the Cure4Kids user base included more than 16,000 health-care professionals in 164 countries. Cure4Kids contains more than 1,200 on-demand seminars (with slides and audio), more than 30 international conferences (recorded seminars with conference proceedings in PDF), 20 self-paced online courses (recorded lectures with supporting notes and documents), and a digital library of online textbooks and

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selected journal articles. Since the site's inception in 2002, Cure4Kids users have accessed or downloaded individual content items more than 2.1 million times.

Cure4Kids also hosts a global community whose members routinely use the site for online collaboration. More than 2,000 Cure4Kids users in 200 international groups hold monthly, live meetings using Web conferencing technology provided by Cure4Kids. The same online meeting technology was used by the international team responsible for the design and launch of Oncopedia. Contributors to the initial Oncopedia development effort included Web developers in Memphis and physicians in the United States, Argentina, and Brazil.

Oncopedia Content

The main purpose of Oncopedia, launched in May 2007, is to provide a forum in which registered Cure4Kids users can participate in discussions of critical issues related to pediatric oncology and hematology. It combines the open participatory features of collaborative Web sites like Wikipedia (*www.wikipedia.org*) with the benefits of an international editorial board composed of subject-matter experts. Initially, Oncopedia content consisted of case reports, images, and chapters. In 2008, polls, image challenges, and videos were added as tools for education and interaction.

Members of the Oncopedia editorial board are volunteers with expertise in the diagnosis and treatment of a variety of diseases and conditions, including bone tumors, renal tumors, malignancies of the central nervous system, leukemias, and sickle-cell disease. The board is headed by the Oncopedia editor-in-chief. Oncopedia case-report and image-document submissions are reviewed by this editorial board before they are published on the Web site.

Although Oncopedia is only 2 years old, it has been used extensively. By the end of 2008, Oncopedia contained 38 case reports, 86 image documents, and 14 chapters. From 1 May 2007 through 31 December 2008, 3,331 unique users in 125 countries accessed Oncopedia over 30,000 times (access counts are per case, image, or chapter; page views number many more than 30,000).

Case reports. These documents contain information on complex or unique clinical cases. They may include, in addition to a description of the patient's clinical signs and symptoms, such items as laboratory results, photographs or diagnostic images, and information on treatment and outcomes. A case report may also include a discussion section containing general information pertinent to the particular patient's circumstances. For example, a recent case report on a boy with myeloid sarcoma included a discussion of the incidence of the disease in pediatric and adult populations. Users can add comments in the discussion area provided for each document.

Images. Image documents illustrate typical findings in pediatric oncology, hematology, and infectious diseases. They typically contain two or three photographs or diagnostic images and a brief description of the significance of the images and reference citations for related resources. The visual content in an image document is also provided in a PowerPoint file that can be downloaded and used in presentations, lectures, and other educational activities. To ensure that credit is given to the correct source, each PowerPoint file lists the names of all contributors.

Chapters. Oncopedia chapters serve the same purpose as those in traditionally published books with one critical difference. Chapters on Oncopedia are posted in wiki

style with a text editor available to any user who wishes to edit or add to a chapter. The text-editing tool allows Cure4Kids users, working online, to update chapter content and references, clarify points, or add ideas. After submission, these contributions are verified by volunteer disease experts for each chapter or by the Oncopedia editor-in-chief before they are published online. Users who want to comment on a chapter without making changes to its text may initiate interactive discussions by posting in the chapter's discussion area.

To provide further opportunities for user interaction, Oncopedia introduced two content types, polls and image challenges, in fall 2008. Currently, Oncopedia's editor-in-chief selects the topics for polls and image challenges, and new content is posted monthly. Polls are intended to stimulate discussion of controversial or current issues of interest to the Oncopedia community, such as treatment with particular chemotherapy drugs. Image challenges feature diagnostic or pathology images with short descriptions of the cases related to the images. On the basis of an image and description, users are invited to select the correct diagnosis from a list provided. Another recent addition to Oncopedia is educational videos. They offer further examples of signs or symptoms discussed in the case reports, image documents, and chapters. At the end of 2008, 15 videos were available for viewing on the Web site.

Peer Review

The Oncopedia publication process resembles that of traditional biomedical journals in that peer review is a critical component. During the review process, members of the peer-review committee review a document and submit their comments or concerns to an online discussion board restricted to use by the editor-in-chief and review committee. The editor-in-chief supervises the review process and is responsible for working with the review committee and contributors to develop the content of Oncopedia documents.

The purpose of peer review at Oncopedia is not only to develop sound scientific content but to allow contributors to learn from

Oncopedia homepage

the submission process. Members of the Oncopedia review board are not anonymous and often interact directly with contributors. Instead of rejecting a poorly written or incomplete document, Oncopedia peer reviewers often work with authors to improve their content, sometimes going through several iterations of text to reach a publishable product. After an Oncopedia document has passed peer review, it undergoes copyediting, final layout, and document release—steps that are coordinated by Oncopedia developers.

Challenges

Oncopedia's greatest challenge has been the acquisition of high-quality, user-generated content. By the end of 2008, Oncopedia had received 213 case-report and image-document submissions, of which 140 were published on the Web site; 18 were in review and nine in the final publication stage at the time of writing, and 46 were rejected, making Oncopedia's overall rejection rate 22%.

There is a wide discrepancy between the number of users who have accessed Oncopedia and the number who have submitted content: 3,331 separate users have viewed content on Oncopedia, but only 64 have contributed content. One possible explanation of the low number of submissions might be that most users are international and have little experience in submitting content for publication in English.

Although interactive discussions were intended to be a key feature of Oncopedia, one challenge has been eliciting more such activity. Compared with the number of times that content has been accessed, the number of discussion posts is low. In 2008, there were only 69 discussion posts for case reports, image documents, and chapters. The low incidence of posts is disproportionate to the number of times that discussion posts have been viewed—3,143 views in 2008. The addition of anonymous posting and the introduction of polls and image challenges have helped

Oncopedia continued

to stimulate new discussion posts, and the average number of posts per month has increased from 0–2 to 6–10.

Since their introduction in fall 2008, polls and image challenges have been used by 925 people, and 56 discussion posts related to polls have been submitted. The number of discussion posts to polls and image challenges is nearly equal to the number of discussion posts submitted for case reports, images, and videos combined. One possible explanation of the difference between the number of discussion posts and the number of times that users have viewed these posts is that language is a barrier to spontaneous social interaction in the multinational setting of the Oncopedia community.

Another challenge facing Oncopedia is related to the writing skills of contributors. Submissions from Oncopedia authors require various levels of editorial review and copyediting: Some contributors are experienced scientific writers, others are novices. Clearly and effectively written content is critical for the long-term success of the Web site as an educational resource for an international audience. With that in mind, Oncopedia developers, working with a professional biomedical editor, have produced an Oncopedia style guide. The style guide summarizes some of the best practices of scientific writing that are more fully elaborated in such texts as *Scientific Style and Format: The CSE Manual for Authors, Editors, and Publishers* and AMA *Manual of Style: A Guide for Authors and Editors*. Its focus is on elements of style that improve readability, particularly for those without full command of English.

The style guide also contains detailed information on how to format Oncopedia documents and cite references. Many of the instructions reflect the dynamic status of the online content. For example, each section of an Oncopedia chapter has its own numbered reference list, rather than there being a single numbered list for the entire chapter. Similarly, tables and figures are not numbered consecutively throughout the chapter but instead are labeled by chapter section. Section-by-section numbering of references, tables, and figures makes it easi-

er to update chapters and avoid introducing errors when references are renumbered.

Although a completely electronic submission and development process has many advantages, access issues and technology literacy are major barriers to participation in Oncopedia. Inadequate access of some contributors to Internet connections often results in delays in the publication process. Questions addressed to a contributor may go unanswered for some time, stalling peer review, copyediting, or document development. Technology literacy is another barrier to efficient chapter development, in that many chapter authors and editors prefer to update and compile chapters by using offline tools. That preference may be due in part to shortcomings in the usability of online text editors that can be integrated into Web sites.

Analogous Projects

Although the principles of collaboration and interaction are not new to online resources, Oncopedia fills a need for reliable, peer-reviewed educational information about pediatric oncology and catastrophic diseases. Examples of other Web sites with an educational focus or interactive components are BMJ Case Reports, Nature Network, the Medpedia project, and Wikipedia.

BMJ Case Reports (*casereports.bmj.com*) is a peer-reviewed Web site that publishes case reports in all medical disciplines. Unlike Oncopedia users, users of BMJ Case Reports pay an annual fee. They can submit as many cases as they like, access all published material, and download that material for personal use or teaching without permission.

Nature Network (*www.network.nature. com*) is an online social-networking Web site created by the Nature Publishing Group. Its purpose is to connect scientists worldwide via blogs, forums, and groups. Users can have online discussions and upload their own content to the site.

Medpedia (*www.medpedia.com*) debuted in early 2009. Its purpose is to collect the best information about health, medicine, and the body and make it freely available worldwide. Several leading medical schools

(for example, Harvard and Stanford) have contributed content. Like Oncopedia content, Medpedia content is created and submitted by users; however, only persons with MD or PhD degrees in biomedical fields are allowed to register as editors. The site opened while this article was in press. It remains to be seen whether there will be sustained content submission and use.

Future Directions

Oncopedia's Editorial Board plans to continue to develop new content types to stimulate user interaction on the Web site. The Board is also exploring other initiatives, such as inviting users to submit material for polls or image challenges. The creation of an Ask Oncopedia section in which users can submit questions about current cases to the Oncopedia community for discussion is being considered. And the Editorial Board has been discussing how to provide contributors with documentation of their work that can be submitted to educational institutions as evidence of volunteer work in their fields or included in their CVs.