

Better Doctors, Better Patients, Better Decisions

Envisioning Health Care 2020

EDITED BY

Gerd Gigerenzer and
J. A. Muir Gray



STRÜNGMANN FORUM REPORTS

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Strüngmann Forum Reports

Julia Lupp, series editor

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Gerd Gigerenzer, J. A. Muir Gray, Günter Ollenschläger,
Lisa M. Schwartz, and Steven Woloshin

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The Ernst Strüngmann Forum

Founded on the tenets of scientific independence and the inquisitive nature of the human mind, the Ernst Strüngmann Forum is dedicated to the continual expansion of knowledge. Through its innovative communication process, the Ernst Strüngmann Forum provides a creative environment within which experts scrutinize high-priority issues from multiple vantage points.

This process begins with the identification of themes. By nature, a theme constitutes a problem area that transcends classic disciplinary boundaries. It is of high-priority interest and requires concentrated, multidisciplinary input to address the issues involved. Proposals are received from leading scientists active in their field and are selected by an independent Scientific Advisory Board. Once approved, a steering committee is convened to refine the scientific parameters of the proposal and select the participants. Approximately one year later, a focal meeting is held to which circa forty experts are invited.

Preliminary discussion on this theme began in 2008, when Gerd Gigerenzer brought the problem of literacy in health care and its impact on the health care system to our attention. In October, 2008, the steering committee—comprised of Gerd Gigerenzer, Muir Gray, Günter Ollenschläger, Lisa Schwartz, and Steven Woloshin—met to identify the key issues for debate and select the participants for the focal meeting, which was held in Frankfurt am Main, Germany, from October 25–30, 2009.

The activities and discourse surrounding a Forum begin well before participants arrive in Frankfurt and conclude with the publication of this volume. Throughout each stage, focused dialog is the means by which issues are examined anew. This often requires relinquishing long-established ideas and overcoming disciplinary idiosyncrasies which might otherwise inhibit joint examination. However, when this is accomplished, a unique synergism results and new insights emerge.

This volume conveys the synergy that arose from a group of diverse experts, each of whom assumed an active role in the process, and is comprised of two types of contributions. The first provides background information on key aspects of the overall theme. These chapters have been extensively reviewed and revised to reflect current understanding. The second (Chapters 8, 12, 13, and 19) summarizes the extensive discussions that transpired. These chapters should not be viewed as consensus documents nor are they proceedings; instead, they transfer the essence of the multifaceted discussions, expose the open questions that remain, and highlight directions for future work.

An endeavor of this kind creates its own unique dynamics and puts demands on everyone who participates. Each invitee contributed not only their time and congenial personality, but a willingness to probe beyond that which is evident, and I wish to extend my sincere gratitude to all. A special word of thanks goes

to the steering committee, the authors of the background papers, the reviewers of the papers, and the moderators of the individual working groups (Johann Steurer, Ingrid Mühlhauser, Hilda Bastian, and Heather Buchan). To draft a report during the Forum and bring it to its final form in the months thereafter is no simple matter, and for their efforts, we are especially grateful to Gerd Antes, Markus Feufel, Talya Miron-Shatz, Norbert Donner-Banzhoff, and Ralph Hertwig. Most importantly, I wish to extend my appreciation to Gerd Gigerenzer, whose tireless efforts throughout the entire process proved to be invaluable.

A communication process of this nature relies on institutional stability and an environment that encourages free thought. The generous support of the Ernst Strüngmann Foundation, established by Dr. Andreas and Dr. Thomas Strüngmann in honor of their father, enables the Ernst Strüngmann Forum to conduct its work in the service of science. In addition, the following valuable partnerships are gratefully acknowledged: the Scientific Advisory Board, which ensures the scientific independence of the Forum; the Deutsche Forschungsgemeinschaft (German Science Foundation), which provided financial support for this theme; and the Frankfurt Institute for Advanced Studies, which shares its vibrant intellectual setting with the Forum.

Long-held views are never easy to put aside. Yet when this is achieved, when the edges of the unknown begin to appear and gaps in knowledge are able to be identified, the act of formulating strategies to fill these becomes a most invigorating exercise. But this is hardly the end, for if people are to achieve health literacy and if current health care systems are to evolve into patient-centered entities, multiple efforts on many levels are needed. It is our hope that this volume will contribute to these efforts.

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Health Literacy:
Is the Patient the Problem?

Launching the Century of the Patient

Gerd Gigerenzer and J. A. Muir Gray

Abstract

Efficient health care requires informed doctors *and* patients. The health care system inherited from the 20th century falls short on both counts. Many doctors and most patients do not understand the available medical evidence. Seven “sins” are identified which have contributed to this lack of knowledge: biased funding; biased reporting in medical journals; biased patient pamphlets; biased reporting in the media; conflicts of interest; defensive medicine; and medical curricula that fail to teach doctors how to comprehend health statistics. These flaws have generated a partially inefficient system that wastes taxpayers’ money on unnecessary or even potentially harmful tests and treatments as well as on medical research that is of limited relevance to the patient. Raising taxes or rationing care is often seen as the only viable alternative to exploding health care costs. Yet there is a third option: by promoting health literacy, better care is possible for less money. The 21st century should become the century of the patient. Governments and health institutions need to change course and provide honest and transparent information to enable better doctors, better patients, and, ultimately, better health care.

Introduction

Patients appear to be the problem in modern high-tech health care: they are uninformed, anxious, noncompliant folk with unhealthy lifestyles. They demand drugs advertised by celebrities on television, insist on unnecessary but expensive computer tomography (CT) and magnetic resonance imaging (MRI) scans, and may eventually turn into plaintiffs. Patients’ lack of health literacy and the resulting costs and harms have received much attention. Consider the following cases.

Almost ten million U.S. women have had unnecessary Pap smears to screen for cervical cancer—unnecessary because, having already undergone complete hysterectomies, these women no longer had a cervix (Sirovich and Welch 2004). Unnecessary Pap tests cause no harm to the patient, but in terms of the

health system, they waste millions of dollars which could have been used elsewhere to better health care.

Every year, one million U.S. children have unnecessary CT scans (Brenner and Hall 2007). An unnecessary CT scan equates to more than a waste of money: an estimated 29,000 cancers result from the approximately 70 million CT scans performed annually in the United States (González et al. 2009); people who have a full-body CT scan can be exposed to radiation levels comparable to some of the atomic-bomb survivors from Hiroshima and Nagasaki (Brenner and Hall 2007). Why don't parents protect their children from unnecessary doses of radiation? They probably would if only they knew. When a random sample of 500 Americans was asked whether they would rather receive one thousand dollars in cash or a free full-body CT, 3 out of 4 wanted the CT (Schwartz et al. 2004).

The uninformed patient is not restricted to the United States. A representative study of 10,228 people from nine European countries revealed that 89% of men and 92% of women overestimated the benefit of PSA and mammography screening tenfold, hundredfold and more, or did not know (Gigerenzer et al. 2007). Why don't people know, or want to know?

Answers that have been proposed range from the perception that patients are not intelligent enough to they just do not want to see numbers, even though most American 12-year-olds already know baseball statistics and their British peers can easily recite the relevant numbers of the Football Association Cup results. Scores of health psychologists and behavioral economists add to the list of suspected cognitive deficits by emphasizing patients' cognitive biases, weakness of will, and wishful thinking. In this view, the problems in health care stem from people who engage in self-harming behavior, focus on short-term gratification rather than long-term harms, suffer from the inability to make forecasts of their emotional states after a treatment, or simply do not want to think but prefer to trust their doctor. The recommended remedies are consequently some form of paternalism that "nudges" the immature patient in the right direction (Thaler and Sunstein 2008). The 20th century has focused the spotlight on the patient who lacks health literacy.

We take a different position. Today's problem is less the patient than the health system we inherited. The patient is only the last element in a chain that actively creates and sustains health illiteracy. In this chapter, we identify seven "sins" of the 20th-century health care system and advocate a change toward a 21st-century system centered around patients—not industries, organizations, or doctors.

Raising taxes or rationing care is often viewed as the only alternative to exploding health care costs. We argue that there is a third option: by promoting health literacy, we can get better care for less money. However, what is ultimately at stake is more than just health and money: an educated citizenry is the lifeblood of a modern democracy. We begin with an example that demonstrates

how difficult it can be for a patient to make sense out of the barrage of misinformation, so as to be able to make an informed decision.

Misinformed Men: John Q. Public and Otto Normalverbraucher

In his early fifties, John Q. Public intends to make an informed decision about whether to participate in prostate cancer screening with PSA tests. He lives in New York and recalls what Rudi Giuliani, former mayor of New York City, said in a 2007 campaign advertisement (Dobbs 2007):

I had prostate cancer, 5, 6 years ago. My chance of surviving prostate cancer—and thank God, I was cured of it—in the United States? Eighty-two percent. My chance of surviving prostate cancer in England? Only 44 percent under socialized medicine.

John concludes that he is lucky to live in New York rather than York. He also recalls that back in the late 1990s, Congress initiated a postal stamp featuring “Prostate Cancer Awareness,” which promoted “annual checkups and tests.” Giuliani and the U.S. Postal Service were obviously of one mind. Yet John looks for further information. He reads that US\$3 billion is spent every year on PSA tests and follow-ups, and that the majority of primary care physicians perform routine PSA testing, even in men over 80 years of age. What finally convinces him is that 95% of male urologists and 78% of primary care physicians 50 years and older report that they have undergone PSA screening themselves (Barry 2009). He believes he has enough information and decides that he will take PSA tests because they save lives and lead to little or no harm. Has John Q. Public made an informed decision?

No, but he will likely never know. For one, he may not realize that he was misled by Rudi Giuliani, who presented high 5-year survival rates as suggestive evidence for lower mortality, when in fact differences in survival rates are *uncorrelated* with differences in mortality rates (Welch et al. 2000). In reality, mortality from prostate cancer is about the same in the United States and the United Kingdom, even though most American men take the PSA test and most British men do not. There are two reasons why high survival rates tell us nothing about lower mortality in the context of screening: Screening results in early detection and thus increases 5-year survival rates by setting the time of diagnosis earlier (*lead-time bias*). In addition, it also increases survival rates by including people with non-progressive cancers, which by definition do not lead to mortality (*overdiagnosis bias*; Gigerenzer et al. 2007). Giuliani is not the only one to have misled the public with survival rates; prestigious U.S. cancer centers such as MD Anderson at The University of Texas have done this as well (Gigerenzer et al. 2007). But surely, one might think, John’s doctor would provide him with the truth. This, too, is unlikely, because very few doctors know that in screening, survival rates reveal nothing about mortality,

just as many do not understand what lead-time bias and overdiagnosis bias are (Wegwarth, Gaissmaier, and Gigerenzer, submitted). This lack of statistical literacy in health may explain why so many urologists themselves take the test. John Q. Public is also unlikely to learn that a U.S. randomized trial found *no* reduction of prostate cancer deaths from combined screening with PSA and digital rectal examination (Andriole et al. 2009), but that one- to two-thirds of men could expect harms such as incontinence and impotence from surgery or radiation.

The American market-driven health care system has no monopoly on producing misinformed patients. In Germany, John Q. Public is known as Otto Normalverbraucher. Otto wants to make an informed decision, too, and—in keeping with the fact that Germans read more health pamphlets than any other European (Gigerenzer et al. 2009)—opens the 114-page pamphlet on prostate cancer published by the Deutsche Krebshilfe (2009), a highly respected nonprofit cancer care organization that receives large amounts of donations from the public. Otto reads that, according to experts, PSA tests are an important method for early detection, and that 10-year survival rates are higher than 80% (Deutsche Krebshilfe 2009:15). He also consults a press release about a recent European randomized trial on prostate cancer screening, which states that PSA screening reduced mortality from prostate cancer by 20%—not as exciting as 80%, but impressive all the same. In the news, Otto reads the unequivocal statement from the president of the German Urology Society: “The study shows without doubt that PSA testing saves lives” (*The Epoch Times*, 26 April 2009). The president is joined by German sport celebrities who recount their personal stories about how early detection saved their lives on TV talk shows and remind Otto to take responsibility for his health—without delay. Just to be sure, Otto consults his urologist, who recommends screening as well. Everything falls into place and he follows suit. Has Otto Normalverbraucher made an informed decision?

No. However, just like John, he will probably never notice. To begin, he may not learn that he has been misled by the 20% figure. What it refers to is a reduction from 3.7 to 3.0 in every 1,000 men who participate in screening, which is an absolute reduction of 0.7 in 1,000, as reported in the original study (Schröder et al. 2009). Framing benefits in terms of *relative risks* (20%) is a common way to mislead the public without actually lying. Second, Otto may not know the subtle distinction between reduced cancer mortality and reduced prostate cancer mortality (multiple cancers exist, which can make it difficult to make correct attributions). The European randomized trial did not report on total cancer mortality, but the U.S. trial did and found no difference in cancer mortality: in the screening group, 23.9 out of 1,000 men died of cancer, compared to 23.8 in the control group. This information is virtually never mentioned in health brochures, which seem more intent on increasing attendance rates than on informing patients. Finally, chances are slim that his urologist knows the scientific evidence and is able to explain to him the pros and cons

of PSA screening. Out of a random sample of 20 Berlin urologists, only 2 knew the benefits and harms of PSA screening (Stiftung Warentest 2004). Even when physicians know the evidence, they may practice defensive medicine out of fear of litigation and recommend the test. For instance, only about half of 250 Swiss internists believed that the advantages of regular PSA screening outweigh its harms in men older than 50 years of age, but 75% recommended regular PSA screening to their patients. More than 40% of physicians recommended screening for legal reasons—to protect themselves against potential lawsuits (Steurer et al. 2009).

The scenarios of John Q. Public and Otto Normalverbraucher illustrate some of the ways in which the patient is misled by the health system inherited from the 20th century. In the following sections, we will explain these in more detail. The deluded patient is the victim of a chain of biased information. Such a health care system wastes taxpayers' money, physicians' time, and causes potential harm to patients' health. The main problem is not the patient, but the health care system itself.

The 20th-Century Medical System Produces Health Illiteracy

Why are patients and doctors misinformed about available evidence concerning standard tests and treatments? The problem begins even before medical research starts—with the funding of research. It continues with biased (incomplete or nontransparent) reporting of the results in medical journals and health brochures, and ends with innumerate physicians who misunderstand health statistics. Throughout, seven elements contribute to misinform patients and prevent them from noticing the facts (Table 1.1). It is not an exhaustive list, but constitutes what we believe are some of the most important sources of distortion and confusion.

There are additional factors outside the health care system which cannot be addressed here, such as the remarkably slow pace of educational systems to adjust their curricula to the 21st century so as to include statistical literacy as

Table 1.1 Important sources that contribute to the health illiteracy of patients.

	Biased funding of research
+	Biased reporting in medical journals
+	Biased reporting in health pamphlets
+	Biased reporting in the media
+	Commercial conflicts of interest
+	Defensive medicine
+	Doctors' lack of understanding of health statistics
=	Misinformed patients

a central topic, and the resulting blind spot in teaching health and financial literacy (Gigerenzer et al. 2007). We would like to emphasize that in pointing out the flaws of the 20th-century health system, our aim is not to criticize particular doctors, politicians, or industries but to analyze a system whose primary goal has not always been to provide the best outcome for the patient. Knowledge of the system is essential if we are to change it into a more efficient one that serves the patient.

However, before we continue, let us clarify terms. We use the terms “health literacy” and “statistical literacy” as two overlapping bodies of knowledge, whose intersection is “statistical literacy in health” (Figure 1.1). Statistical literacy in health does not require a degree in statistics. Rather, it means that patients and health care providers have basic competencies in understanding evidence and, most importantly, know which questions to ask. Health literacy, in turn, intersects with “health system literacy” (a basic understanding of how the health system works). For further information, see Gigerenzer et al. (2007) for a detailed definition of “minimal statistical literacy in health” and Bachmann et al. (2007), who have designed a short test for minimum health literacy.

The term “century of the patient” refers to a society where greater investments in health do not mean more profit for the industry, but rather more knowledge for doctors and patients. In fact, shortage of money (e.g., due to the recent financial crises) can be an enabler for the revolution we envision.

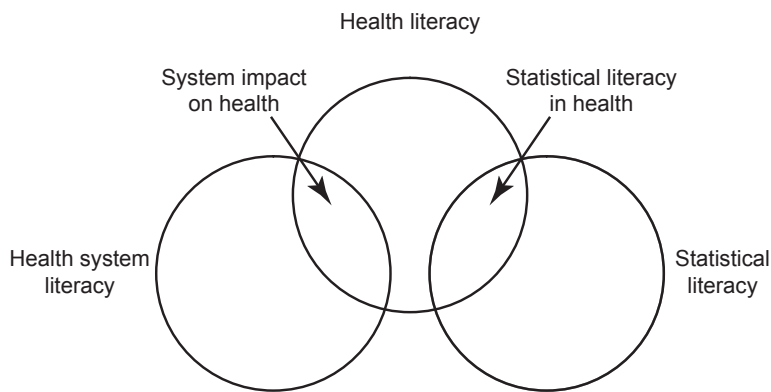


Figure 1.1 Three basic competencies for doctors and patients in the 21st century. Health system literacy entails basic knowledge about the organization of a system and the incentives within it, such as the widespread practice of defensive medicine as a reaction to the threat of litigation. Health literacy entails basic knowledge about diseases, diagnostics, prevention and treatment, and ways to acquire reliable knowledge. Statistical literacy involves the ability to understand uncertain evidence, including concepts such as 5-year survival rates and false positives. The health care system inherited from the 20th century has done little to develop these basic competences in doctors and patients, promoting drugs, patents, and health technology instead.

Biased Funding

The formation of misinformed doctors and patients begins with the funding of research. Given the increasing role of private industry, profitability has become a primary motive for funding and guides the selection of research topics. In 2008, an estimated US\$160 billion was spent on health research and development (R&D) in the United States, and more than half originated from industrial sources; that is, pharmaceutical, biotechnology, and medical technology companies (see Nelson, this volume, for other countries). The rapid rise of the industry began with the election of Ronald Reagan in 1980, when Congress enacted a series of laws, including the Bayh–Dole Act, which enabled universities and small businesses to patent discoveries sponsored by the National Institutes of Health (NIH). Before 1980, taxpayer-financed discoveries belonged in the public domain and could be used by any company (Angell 2004). Today, discoveries made by taxpayer-funded research are no longer public; they can be patented and sold to industry, which in turn can charge large sums until the patent expires or competitors are allowed to introduce generic drugs. Before 1980, medical researchers worked largely independently of the companies that sponsored their work, but this is no longer the case. The Reagan years gave a tremendous boost to the “technology transfer” between universities and industry, where medical schools and their faculties entered into lucrative financial arrangements with drug companies. By funding research at universities and outside, industry is able to introduce bias in three ways: by determining the topics that are funded, the design of clinical trials, and the reporting of the results in journals.

The term “biased funding” refers to research funded because it is likely to be profitable, not because it is likely to be relevant for patients. Profitability and relevance can coincide, but often do not. The James Lind Alliance (www.lindalliance.org), for instance, identifies unanswered relevant questions from patients to ensure that those who fund health research are aware of what matters to patients. We illustrate biased funding by pinpointing three blind spots: patient safety, innovative drugs, and physicians’ statistical literacy.

Patient Safety

Checklists provide a simple, inexpensive tool for improving safety. Introduced by the U.S. Air Force after the B-17 proved to be too much of an airplane for any one person to fly, checklists have become the safety backbone in commercial aviation. For instance, during the successful emergency landing of US Airways Flight 1549 in the Hudson River, the two pilots relied on the relevant checklists, including those for engine failure and evacuation (Gawande et al. 2009). Whereas customer safety is a priority in aviation, and all pilots are trained to use checklists, neither is the case in medicine. For instance, each year, central venous catheters cause an estimated 80,000 bloodstream infections and,

as a result, up to 28,000 deaths in intensive care units (ICU) in U.S. hospitals. Total costs of these infections are estimated at US\$2.3 billion annually. To save lives, Peter Pronovost developed a simple checklist of five steps (including hand washing and cleaning the skin with chlorhexidine) for ICU doctors to follow before inserting an IV line to prevent the introduction of bacteria. The checklist reduced the infection rate to almost zero at some one hundred ICUs in hospitals in Michigan (Pronovost et al. 2006). One might think that funding would focus on such strong effects and that hospitals would rush to implement checklists. Yet most ICU physicians do not use them. Infection control has not been a priority of administrators, who focus on hospitals' profits rather than on patient safety. Nor is the hierarchical structure in hospitals fertile ground for checklists, which might require a nurse to remind a surgeon to follow the instructions. But a fundamental reason why so little funding has been made available to develop and implement checklists appears to be that they are cheap, and thus do not promise high-profit patents.

Patient safety is a major problem. The Institute of Medicine estimated that some 44,000 to 98,000 patients are killed every year in U.S. hospitals by documented, preventable medical errors (Kohn et al. 2000). In 2009, the WHO reported that nearly 1 in 10 patients are harmed while receiving care in well-funded and technologically advanced hospitals (WHO 2009a). Little is known about non-hospital settings, where the majority of care is delivered. In 2008, the WHO Patient Safety initiated a grants program to provide seed funds for twenty to thirty small research projects on safety. Patient safety needs to become a major focus of funding.

Me-too Drugs

To gain approval by the U.S. Food and Drug Administration (FDA), a company needs only to show that its drug is better than a placebo, not that it is better than an already existing drug. The same is true in Germany and other European countries. As a result, there is little incentive for a company to fund innovative research for better drugs; all they need to do is to change a few molecules of an old, already approved one and produce a "me-too" drug. Research on me-too drugs has a smaller risk of failure than innovative research. Of the 78 drugs approved by the FDA in 2002, 71 were me-too drugs (Angell 2004:17). Research that results in drugs that are not better than already existing ones—only more expensive as long as the patent lasts—is not in the interest of the patient.

Research that is relevant for patients has a different goal: Is the new drug better or worse than the old one? Sometimes, such comparative effectiveness research is conducted. For instance, consider high blood pressure (hypertension), a condition for which about 25 million Americans are treated. A trial not sponsored by a drug company compared four drugs for treating hypertension: Norvasc[®] (amlodipine besylate), the fifth best-selling drug in the world in 2002 sold by Pfizer; Cardura[®] (doxazosin), also from Pfizer; an ACE inhibitor sold

by AstraZeneca as Zestril[®] (lisinopril) and by Merck as Prinivil[®]; and a generic diuretic (“water pill”) of a type that has been on the market for over fifty years. The study found that the old-time diuretic was just as effective in lowering blood pressure and better for preventing heart disease and stroke (ALLHAT Collaborative Research Group 2002). Last but not least, diuretics were priced at about US\$37 a year in 2002, while Norvasc[®] costs \$715. Comparative studies are, however, rare. Drug companies do not like head-to-head comparisons with older drugs and use their influence to make certain that the FDA or similar institutions do not request that research answers the comparative question relevant for the patient. The design of research is directly influenced when pharmaceutical companies require researchers to compare a new drug with a placebo rather than with an already existing drug (Angell 2004).

If comparative research is conducted, the drug of the supporting manufacturer is sometimes given at a higher dose than the comparator drugs. (This can make a new drug look good even if it might actually be worse than the older one; yet in the absence of proper studies, no one will know.) Consider Prilosec[®] (omeprazole), a heartburn drug made by AstraZeneca which was once the top-selling drug in the world with US\$6 billion in annual sales. When the blockbuster was set to go off patent in 2001, the company faced competition from generic manufacturers who would sell Prilosec[®] at a much lower price. To avoid loss in sales, AstraZeneca patented a virtually identical drug, Nexium[®], and spent a half billion dollars the same year on advertisements, discounts to managed care plans and hospitals, free samples to doctors, coupons in newspapers, and other ways of persuading consumers to switch from Prilosec[®] to Nexium[®]. AstraZeneca conducted four comparative trials; in two of these, Nexium[®] came out marginally better than Prilosec[®]. But the company had loaded the die by using different doses: 20 mg of Prilosec[®] were compared with 40 mg and 20 mg of Nexium[®]. Biased comparative research is not helpful for patients, who could simply double the dose of Prilosec[®] or buy a much cheaper generic.

Research on me-too drugs that does not conduct comparative studies with existing drugs is not in the interest of the patient. Ironically, the patient pays twice: as a taxpayer for the research supported by the NIH or other government organizations, and as a patient for the overpriced drugs sold by the pharmaceutical companies that acquired the patents without conducting innovative research.

Physicians’ Statistical Literacy in Health

The general public believes that every physician understands medical evidence such as health statistics. Yet the few existing studies indicate that this is not the case, even in the physicians’ own specialty. For instance, one of us (GG) trained about 1,000 German gynecologists in risk communication as part of their continuing education in 2006 and 2007. The majority of gynecologists

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