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A Call to Make Patients Effective Partners in Medical Research

Imogen Evans, Hazel Thornton, Iain Chalmers. Testing Treatments. Better Research for Better Healthcare. London: The British Library, 2006. ISBN 0-7123-4909-X (Paperback). GBP 12.95, EUR approx. 19.00. 116 pages.

This book can be highly recommended to general practitioners and users of healthcare services (all of us!), because it is enlightening about how clinical trials are designed, how their results are analysed and communicated, and how biases in the creation of new medical knowledge can influence treatment decisions, and thus the quality of healthcare. By targeting the book to both healthcare users and healthcare providers, the authors hope to teach both how to tell the difference between biased and trustworthy information, so that they can more confidently judge the reliability of data, research reports, advertisements, and other sources of information.

In clear, sensible prose (a credit to the authors' writing skills and to the adroit copyeditor), the three authors show "how the existing 'drivers' for research—commercial and academic—have not done enough to identify patients' priorities" (p. 96). Their goal is to convince readers that "better testing of treatments in the future should come from productive partnership between researchers and patients" (p. 80). The topics chosen for inclusion, the straightforwardness of the authors' reasoning, and the evidence from medical journals, the lay press, and patient-advocacy groups, make for a convincing read. The information sources are rigourous, and the information itself, some of which involves complex concepts related to research study design and methods, is explained in a way that is not at all condescending, but rather encourages readers to learn more. The authors' successful transfer to a wider audience of information usually intended for specialists in biomedical and pharmaceutical research is a lesson for writers and editors who aspire to publish effective consumer outreach and education materials.

The book starts with an Acknowledgements section, a Foreword and an Introduction, which are followed by eight chapters that identify specific shortcomings in current medical research, explain why these problems make the research less useful than it could be, and suggest ways in which the problems could be overcome. At the back of the book are an up-to-date reference list, a brief list of additional resources (some of which are worth investigating for medical writers, translators and editors), and an index.

Chapter 1 explains why "too much medical decision-making is based on poor evidence" (p. 2)—a claim that might surprise readers who assume that all researchers, medical affairs managers, journal editors, and government agencies know what they're doing. In subsequent chapters the authors explain the basic principles of testing treatments, and tell readers how reliable evidence of treatment effects can be obtained. Chapter 2 lays out the dangers of using treatments that, despite their widespread acceptance by healthcare professionals and patients, are not based on sound evidence. The authors then explain how "fair" (i.e., unbiased) experimental or comparative studies should be designed (Chapter 3), and lift the veil on clinical trials by explaining the ideal methodological characteristics of this "gold standard". The examples of how blinding, double-blinding, and randomization are used to overcome potential sources of bias in study design and interpretation are especially helpful. In Chapter 4, strategies that clinicians, patients and researchers can use to reduce uncertainty in making treatment decisions are described, and consumers are encouraged to participate more actively in treatment decisions. Problems that can compromise the trustworthiness of the results of clinical trials are analysed in Chapters 5 and 6.

Especially instructive is the authors' explanation of how the choice of research topics is influenced by pharmaceutical firms' commercial interests and researchers' need to obtain professional recognition—two powerful socioeconomic factors that can prevent certain health problems from receiving the attention they deserve. The book concludes (Chapter 7) with a strong plea for patients to organize and become more actively involved in setting the medical research agenda. The authors then give us a seven-point "blueprint for a revolution" (Chapter 8), and an action plan for users of healthcare services who wish to become better informed about the quality of care and of the evidence it is based on.

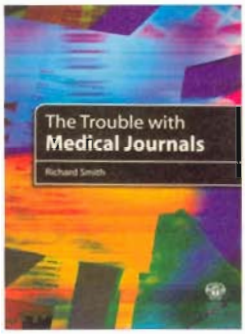
The text itself is highly readable, and the way the book is organized into short chapters is also reader-friendly. The layout was probably chosen on the assumption that reading will be frequently interrupted (as is likely for most general practitioners and other busy people), so readers can come back to the text later without losing the thread. Boxed quotes provide referenced examples and supporting material for readers with a bit more time, and each chapter ends with a short list of key points that summarize the main messages.

To help improve the quality of medical research, the authors advocate active participation by patients and user groups in designing research and evaluating the evidence, and recommend that clinicians and patients improve their ability to critically evaluate research to detect biases and

inaccuracies. In addition to its didactic value as an introduction to biomedical research methods, the book contains both an effective consumer-enabling message and important insights (for clinicians as well as patients) into how research can fail to meet the goal of providing better healthcare. This short, educational book encourages users and providers of healthcare to question assumptions, detect biases, raise questions about the quality of the evidence if they find it unconvincing, and work together to ensure that the right research questions are asked, and the right research is used to find the answers.

Can You Trust What You Read in Medical Journals?

Richard Smith. The Trouble with Medical Journals. London: The Royal Society of Medicine Press, Ltd., 2006. ISBN 1-85315-673-6 (Paperback). GBP 19.95, EUR approx. 29.25. 292 pages.



As editor of the *BMJ* from 1991 to 2004, Smith witnessed many types of misconduct and questionable practice by researchers, reviewers, editors, clinical trial sponsors, and medical journal publishers, and he remains at the forefront of efforts to professionalize medical journal editing. In this book the author describes some of the challenges the *BMJ* faced during his tenure as editor, examines how other journals have dealt with their own challenges, and explains why the trouble with medical journals should matter to everyone. He melds his first-hand experiences with a non-systematic but wide-ranging review of the editology literature pertaining to biomedical journals, and the result is a spicy story of the factors that conspire to make journals less effective, less reliable, and less accountable for their errors than Smith, for all his pungent criticisms, passionately wishes they could be.

The contents are divided into seven sections comprising one to five chapters each, with no illustrations or tables. Section 1 consists of a single chapter titled 'Introduction: medical journals are probably a force for good but need considerable reform'. This statement is supported by evidence presented in the subsequent six sections, 'The nature of medical journals', 'The processes of publishing medical research', 'Problems in publishing medical research', 'Important relationships of medical journals', 'Ethical accountability of researchers and journals', and 'The future'. A total of 418 references are cited; it would have been helpful to place them at the end of each chapter rather than list them all at the end of the book, where they are harder to check as one reads (especially as no headings were used to identify which chapter the references belong to). The index at the back of the book is helpful but not as thorough as it might have been given the very large range of topics mentioned; some cross-references and pages on which entries and subentries are mentioned seem to have been missed. But interested readers will nonetheless find much to make the book worth reading cover to cover.

Smith gives us the human side of journal editing, and emphasizes that problems with journals are unavoidable because many of the decisions that reviewers and editors make are based as much on judgement and opinion as on fact. Sources of pressure and conflicts of interest that can bias decisions about what to publish are also identified and discussed with reference to cases in the *BMJ* and elsewhere. The mixture of case histories of editorial mishaps and Smith's analysis of their implications for the trustworthiness of journals makes the book a valuable educational resource for editors and reviewers, and a gold mine of data for journalologists.

The author is careful to point out that the *BMJ* and *The Lancet* (mentioned several times for purposes of comparison) are not typical medical journals, because their editors were (or are, in the case of Richard Horton, Editor-in-Chief of *The Lancet*) unafraid to publish provocative articles, try innovative editorial policies, and embroil their journals in controversy. These journals are well-off financially and highly respected, and so can afford to be bolder than most others, whose editors may consider discretion, rather than risk-taking, as the better part of valour. Both of the UK's top general medical journals have enjoyed huge successes and survived painful mistakes, but as Smith has declared more than once with regard to the journal he edited, "the BMJ is not in the truth business but the debate business" (p. 30).

A couple of chapters are not directly relevant to Smith's analysis of the trouble with medical journals, and the writing is, in a few places, so impetuous that passion has overridden clarity. The rather critical review of the book that was published in the *BMJ* [1] took issue with Smith's views on specific issues, while overlooking the book's timeliness and usefulness. Smith is indeed opinionated, but is nonetheless one of the world's experts in peer review and good professional practice for editors. Even if your job does not involve gatekeeping responsibilities, his analysis and opinions are worth reading as a record of how well medical journals are performing now that the media, the public, and regulatory institutions have become aware of the abuses that can undermine their reliability as sources of information.

So, can you trust what you read in medical journals? The author would answer, "Sometimes, but not always". Journals document advances in basic and clinical research, and perform the necessary roles of screening information, improving how the research is reported, and disseminating the results. As filters, journals are not one hundred percent accurate at distinguishing between good and bad research; as a manuscript review and editing service, peer review is

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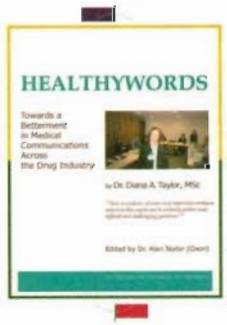
only partly effective in improving how accurately and transparently the research is reported; as information transfer tools, journals are not always published in ways that facilitate access to the information in resource-challenged settings. To make journals more useful sources of information, editors and reviewers need more support in learning how to make their journals better. Smith's book helps by educating gatekeepers, researchers, health care users, and ethics experts alike about the limitations of medical journals. In showing which processes are most vulnerable to abuse or incompetence, the author has done all users of medical journals a huge favour by suggesting how to avoid many of the pitfalls that arise from the human efforts needed to publish them.

References:

1. Derbyshire SWG. Medical journals: past their sell by date? BMJ 2007; 334 (6 January): 45

Medical Writing for Managers

Diana A. Taylor. Healthywords. Towards a Betterment in Medical Communications Across the Drug Industry. An Operational Handbook for Managers. Alan Taylor, ed. Marburg: Tectum, 2006. ISBN 3-8288-9083-0 (Paperback). EUR 24.90. 187 pages.



Taylor has made a career of advising medical information and medical affairs (MI/MA) managers on how to develop their staff's collaborative writing skills and use them effectively to support pharmaceutical firms' goals. In this book the author has set herself the ambitious task of using research in text readability and her knowledge of current European regulations aimed at protecting patients' rights to explain why MI/MA managers need to develop medical writing teams that function as a "knowledge-creating community" within the company.

Healthywords goes part of the way toward explaining the processes road-mapped in book's Summary and Outlook section:

- How data becomes information, becomes knowledge
- How issues of literacy have a bearing on the writing of texts by corporate scientists
- How these texts are to be fully understood and acted upon by their assumed audiences/readers
- How the same corporate scientists are to be trained as collaborative corporate rhetors
- How the company is itself constructed as a text to be 'read' in the competitive market.

To explicate how these different processes can be optimized, the author has combined research on text usability, commentary on postmodern research in text analysis, and discussions of the medical writers' place within their corporate culture. The mixture of scholarly and applied information, and the frequent switches between knowledge-oriented and practice-oriented content, make *Healthywords* somewhat less effective as a handbook (which should provide specific guidance for decision-making and problem-solving) than it could be for managers. Readers must work hard to find the author's useful advice about writing better documents that will satisfy patients' needs and comply with current regulatory requirements.

The book is nicely printed and attractively laid out, apart from some gaps of white space after a few sections and tables. The Acknowledgements, Preface and General Introduction lead into four chapters that deal with working practices within the pharmaceutical industry, rhetorical considerations in the field of medical communication, collaborative environments in medical communication, and the role of pharmaceutical industry managers' training, education, and social responsibility. The chapters and their sections are clearly sign-posted, and the book concludes with a Reference section and a Bibliography for those interested in further reading. The typesetting reflects a sometimes odd combination of English and non-English conventions, but most readers would probably not be too distracted by this.

Busy managers in highly competitive pharmaceutical and communications industry environments could benefit from the knowledge and insights compiled in this book—but their information retrieval task would be made much easier by a careful revision and restructuring of the text to highlight the elements of practical guidance. Perhaps a second, revised edition will allow Taylor's valuable contributions to shine through the rest of the intriguing but less useful content on postmodern rhetorical analysis.

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Call for contributions

TWS welcomes articles (800-2800 words) or boxes (up to 800 words) on topics of interest to medical writers, particularly on the future themes: 'perception vs proof' (where there is no evidence to support what is rightly or wrongly accepted as fact) and titles (article titles or academic titles). Ideas for future themes are very much appreciated as are letters commenting on anything you have read in *TWS* or would like to say to or about EMWA. Please submit to Elise at langdoe@baxter.com.