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Vision for a National Patient Library

Statement by Jeffrey C. Lerner, Ph.D., President and CEO, ECRI Institute

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VISION FOR A NATIONAL PATIENT LIBRARY™
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My recommendation to you today is to fund a National Patient Library of evidence-based information on what works best in healthcare. At first blush, the idea may seem a mild, "nice to have" concept. By second blush, perhaps you will see it as I do, as a proposal that will have a significant impact on the use of appropriate techniques and technologies in clinical decision making. The library would be a key driver of the value equation.

"The National Patient Library would not be a simple analogue of the National Library of Medicine....patients and their families would participate in clinical decision making in a markedly different way than they can today."

The National Patient Library (NPL) would not be a simple analogue of the National Library of Medicine (NLM). Rather, the NPL would be a research-driven entity that seeks to use researchable questions from patients and their families to drive the generation of syntheses of the best available data and information on various conditions, with supporting material on how patients can use it with their clinicians to make their care decisions. Thus, it would generate new research and work products built, from the get-go, to represent patients' interests and concerns. Using this information, patients and their families would participate in clinical decision making in a markedly different way than they can today.

"...a trusted resource producing objective systematic reviews and other high-quality evidence to answer key research questions that matter to patients and their caregivers."

The NPL would become the nation's central repository—a trusted resource producing objective systematic reviews and other high-quality evidence to answer key research questions that matter to patients and their caregivers. This enterprise is not the same as "translating" research and evidence-based reviews originally designed to serve professionals, although the NPL would carry out "translations" as well as *de novo* work. The NPL would combine our growing knowledge about the value of pharmaceuticals, medical devices, and clinical procedures with research from behavioral economics and cognitive science on how to make this information understandable and useful to patients. It would become a home for experimenting with newer forms of information technology, such as social networking Web sites and the applications that will shortly involve more extensive use of electronic health records and personal health records. It would step beyond a narrow view of the health services research field to bring to bear the available research from the study of communications and from other social sciences.

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ECRI Institute has been among the pioneers in developing evidence-based information for patients. The case example from our first effort in an NPL vein is particularly instructive. In the early 1990s, ECRI Institute produced a series of technology assessments for professional audiences on high-dose chemotherapy with autologous bone marrow transplant (ABMT) for metastatic breast cancer. There was not a single controlled, let alone randomized, study of this procedure at the time, yet the technology was diffusing rapidly because many parties, including leading oncologists, consumer groups, and the media, were wrongly certain that it was greatly superior to standard chemotherapy. Without randomized controlled studies, a classic meta-analysis could not be performed. Our study constructed a model of a clinical trial and used a series of regression analyses to generate data. Our results showed more harm than benefit. The literature published in 1994 showed an average of 17% of women dying from the procedure, not from their breast cancer.

Most professional parties ignored our findings, and this led us to seek a different route for providing evidence-based information. Together with some leading health advocacy groups that respected evidence-based information—including the National Breast Cancer Coalition, the National Women's Health Network, and the Boston Women's Health Book Collective—we produced a patient reference guide that spoke directly to patients, their families, and their clinicians. It presented the results of our study in language that could be understood by highly motivated readers. It ignored government policies such as those mandating that information be presented at a sixth-grade comprehension level—a reading level that would not permit using words like "chemotherapy."[1] The guide didn't say "don't undergo this therapy," but instead presented the numbers and gave guidance on how a patient could talk with her clinician about whether the therapy was right for her, given that it was not helpful for most patients in comparison to alternatives, and that it was deadly for some.

(1) Lower literacy levels can be addressed through providing visual media.

The point of this story is that we had to go around the existing parties that were gridlocked and appeal directly to patients and their lay and professional caregivers who cared most about what the science said. It wasn't until four years after we published our guide that randomized controlled trials proved our findings correct. But thousands of women had their lives shortened in the interim, and a lot of money was spent providing the therapy. For example, bone marrow transplants cost up to $200,000 more than the better alternative.

In subsequent guides, we have moved the field forward by designing systematic reviews and supporting materials that from the outset are based on the questions that patients and their families pose. An example is our guide for bulimia treatments, available, like the ABMT guide, for free at our Web site at www.bulimiaguide.org. An NPL could produce and help guide the production of "translated" material, like the ABMT guide, and purpose-built consumer information like the bulimia guide.

Although we have made progress demonstrating that good evidence-based information geared to consumers and, in fact, generated by their questions can be useful, there is a long way to go in terms of the scalability of producing patient information and gathering and conducting the research necessary to make an NPL a regular feature of the healthcare system. This listening panel has heard testimony from other groups, such as Consumers Union, which support producing reliable consumer information. The NPL is a specific step in this direction.

"I am arguing for taking this much further, providing much more funding, and constructing a national resource that all patients can trust."

The stimulus money that goes into comparative effectiveness research intended for professionals may have long-standing consequences. It will ruffle feathers. Some of the information will be attacked as biased through an underlying motive simply to control costs by subterfuge. It will be argued that personalized medicine will make comparative effectiveness irrelevant or plain wrong in some instances. The science of technology evaluation must evolve along with understanding how that information is perceived and how to communicate it effectively. The entities doing this must be trusted. Many necessary elements are already in place. The Agency for Healthcare Research and Quality's (AHRQ) Eisenberg Center already provides patient information from the Effective Health Care Program. AHRQ and other agencies have additional reliable consumer-oriented material, and some excellent information is available in the private sector. I am arguing for taking this much further, providing much more funding, and constructing a national resource that all patients can trust. Their clinicians will be able to trust it, too.

"The National Patient Library would put the interests of consumers—the people for whom we have a medical system—at the forefront."

A National Patient Library is intended for use by clinicians as well as patients and their families. It is well understood by clinicians that much of medicine lacks proven science. But clinicians can use what science is available, better weighing its limitations and its strengths, if they can draw on a resource that is not tainted by conflicts of interest or the motivation to sell products or to advance the interests of particular clinical specialties. Clinical choice can be enhanced when it is based on the best available information as a major ingredient in shared decision making. The National Patient Library would put the interests of consumers—the people for whom we have a medical system—at the forefront.

It will be expensive to create a really vibrant NPL, but the effort will drive other changes, such as the creation of a far more robust peer-reviewed literature that is written to address the patient perspective. Currently, this has too little academic credibility and an inadequate reward system and funding. The amounts of money available under the American Recovery and Reinvestment Act could change that, but it would take a bold initiative to achieve this goal. I invite you to examine the existing efforts and to consider in greater depth what might be achieved through a National Patient Library. ■

WE WANT TO HEAR FROM YOU.

For comments or questions about the National Patient Library, please contact ECRI Institute by e-mail at info@ecri.org or call (610) 825-6000.

ABOUT ECRI INSTITUTE

ECRI Institute is an independent nonprofit organization that has been researching the best approaches to improving patient care since 1968. It is designated as an Evidence-based Practice Center by the U.S. Agency for Healthcare Research and Quality (AHRQ) and is assigned to work on projects on behalf of the Centers for Medicare & Medicaid Services (CMS). Its assessments are also used by Medicaid programs and private insurers. ECRI Institute's brand and model laboratory-based evaluations of medical devices and systematic reviews of drug therapies, devices, and clinical procedures are used by thousands of hospitals and health agencies worldwide. ECRI Institute maintains offices in Europe, the Middle East, and Asia. ECRI Institute is a Collaborating Center of the World Health Organization and is listed as a Patient Safety Organization by the U.S. Department of Health and Human Services. Its more than 300 staff members include professionals from a great variety of scientific and clinical disciplines, as well as from the legal profession, healthcare planning, and business.

ECRI INSTITUTE WEB RESOURCES

ECRI Institute Web Site: www.ecri.org

Information for Patients: www.ecri.org/Patients/Pages/default.aspx

Vision for a National Patient Library: www.ecri.org/Patients/References/Pages/ecri_institute's_vision_for_a_national_patient_library.aspx

Patient Reference Guides: www.ecri.org/Patients/References/Pages/default.aspx

Comparative Effectiveness Resource Center: www.ecri.org/ce