

An Exclusive Interview With Creators Of The People's Epidemiology Library

Goal Is Improving Public Understanding To Help Reduce Anxiety About Early Health Findings

The People's Epidemiology Library (PEL), a website devoted to using the history of epidemiology to tell the story of epidemiology for the public, is scheduled to launch officially in August 2011 at the International Epidemiological Association World Congress in Edinburgh Scotland. Its creators, Alfredo Morabia from City University of New York and Columbia University, and Jan Vanderbroucke from the Leiden University Medical Center and the Royal Academy of Arts and Sciences in the Netherlands, recently conducted an essay contest in the epidemiology community to identify an epidemiologist/writer who could prepare six essays explaining in simple straightforward language key concepts of epidemiology. The contest winner was McMaster University's Stephen Walter (see related story in this issue) who will travel to Edinburgh in August to help unveil these essays and participate in the official launch of the PEL at a special symposium to be held in conjunction with the Congress.

Because the vision for the PEL is expected to have a wide appeal across the epidemiology community, we conducted an exclusive interview with Vandenbroucke and Morabia in advance of the upcoming Congress to get a preview of their vision for the PEL and their future plans following its launch in August.

EM: What is the basic idea behind the PEL?

Morabia: We had several ideas in mind. The PEL is an extension of the James Lind Library (JLL) which is all about the history of fair trials or the evaluation of treatments using randomized trials. The JLL needed to expand because there were observational methods that were used to develop evidence during the history of medicine that did not fit the criteria of randomized trials yet were important advances that were called for in light of the circumstances at the time. Thus, the PEL was created to focus on the history of observational methods.

Secondly, we wanted the PEL to be rigorous and academic, that is, we wanted the website to contain both historical documents describing innovative approaches while at the same time including the work of current scholars who could comment on the context of the times and point out the strengths and weaknesses of the historical advances.

Thirdly, we wanted the PEL to be accessible for the public. We are strong believers that history is a good way to explain the roles of epidemiology in our societies. We believe this is so because when a need arises and an advance in public health is made in a specific historical situation, this event is favorable to explaining epidemiology. That is, we can use history to familiarize the public with the role and importance of epidemiology.

EM: Is it not a conflict to want to create a rigorous, academic website while at the same time wanting to make the site accessible to the public?

Morabia: It could be viewed that way. Admittedly, there is a tension. However, epidemiologists trying to reach a wider public try to leave the jargon behind. Because history is a good domain from which to tell stories, we can tell stories, remove jargon, and explain things in an understandable way. I think the tension you point out in our goals is resolvable.

EM: What did you think about the submissions you received for the essay contest?



Morabia: We wanted to be surprised by them and we were. We received five high quality entries. The quality was awesome. We received applications from teachers in different parts of the world who gave evidence of thinking deeply about how to transmit epidemiology theory in a simple, common sense way. We were extremely pleased by the submissions.

And I want to acknowledge the help from The Epidemiology Monitor. We are absolutely convinced that we would not have been able to obtain such a great response in such a short time for a high investment application process without the help of the Epi Monitor. Our success is a reflection of the wide audience of the Epi Monitor.

EM: Thank you for the compliments. What are your goals and hopes for the PEL in its first year after it is officially launched at the Scotland Congress?

Morabia: We have four goals for the first year.

- 1) We want to post the essays on the web by the end of July and be able to upload the final versions in the fall. We are planning to conduct an internal review after the essays are received and then to conduct a review process. We have not yet discussed how this review process will be carried out, but it might be conducted as an open process during which the epidemiology community and others would be invited to comment.
- 2) We want to add ten new commentaries to the PEL.
- 3) We want to create a final version of the website.
- 4) We want to gain more visibility by increasing visitors to the site.

EM: Can epidemiologists who are sympathetic to your vision and mission participate in the PEL?

Vandenbroucke: For the majority of epidemiologists, the principal way of participating will be to use the materials on the PEL for teaching and provide feedback to us. For a minority of epidemiologists, writing commentaries for the PEL will be a viable means of participating in the PEL. And finally, for a handful of colleagues, a seat on the advisory board may be possible to help in the guidance and management of the site.

Morabia: Other ways to get involved are to acknowledge the use of materials from the PEL when they are used in publications or otherwise, and helping us to translate the materials on the site into other languages.

EM: Where does the funding for the PEL come from, and what are your plans for attracting future funding?

Vandenbroucke: For now we are proceeding without full funding. The funding we do have is from our respective institutions which are paying our salaries and permitting us to devote some time to the PEL. We have received a small but very helpful support from the American College of Epidemiology which enables us to hire an assistant from time to time to work on the website material and which will help fund the prize for the essay contest. I have a grant from the Netherlands Royal Academy of Arts and Sciences which also gives some support for the prize and the activities. For the most part, we are unfunded externally and we are hoping to attract funds from the professional associations of epidemiologists.

EM: Do you know of other ventures similar to the PEL that have been successful?

Vandenbroucke: Only the James Lind Library really.



Morabia: We would like to reach out to those who are teaching epidemiology to undergraduates in high schools and colleges. It would be a benefit to interact more with those colleagues.

EM: What do you consider to be the greatest need that epidemiology has in the area of public understanding of epidemiology?

Vandenbroucke: It is very important for the public to understand that the greatest strength of epidemiology is also its greatest weakness. Its greatest strength is that it examines the exposures that people have in real life. It looks at the diseases they develop in the actual communities they live in, not in a lab or in artificial conditions. What epidemiologists study is "true to life".

At the same time, and for the same reason, epidemiologists can usually not completely isolate or separate out the specific exposures of interest from other exposures occurring in real life. This public realization, that epidemiology works like this, that on the one hand it can reach very important conclusions while on the other hand it is always at risk of being challenged, that public understanding would be very important.

I say this because almost all health actions people take are based on medical evidence that is almost always epidemiological evidence. Understanding this would be immensely important. This is the theme in Alfredo's new book which translated into English is "Health—Distinguishing Beliefs From Knowledge"

EM: But what difference would this understanding actually make in what people do or how they act?

Vandenbroucke: It would help people to understand how evidence develops and that it is normal to have a diversity of opinion. It takes time for questions to be resolved. For example, with smoking and cancer, it has taken more than fifty years to reach the current situation where one can go outside of public places and read a sign which says "No Smoking Inside". Disputes about drug treatments are not settled in a few days. Increased public understanding would bring with it increased public patience with the science.

Morabia: Before scientific breakthroughs in understanding occur, people have beliefs about causality which generate anxiety. Take cholera or pellagra. People saw threats everywhere. Epidemiology helped to focus on one. Increased public understanding of epidemiology would reduce artificial threats and make people less anxious. Thus, epidemiology is important for differentiating beliefs from knowledge in everyday life.

EM: Thank you both for answering our questions. We will publish this interview online and make it possible for readers to comment and carry out further discussion if colleagues are interested in doing that. We wonder if readers will agree with you about the value of increasing public understanding of epidemiology and the strengths and weaknesses of its findings. Certainly other epidemiologists such as <u>Geoffrey Kabat</u> who has written a book entitled "Hyping Health Risks" about overblown health hazards shares your concern for reducing needless anxiety and public confusion about which risks to act on and which to ignore. We invite reader comments at www.epimonitor.net