Unique, multilingual resource on testing health-care treatments

Clinical trial results are often reported in the media, but few people – apart from scientists – understand how the results are obtained and interpreted. The James Lind Library aims to change that by providing clear, accessible information in several languages. Kathryn Senior investigates.

More than 50 000 unnecessary cot deaths in Australia, Europe and the United States of America (USA) occurred over a 25-year period from the mid-1970s because Dr Benjamin Spock, the American child health guru of the 1950s, told parents to put babies to sleep on their fronts. There was no evidence that this was beneficial and research in New Zealand and elsewhere went on to show that this was one of the main causes of cot death. When campaigns advised parents to put babies to sleep on their backs or sides, cot deaths dropped dramatically.

This is a perfect example of how unnecessary loss of life can result from ignoring the need for fair tests. A primary goal of the web-based James Lind Library is to explain why it is important to base decisions about health care on a firm foundation of sound experimental evidence, based on fair tests. The library aims to improve our understanding of the basic concepts used in the design and analysis of research that assesses the effects of health-care practices. The library includes documents from researchers all over the world to illustrate how these important ideas have evolved and to show that some writers who lived centuries ago understood the concept of fair tests better than many people today.

“The bulk of the information is in the form of essays in seven languages. A 100-page book, entitled Testing treatments, is also downloadable free in Arabic, Chinese, English and Spanish,” explains Sir Iain Chalmers, the editor of the online library. “The James Lind Library presents some of the most compelling examples of the importance of fair evaluations of health-care interventions with great clarity,” notes Luis Gabriel Cuervo, senior advisor for research promotion and development at the Pan American Health Organization/World Health Organization (PAHO/WHO).

The essays provide examples of the harm that has been done by failing to apply the principle of fair tests. For example, in one essay David Grimes describes the problems caused by diethylstilbestrol (DES). On the recommendation of two Boston experts in the 1940s, this drug was widely used in the belief that it reduced miscarriages and later fetal death. Although a placebo-controlled trial in 1953 failed to show that DES had any beneficial effects, this was ignored. Even in the mid-1970s, by which time over 200 cases of vaginal cancer in women born to mothers who had taken DES were reported, doctors in the USA and elsewhere continued to prescribe it until its use in pregnant women was finally banned by the US regulatory body, the Food and Drug Administration.

Cuervo regards the well-chosen examples available through the James Lind Library as highly relevant in most settings and invaluable for their historical perspective. “Luis Gabriel Cuervo first proposed that we translate these texts and took responsibility for the French, Portuguese and Spanish versions,” adds Chalmers. Chinese and Russian texts were commissioned by the translation department of WHO; and Najeeb Al-Shorbaji, director of the department of Knowledge Management and Sharing at WHO, arranged for Arabic translations while he was working at WHO’s Office for the Eastern Mediterranean (EMRO) in Cairo.

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This material is being used widely for education and has become extremely popular: the text of the 100-page Testing treatments, for example, has been downloaded nearly 100 000 times since it became freely available just over a year ago. “The library brings evidence to the masses in languages and formats that people understand,” says Al-Shorbaji of WHO. “We have taken formal steps to designate the James Lind Library as a WHO Collaborating Centre. We hope that through this collaboration we will be able to work with more countries to translate the essays into more languages as part of our multilingualism programme.”

Another, more academic goal of the online library is to illustrate the evolution of scientific thinking about how treatments are tested. “People could be forgiven for thinking that the clinical trial was devised by the Medical
Identifying relevant material in Arabic, Chinese, Japanese and Sanskrit documents presents a particular challenge. “These languages present a double layer of inaccessibility; we know what to look for but cannot read them; academics familiar with the scripts are able to read them but don’t know what we’re looking for,” he says. One of Chalmers’s initiatives was to seek help in addressing this challenge from a small group of scholars of Islamic science. “I asked these experienced academics to identify passages relevant to scientific medical thinking by looking afresh at familiar medieval documents with this specific purpose in mind,” says Chalmers. “So far, this has identified four such passages, and these have now been added to the James Lind Library, with accompanying commentaries,” he adds.

Adel M Shokr, Health Education Department, Riyadh, Saudi Arabia, considers the James Lind Library to be “extremely important” and he would like to see further initiatives to identify and translate relevant passages currently available only in Arabic. Shokr believes that EMRO should take a more proactive role. Nagi Homesh from Sana’a University, Yemen, agrees and draws attention to the growing interest also in translating key studies into Arabic. “The WHO office in Cairo [EMRO] is very involved in this,” he says.

The James Lind Library has achieved much since its launch in 2003, on the 250th anniversary of the publication of James Lind’s *Treatise of the scurvy*. The quality of information on the site and its presentation belies the fact that the library currently runs without any formal funding. Most of the original material on the site comes from the Sibbald Library at the Royal College of Physicians in Edinburgh, Scotland, and work on these documents and other information in the online library is done by volunteers. “The James Lind Library has achieved a great deal with very few resources,” says Chalmers, “but it goes without saying that we could do much more with dedicated funding.” Cuervo agrees, stressing that the library produces information of the highest quality. “It is important that the library continues to be open access; these resources are a treasure,” he concludes.