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Habilitationsschrift

"Statistical literacy in medicine: Physicians' and patients' understanding of health statistics in cancer screening and prevention"

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von
Dr. rer. nat. Odette Wegwarth
geboren in Salzwedel

To all the fabulous, open-minded, and inquiring physicians who believed in the importance of my research and were willing to divulge their weak spot, health statistics.

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1. Introduction: What is statistical literacy in medicine and why does it matter?

No other month has become so prominent in disease awareness than October. For one, October is breast cancer awareness month, during which many Western countries such as the US or Germany turn "pink." No other organization has done more to promote this observance than the world's largest breast cancer charity Susan G. Komen, creator of the ubiquitous "pink ribbon"[1]. While laudably working hard to empower people with breast cancer and ensure good quality of care for all, Komen is best known for promoting mammography screening[1]. During the 2011 breast cancer awareness month, the charity promoted mammography screening with a public advertising campaign (Figure 1) telling women that the key to surviving breast cancer is to get screened. To accentuate this claim, the ad presented two impressive figures: a 5-year survival rate for those who regularly attend screening of 98% and a 5-year survival rate for those who do not attend screening of 23%. The difference of 75% in 5-year survival between the screened and the unscreened group is so dramatic that it is hard to imagine why any woman would reject mammography screening[1]. Yet, the question is whether these numbers really tell what they seem to tell?

Patients and asymptomatic people alike are bombarded with statements and advertisements concerning screening and medical treatments similar to the one above. Most of these messages deliberately use health statistics that are either intransparent or inappropriate for the context chosen[2]. In the classical view of informed decision making, physicians have sufficient knowledge about health statistics and the benefit and harms of medical interventions, which they are mandated to share with their patients. When a women confronted with the above numbers indicating a 75% increase

in 5-year survival asks her physician whether mammography screening (or any other medical procedure) is beneficial to her, risk communication comes into play. Good risk communication requires statistical literacy: the ability to know that different statistical formats for expressing benefit (risk reduction) and harm (risk increase) exist, to know that some formats are appropriate for expressing some risks but not others, and to know that there are transparent and intransparent ways of communicating benefit and harms to the patient. Statistical literacy does not require a degree in statistics. Rather, it means having basic competencies in health statistics, as the following paragraphs will illustrate.
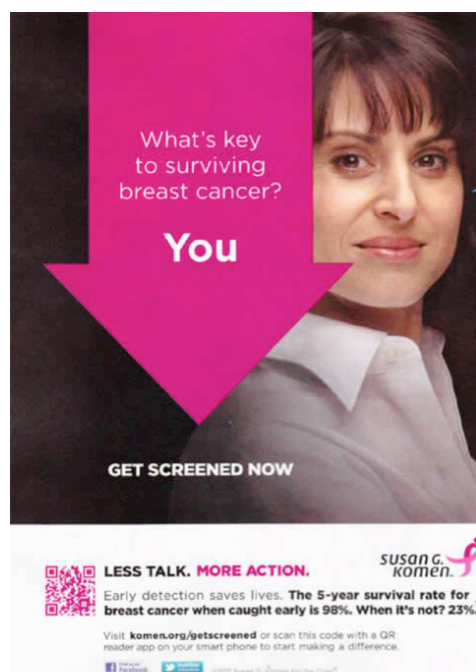
Figure 1: *The public mammography screening advertisement during the breast cancer awareness month 2011 of the charity Susan G. Komen.*

1.1 Benefit and harms can be expressed in different statistical formats

Information on benefit (risk reduction) and harm (risk increase) can be communicated in different "currencies." Ratio measures such as odds ratios

or relative risk information are the most commonly used formats in medicine. The problem with ratio measures, however, is that the underlying absolute risk information is concealed, making it impossible for most readers to judge the clinical significance of the effect correctly. Consider the following example. When data on Europe's first randomized controlled trial on the effectiveness of prostate cancer screening (*ERSPC* trial)[3] involving more than 182,000 men were published, the respective press release announced that prostate cancer screening was found to reduce the chances of dying from prostate cancer by 20%. What this relative risk statement suggests to most readers is that of 100 people who are screened, 20 less will die of prostate cancer. But this is not what the number is saying. Without being told the underlying absolute risks—the absolute numbers of prostate cancer deaths in the screening group as well as in the non-screening group—the information is incomplete[7]. A fact that often goes unnoticed by both lay people and fully licensed physicians[4,5] alike.

What lies behind the 20% risk reduction of prostate cancer death announced by the investigators of the PLCO trial? After an 11-year follow-up, 5 men of 1,000 in the screening group and 4 men of 1,000 in the non-screening group died of prostate cancer[3]. Hence, the 20% relative risk reduction of prostate cancer death corresponds with an absolute risk reduction of 0.1%. In terms of overall mortality, the screening and non-screening groups did not differ. Unmentioned in the press release were the harms of screening: overdiagnosis and overtreatment. For every man saved from prostate cancer death due to screening, 36 men are overdiagnosed and overtreated as a consequence of this screening[3]. The misleading reporting of the PLCO trial results is not an exception in the reporting of cancer screening results. Take the reporting of mammography screening. For more than two decades, the constantly updated findings of large-scale randomized

controlled trials on the effectiveness of mammography comprising approximately 600,000 women, reported in a Cochrane review, have been showing that regular mammography screening for more than 10 years reduces the chances of dying from breast cancer for no more than 1 in 1,000 women (from 5 to 4 in 1,000) at best[6]. The reduction is already the least conservative estimate, given that it also encompasses trials of poorer quality. If high-quality trials alone are considered, the absolute reduction is estimated to be about 8 to 7 in 2,000[6]. The Cochrane review further points out that for every woman saved from breast cancer death per 1,000, 5 women will be wrongly overdiagnosed and unnecessarily overtreated[6]. Are women informed about the delicate benefit-harm ratio? Unfortunately not. The "Kooperationsgemeinschaft Mammographie-Screening," responsible for organizing the systematic screening programme for breast cancer in Germany and informing women about its benefit and harms, still uses relative risk reduction information (20% to 30%) in their evaluation report, available free for download online. In their print-version leaflet, which is sent to all women invited for screening, they do better by reporting absolute numbers, yet these numbers are far removed from any internationally accepted evidence.

Let us return to the reporting of the 20% relative risk reduction of prostate cancer death. If this 20 percent corresponds with a 0.1% absolute risk reduction, where does the number "20%" come from? Ratio measures such as relative risks ignore the number of all people examined and concentrate only on the number of those experiencing the event: in our example, 5 prostate cancer deaths (100%) in the non-screening group versus 4 prostate cancer deaths (80%) in the screening group (= difference of 20%). Relative information on risk is widely misunderstood because the generated numbers are compatible with a wide range of changes in the risk: for instance, a 20% risk reduction would also occur if the investigators had found a decrease from

500 to 400 deaths, from 50 to 40, or from 0.0005 to 0.0004. While some of these reductions would be considered clinically relevant, others would not. Effects presented in relative terms thus communicate very little about the absolute size and the clinical relevance. As most people are not aware of the different "currencies" of risk communication, relative information impresses (and thereby misleads) physicians[2,4,5,7], policy makers[8], and patients[9] much more than absolute risk information does. As the numbers above indicate, this is because relative risk information typically yields big numbers (e.g., 20%) and absolute risk information yields small numbers (e.g., 0.1%).

The different effect of these different risk formats on our perception and judgment is sometimes used deliberately to make screenings, drugs, or treatments look more compelling to medical consumers than they actually are. To meet this goal, benefits are reported in relative numbers (= big numbers) and the harms in absolute numbers (= small numbers). This technique, called mismatched framing[2], has even been found in reports of medical research in high-ranking medical journals[10 11], and from there easily disseminates to patients' brochures and the media[8].

1.2 Not all health statistic formats are appropriate for all settings

Let us come back to the example in the introduction, which highlighted the Komen charity's use of 5-year survival rates for promoting mammography screening. Five-year survival rates are a commonly used survival statistics[2], even though they are inappropriate in the context of screening. It is easy to infer that improved survival or increased detection of early-stage cancers proves that a screening test will save lives. But that assumption is wrong. Unless a screening (= a procedure for detecting abnormalities early) is completely worthless, any screening test must lead to earlier diagnosis and thus to finding more early-stage disease. And since the countdown for

survival statistics begins at the time of diagnosis, survival is always better for screen-detected cancers than for symptom-detected cancer. The propensity of screening to detect abnormalities early leads to an inflation of 5-year survival rates without any bearing on mortality rates. In fact, for the 20 most common solid tumors, an increase in 5-year survival has zero correlation with a decrease in mortality rates[12]. To understand why, it is helpful to look at how the 5-year survival statistic is calculated:

$$5-year\ survival\ rate\ =\ \frac{number\ of\ patients\ diagnosed\ with\ cancer\ still\ alive\ 5\ years\ after\ diagnosis}{number\ of\ patients\ diagnosed\ with\ cancer}$$

In this calculation, the key term to notice is *diagnosed*, which appears in the numerator and denominator of the survival statistic. Cancer can be diagnosed by either symptoms or screening. By definition, screening detects cancer at a microscopic state long before it causes symptoms. Due to this property, screening biases the survival statistic in two ways: (a) by prolonging the period in which a patient is known to have cancer and (b) by including people with nonprogressive cancer in this statistic[2]. The first, called *lead-time bias* (Figure 2), accounts for the fact that screening may only move forward the time when a patient is diagnosed, without moving back the time of death. Imagine 100 men who do not attend prostate cancer screening. Imagine further that after showing symptoms, all of them are diagnosed with prostate cancer at the age of 67 and die of the disease by the age of 70. The 5-year survival rate of this group of 100 men is zero. Now imagine that the very same group of men instead did attend prostate cancer screening. The screening test detects the prostate cancer at the age of 60; but again all 100 men die of the disease by the age of 70. This time the 5-year survival is 100%, in spite of the fact that screening did not prolong the men's lives by a single year.[2]
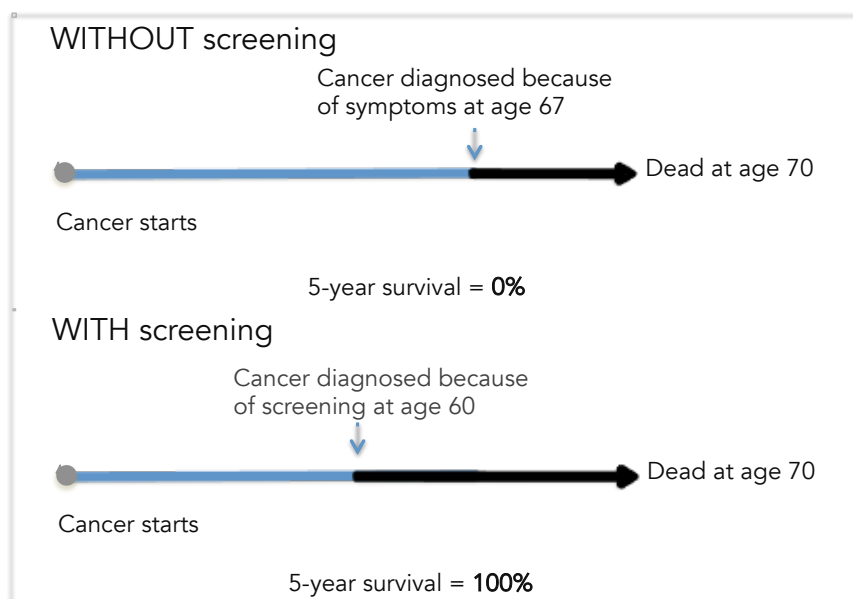
Figure 2. *Lead-time bias. Even if the time of death has not changed due to screening, advancing the time of diagnosis already leads to a dramatic but meaningless increase in the 5-year survival rate.*

The second phenomenon, called *overdiagnosis bias* (**Figure 3**), occurs when cell abnormalities are detected that meet the pathologic definition of cancer yet would never become clinically significant, due to their prolonged preclinical phase or their lack of propensity to progress. The inclusion of nonprogressive and slowly progressive cancer inflates the incidence rate—the denominator of the 5-year survival statistic—and thus the 5-year survival rate itself.[12,13] Imagine a population of 100,000 people who do not attend screening, 1,000 of whom have progressive cancer (see **Figure 3**, top). After 5 years, 440 are alive and 560 are dead, resulting in a 5-year survival rate of 44%. Now imagine that the same population attends screening. Next to the 1,000 people with progressive cancer, the test detects an additional 2,000 people with nonprogressive cancer (see **Figure 3**, bottom). Per definition, these 2,000 will be alive 5 years later, independent of whether their nonprogressive cancers are detected or not. But they are now added to the survival statistics and inflate it dramatically to 81%.

WITHOUT screening

| 1,000 progressive tumors | 5 years later... → | 440 alive |
| | | 560 dead |

5-year survival: 440/1.000= 44%

WITH screening

2.000 nonprogressive tumors	5 years later... →	2,000 alive
1,000 progressive tumors		440 alive
		560 dead

5-year survival: 2.440/3.000= 81%
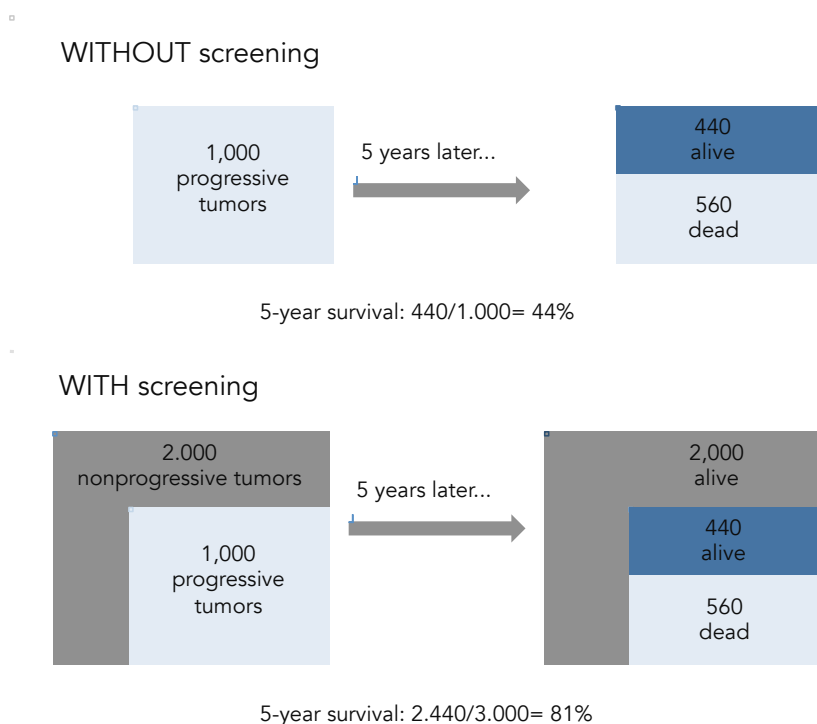
Figure 3. Overdiagnosis bias. Even if the number of people who died did not change with screening, the propensity of screening to detect nonprogressive cancer inflates the 5-year survival rate.

Due to these biases, changes in 5-year survival rates do not allow for a reliable judgment on improved cancer control by cancer screening. Instead, mortality rates provide meaningful numbers [14].

$$5-year\ disease-specific\ mortality = \frac{number\ of\ people\ who\ die\ from\ cancer\ over\ 5\ year}{number\ of\ all\ people\ in\ the\ group}$$

As the calculation shows, the statistic does not depend on diagnostic procedures because the denominator includes all (not just diagnosed) people in the screened and unscreened population and therefore is not prone to screening-induced biases.

Not only US charities use 5-year survival rates to promote screening. At the beginning of 2014, the accredited and federally supported German organization "Kooperationsgemeinschaft Mammograhie Screening"

announced the first signs of success of Germany's systematic breast cancer screening in a press release, saying: "There is a lot of discussion about breast cancer mortality reduction. Yet, over the last years, the 5-year survival for breast cancer has constantly improved up to 87%..." (http://www.mammo-programm.de/presse/archiv-meldungen-details.php?id=138). The press release is deceptive in that it not only moves readers' attention away from a valid to an invalid health statistic, but also ignores the harms: overdiagnosis and overtreatment. People need more than marketing slogans about screening. They need and deserve facts, a rare good in the politics of health information.

1.3. Statistical literacy and transparency: The fundament of informed decisions

Misunderstanding and misuse of health statistics can stimulate enthusiasm for unproven tests and procedure. Physicians who do not understand the difference between ratio measures such as relative risk and absolute risk or do not know that 5-year survival and early detection rates are biased in the context of screening may mistakenly conclude that a test is worth doing when in fact it may only lead to harm, such as by overdiagnosis (diagnosis of cancers never destined to do harm)[15-18]. Because physicians influence patients' understanding of health issues, deceptive campaigns directed at vulnerable physicians could easily influence patients as well. In this way, shared statistical illiteracy threatens to become a stable phenomenon, whose existence is unlikely noticed. The more widespread physicians' health illiteracy is, the easier it is to manipulate their opinions and in turn, the opinions of patients. Moreover, this manipulation may well lead to physicians recommending screening and prescribing procedures to their patients that come with more harm than good and can induce unjustified hopes or unnecessary anxiety. A

minimal statistical literacy therefore matters not only for physicians' own interpretational skills but also for how they communicate risk to patients. Minimal statistical literacy entails knowing what counts as transparent health statistics: absolute risks instead of relative risks for communicating benefit and harms of therapies and screening[19-21], natural frequencies instead of conditional probabilities for communicating posterior probabilities of tests (likelihood of a patient having a disease after having tested positive)[22-25] (for more details, see Hoffrage & Gigerenzer, 1998[25]) and mortality rates instead of 5-year survival rates when judging the value of screening. Moreover, physicians should use numbers instead of mere words when describing risks because so-called verbal qualifiers lead to considerable individual variation in understanding risk information[26-28]. Framing information in a way that is most readily understood by the human mind is a first step toward informed and shared decision making in physician–patient consultations and a first step towards more patient safety.

The ability to understand health statistics is the fundament of informed decision-making. The big question is, do physicians have that ability? In health care, statistical illiteracy—the inability to understand health statistics—is typically presented as a problem faced by patients, rarely by physicians. However, for some health statistics such as ratio measures (see section 1.1.) and conditional probabilities[26-28], a sufficient number of studies over the past 3 decades have documented physicians' blind spot in understanding these health statistics themselves. Has the discovery of statistical illiteracy among physicians improved awareness of the problem, improved physicians' state of knowledge of these statistics, and improved their counseling behavior with respect to these numbers? For other health statistics, such as 5-year survival rates and mortality rates, not until recently were two studies undertaken—as

part of this habilitation—to gain more insight into whether physicians correctly interpret these metrics.

The five studies presented in this habilitation thesis all touch upon statistical literacy and its effect on physicians' counseling, recommendation, and patients' knowledge and behavior. The first study investigated whether physicians continue to misunderstand ratio measures by challenging them on their counseling behavior in the context of mammography screening. The second and the third study are the first examinations ever of how physicians understand cancer screening statistics—survival rates, early-detection rates, incidence, and mortality—and sought to learn if physicians are able to distinguish between valid and invalid statistics. The fourth study explored what patients learn about harms of cancer screening—overdiagnosis and overtreatment—when discussing it with their physician, and what they would like to learn about it. The fifth and final study evaluated how transparent versus intransparent presentations of health statistics on the HPV vaccine affect people's knowledge, risk perception, and their actual vaccination behavior.

2. Five studies on physicians' and patients' understanding of health statistics and facts in cancer screening and prevention

2.1. "There is nothing to worry about": Gynecologists' counseling on mammography

In Western countries, breast cancer is reported to be the leading cause of death in women. To offer women something in their fight against cancer death, most countries recommend mammography screening. Over the past decades, public health officials, physicians, and disease advocacy groups alike have spent much effort to persuade individuals of the importance of cancer screening[29]. But just how effective is mammography screening in saving women from death by breast cancer?

Large randomized controlled trials in Europe and the USA including more than 600,000 women and evaluated in a Cochrane review suggest a delicate benefit-harm ratio for mammography when used to screen asymptomatic women. For years, the regularly updated review has provided fairly stable estimates[6,30,31] on the gains and risks for women: Out of 1,000 women regularly attending mammography screening over 13 years, about 1 less woman will die of breast cancer. At the same time, there will be about 100 women who are wrongly alarmed by a false-positive mammogram, of which most are sorted out after further diagnostic procedures, but 5 women remain wrongly diagnosed (overdiagnosis) and are treated for a progressive cancer they do not have (overtreatment).

Established in 2005, Germany's systematic mammography screening program targets women aged 50 to 69. Given that screening for breast cancer means searching for signs of it in an asymptomatic woman, who is

more likely to have no cancer, comprehensive counseling on the benefit and harms of mammography appears to be of particular importance.

In the past, the benefit of mammography has been widely proclaimed to be a relative risk reduction of breast cancer mortality of 20% to 30% by both patient brochures[32,33] and German politicians[2]. Relative risk information is an intransparent health statistic, however, and so it should come as no surprise that it is misunderstood not only by lay people[5,19,34] but also by medical professionals[2,4,35]. Adding to the bad practice of reporting the benefits in misleading statistical formats, brochures or politician rarely if ever touch upon the harms, and when they do, numbers are rarely given.

Yet, for an asymptomatic woman to make an informed and preference-sensitive decision on whether to attend mammography screening, she needs numbers—transparent absolute numbers—and these for both benefit and harms. The following study investigated what information women can expect to receive from their gynecologist when explicitly seeking advice on the benefit and harms of mammography screening. The particular focus of the study was on whether physicians' counseling would follow the practice of good risk communication. That is, does the woman receive numbers over words, absolute risk information instead of relative risk information for both benefit and harms, and does she learn about the screening's biggest harm: overdiagnosis?

Wegwarth, O., & Gigerenzer, G. (2011). "There is nothing to worry about":

Gynecologists' counseling on mammography. *Patient Education and Counseling*, *84*,

251-256. http://dx.doi.org/10.1016/j.pec.2010.07.025

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Patient Education and Counseling

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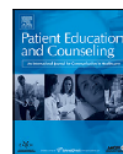
Risk communication

"There is nothing to worry about": Gynecologists' counseling on mammography

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ABSTRACT

Objective: In Germany, approximately 10 million women between the ages of 50 and 69 are eligible for biennial mammography screening. Mammography is at the center of much controversy, however, which means gynecologists must provide women considering mammography with sufficient and transparent information. The present study analyzed the information gynecologists share with a person seeking advice about the benefit and harms of mammography screening.
Method: To receive realistic data, we called 20 gynecologists practicing in different large cities across Germany and took telephone counseling sessions on the benefit and harms of mammography.
Results: The majority of gynecologists described mammography as safe and scientifically well grounded. Harms were rarely mentioned or described as negligible. A minority of gynecologists provided numerical information; when they did, they often quantified the benefit using relative risk reduction and harms using absolute risk increase.
Conclusion: A sample of German gynecologists was not able to correctly *and* transparently communicate the benefit and harms of mammography screening to a patient.
Practice implication: Gynecologists should be taught how to understand and transparently explain medical risk information in simple terms.

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2.2. Deceiving numbers: Survival rates and their impact on doctors' risk communication

Using relative risk information when reporting benefits is one way to promote screening; another is to use 5-year survival rates. In the introduction I gave two examples of how a charity (p. 1) and a federal institution (p. 8 ff.) used survival rates when describing the merits of screening. Yet a misinformed use of this statistic is not restricted to these health care players but is apparently also prevalent among medical editors and researchers. For instance, an article in the *New England Journal of Medicine* concluded that "annual spiral CT screening can detect lung cancer that is curable[36]." The authors reached this conclusion because the estimated 10-year survival for a series of patients with screen-detected stage I lung cancer was 88%, dramatically higher than what clinicians usually see in practice. Other authors claimed in the *Journal of Clinical Oncology* that "our findings add to the accumulating evidence that the use of regular mammography may be beneficial for older women [80 years and older][37]." The authors argued so because regular users of mammography showed "larger percentages of stage I breast cancer than nonusers" as well as better 5-year survival (82% vs. 94%).

As mentioned earlier (p. 5), unless screening is totally worthless, it inevitably detects more early stage cancer than a procedure with no screening does. And, although it may sound plausible to many of us, merely detecting more cancers does not prove that a screening procedure saves any additional lives from cancer death. At the same time, the observed confusion about survival and mortality rate is understandable. It is natural to assume that survival is the same as "1−mortality," which is what the words imply in everyday language. And it is also what survival statistics imply in settings other than screening. For example, in a randomized trial of treatment, if 10%

of the patients die in 1 year, then 90% survive. In the context of screening, mortality has the same meaning, but survival does not. That is because the denominator for survival is no longer the whole group, but only those people diagnosed with cancer. This calculation ushers in two biases—lead-time bias and overdiagnosis bias (see introduction, p. 6 ff.)—which is why a screening test may fail to save a single life (mortality reduction) but still show a big improvement in survival rates. The Mayo clinic lung cancer screening trial is a prime example[38] of such an artificial improvement without any practical correspondence.

Without doubt, survival rates are a misleading statistic in the context of screening, but they continue to be presented nearly everywhere—in high-ranking medical journals, in patient brochures, and in promotional charity campaigns. Sooner or later most patients will be confronted with this health statistic, and some of these may seek their physicians' help in making sense of it. But what do physicians know about survival rates? In the following study, 65 German physicians in internal medicine and its subspecialities were presented with cancer-specific 5-year survival rates, cancer-specific incidences, and cancer-specific mortality rates in the context of screening and then questioned on their screening recommendations, their reasons for a given recommendation, and their judgments of screening's effectiveness.

Wegwarth, O., Gaissmaier, W., & Gigerenzer, G. (2011). Deceiving numbers: Survival rates and their impact on doctors' risk communication. *Medical Decision Making, 31,* 386-394. [doi:10.1177/0272989X10391469](doi:10.1177/0272989X10391469)

Deceiving Numbers: Survival Rates and Their Impact on Doctors' Risk Communication

Odette Wegwarth, PhD, Wolfgang Gaissmaier, PhD, Gerd Gigerenzer, PhD

Background. Increased 5-y survival for screened patients is often inferred to mean that fewer patients die of cancer. However, due to several biases, the 5-y survival rate is a misleading metric for evaluating a screening's effectiveness. If physicians are not aware of these issues, informed screening counseling cannot take place. **Methods.** Two questionnaire versions ("group" and "time") presented 4 conditions: 5-y survival (5Y), 5-y survival and annual disease-specific mortality (5YM), annual disease-specific mortality (M), and 5-y survival, annual disease-specific mortality, and incidence (5YMI). Questionnaire version "time" presented data as a comparison between 2 time points and version "group" as a comparison between a screened and an unscreened group. All data were based on statistics for the same cancer site (prostate). Outcome variables were the recommendation of screening, reasoning behind recommendation, judgment of the screening's effectiveness, and, if judged effective, a numerical estimate of how many fewer people out of 1000 would die if screened regularly. After randomized allocation, 65 German physicians in internal medicine and its subspecialities completed either of the 2 questionnaire versions. **Results.** Across both versions, 66% of the physicians recommended screening when presented with 5Y, but only 8% of the same physicians made the recommendation when presented with M (5YM: 31%; 5YMI: 55%). Also, 5Y made considerably more physicians (78%) judge the screening to be effective than any other condition (5YM: 31%; M: 5%; 5YMI: 49%) and led to the highest overestimations of benefit. **Conclusion.** A large number of physicians erroneously based their screening recommendation and judgment of screening's effectiveness on the 5-y survival rate. Results show that reporting disease-specific mortality rates can offer a simple solution to physicians' confusion about the real effect of screening. **Key words:** decision rules; risk communication or risk perception, shared decision making, health literacy, numeracy. (Med Decis Making 2011;31:386–394)

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2.3. Do physicians understand cancer screening statistics? A national survey of primary care physicians in the United States

The study presented in section 2.2. on physicians' understanding of survival rates[13]—the first study ever on this topic—demonstrated that a small sample of German physicians did not understand 5-year survival rates and erroneously based their recommendations in favor of screening on this health statistic. When presented with survival rates, physicians arrived at numerical estimates of the benefit of screening that were several orders of magnitude larger than the real survival benefit. Furthermore, we found first evidence that physician are misled by a higher incidence of cancer in the screening group, which is actually a sign of screening's harm—overdiagnosis—and not of its benefit. When presented with a condition that showed incidence information and mortality rates next to 5-year survival, many physicians set the difference in incidence between the screened and unscreened group in relation to the nearly indistinguishable mortality rates for the two groups and concluded that the mortality reduction is larger than suggested by the numbers provided.

The study provided clear-cut results showing that most physicians misunderstood increased 5-year survival rates and increased incidence in the screening group, which both came with consequences for their surveyed recommendation behavior. Because the study was the first of its kind, was conducted with a fairly small sample, and revealed phenomena requiring deeper elaboration, we felt the need for setting up a second study addressing the aspects of sample size and open questions. The second study— conducted with a large national sample of 412 U.S. primary care physicians— aimed at replicating the results of the first study[13] and further sought to better apprehend physicians' misunderstandings based on increased 5-year survival rates, increased incidence, and increased detection rates of early-stage

cancer in the screening group compared to a non-screening group. We also tested whether explanatory notes on the invalidity of the 5-year survival and early-detection rates in cancer screening evaluation as well as on the possibility of overdiagnosis when incidence is increased with the screening group would have any corrective effect on physicians' evaluation and recommendation behavior.

Wegwarth, O., Schwartz, L. M., Woloshin, S., Gaissmaier, W., & Gigerenzer, G. (2012). Do physicians understand cancer screening statistics? A national survey of primary care physicians in the United States. *Annals of Internal Medicine*, *156*, 340-349, W-92-W-94. doi:10.7326/0003-4819-156-5-201203060-00005

ORIGINAL RESEARCH | **Annals of Internal Medicine**

Do Physicians Understand Cancer Screening Statistics? A National Survey of Primary Care Physicians in the United States

Odette Wegwarth, PhD; Lisa M. Schwartz, MD, MS; Steven Woloshin, MD, MS; Wolfgang Gaissmaier, PhD; and Gerd Gigerenzer, PhD

Background: Unlike reduced mortality rates, improved survival rates and increased early detection do not prove that cancer screening tests save lives. Nevertheless, these 2 statistics are often used to promote screening.

Objective: To learn whether primary care physicians understand which statistics provide evidence about whether screening saves lives.

Design: Parallel-group, randomized trial (randomization controlled for order effect only), conducted by Internet survey. (ClinicalTrials.gov registration number: NCT00981019)

Setting: National sample of U.S. primary care physicians from a research panel maintained by Harris Interactive (79% cooperation rate).

Participants: 297 physicians who practiced both inpatient and outpatient medicine were surveyed in 2010, and 115 physicians who practiced exclusively outpatient medicine were surveyed in 2011.

Intervention: Physicians received scenarios about the effect of 2 hypothetical screening tests: The effect was described as improved 5-year survival and increased early detection in one scenario and as decreased cancer mortality and increased incidence in the other.

Measurements: Physicians' recommendation of screening and perception of its benefit in the scenarios and general knowledge of screening statistics.

Results: Primary care physicians were more enthusiastic about the screening test supported by irrelevant evidence (5-year survival increased from 68% to 99%) than about the test supported by relevant evidence (cancer mortality reduced from 2 to 1.6 in 1000 persons). When presented with irrelevant evidence, 69% of physicians recommended the test, compared with 23% when presented with relevant evidence ($P < 0.001$). When asked general knowledge questions about screening statistics, many physicians did not distinguish between irrelevant and relevant screening evidence; 76% versus 81%, respectively, stated that each of these statistics proves that screening saves lives ($P = 0.39$). About one half (47%) of the physicians incorrectly said that finding more cases of cancer in screened as opposed to unscreened populations "proves that screening saves lives."

Limitation: Physicians' recommendations for screening were based on hypothetical scenarios, not actual practice.

Conclusion: Most primary care physicians mistakenly interpreted improved survival and increased detection with screening as evidence that screening saves lives. Few correctly recognized that only reduced mortality in a randomized trial constitutes evidence of the benefit of screening.

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2.4. Overdiagnosis and overtreatment: Evaluation of what physicians tell patients about screening harms

The preceding three studies[13,39,40] made it obvious that many physicians have problems in correctly understanding health statistics and therefore in correctly and transparently explaining these to their patients. They became enthusiastic about screening when confronted with survival rates, which misleadingly enhance its benefit, and explained the benefits of screening by using relative instead of absolute numbers. Even when explicitly asked about the harms of screening, not a single gynecologist mentioned the biggest harm of mammography screening: overdiagnosis and overtreatment. This current state of affairs clearly impedes patients' ability to make informed decisions.

Undoubtedly, some cancer screenings can produce benefits: finding true cancer in a person at an early stage can reduce the likelihood of dying from it. But several common screenings can also or even only produce harms: by overdiagnosis and overtreatment[2,41-44]. Overdiagnosis is the detection of pseudodisease, that is, finding cell abnormalities that meet the pathologic definition of cancer but will never progress to cause symptoms in the patient's lifetime. The consequence of overdiagnosis is overtreatment—surgery, chemotherapy, or radiation that turns healthy people into patients and provides no survival benefit but only the side effects of invasive and toxic cancer treatment regimes. Although it is nearly impossible to determine whether individuals have been overdiagnosed, it is relatively easy to detect within randomized controlled trials (RCTs). For instance, a systematic review[6] of RCTs on mammography screening revealed that for every woman saved from breast cancer death, 5 women with nonprogressive breast cancer are overdiagnosed and unnecessarily overtreated for a progressive cancer they did not have. Given that nearly 90% of U.S. women said they already had at

least one mammography screening,[29] tens of thousands of these U.S. women without progressive breast cancer have been overtreated. Similarly, for every man saved from dying from prostate cancer through PSA screening, 36 men are overdiagnosed and overtreated for a cancer that would have not affected their lives[3]. Given that over 70% of U.S. men reported having taken at least one PSA test,[29] tens of thousands of these U.S. men have unnecessarily experienced harms such as incontinence or impotence due to overtreatment.

The following study—conducted with a national sample of U.S. men and women aged 50 to 69 years, a population with the highest exposure to screening programs[29] —sought to learn whether people counseled by their doctors about cancer screening were informed about overdiagnosis and overtreatment. Additionally, it investigated whether knowledge about these harms would influence decisions on screening and what number of overdiagnosed patients per one life saved from cancer death due to screening is considered tolerable.

Letters

LESS IS MORE

Overdiagnosis and Overtreatment: Evaluation of What Physicians Tell Their Patients About Screening Harms

Cancer screening can produce benefits: finding true and treatable cancer at an early stage. However, it also can produce harms by overdiagnosis and overtreatment.[1-3] Overdiagnosis is the detection of pseudodisease—screening-detected abnormalities that meet the pathologic definition of cancer but will never progress to cause symptoms. The consequence of overdiagnosis is overtreatment—surgery, chemotherapy, or radiation—that provides the patient no benefits, but only adverse effects. For instance, for every 2000 women attending mammography screening throughout 10 years, 1 less dies of breast cancer. Concurrently, approximately 10 women with pseudodisease receive a diagnosis of breast cancer and are unnecessarily treated.[4] Are patients informed about overdiagnosis by their physicians when discussing cancer screening? How much overdiagnosis would they tolerate when deciding to start or continue screening?

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Methods | We conducted a national cross-sectional online survey of 317 US men and women aged 50 to 69 years (**Table**), a population with the highest exposure to screening programs. The Ethics Committee of the Max Planck Institute for Human Development approved the study. Participants signed electronic consent forms to enroll in the online study. The sample was drawn from the US panel of Survey Sampling International in December 2010 according to a quota method based on official US statistics[5] concerning sex, ethnicity, and educational level (see eFigure in the Supplement). Two screener questions ensured that only persons who indicated no cancer history and who had been invited to undergo cancer screening by their physicians in the past could access the survey. To ensure that all participants had the same knowledge of overdiagnosis and overtreatment, we introduced these concepts at the beginning of the survey (see eMethods section in the Supplement). Because the survey did not allow item nonresponse, all questionnaires were complete.

Results | Of the sample 19.9% reported having attended 1 routine cancer screening, 36.0% reported 2 screenings, 27.1% reported 3 or more, and 17.0% indicated none. Mammography was the most common cancer screening reported by women, and colonoscopy/sigmoidoscopy and prostate-specific antigen (PSA) testing were the most common reported by men. Of the entire sample, only 9.5% of the individuals (n = 30) said that their physician had informed them about the possibility of overdiagnosis and overtreatment when discussing cancer screening (Table). Nine of these patients indicated that their physician quantified the risk of overdiagnosis. However, with one exception, the numbers participants provided (ranges:

Table. Demographics of Survey Respondents, Their Information Status, and Tolerance of Overtreatment

Characteristic	No. (%) of Survey Respondents	%		
		2008 US Census[a]	Informed of Overtreatment by Their Physicians	Would Not Start Cancer Screening If It Resulted in >1 Overtreated Person per 1 Life Saved
Overall	317 (100.0)	100	9.5	51.2
Sex				
Female	166 (52.4)	52	8.4	51.2
Male	151 (47.6)	48	10.6	52.3
Age, y				
50-59	192 (60.6)	61	9.4	47.9
60-69	125 (39.4)	39	9.6	55.2
Educational level				
Less than high school	22 (6.9)	13	9.1	45.4
High school/some college	203 (64.0)	58	10.3	82.8
College degree	92 (29.0)	29	7.6	50.0
Ethnicity				
White	269 (84.9)	85	8.9	52.0
African American /Asian/other minority	48 (15.1)	15	12.5	39.6

[a] Data obtained from the US Census Bureau, Current Population Survey, 2008 Annual Social and Economic Supplement.[1]

Figure. Proportion of Participants Answering the Question on Overdiagnosis
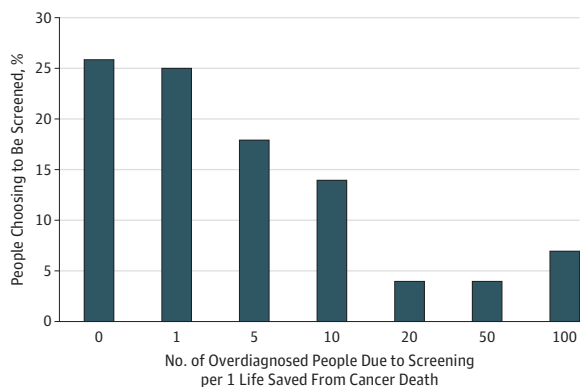
For the survey item on the number of overdiagnosed people per 1 life saved from cancer death due to screening that they would find tolerable while still being prepared to start screening, participants were able to choose from the following options: 0, up to 1, up to 5, up to 10, up to 20, up to 50, and up to 100.

mammography, 10-30; PSA testing, 0-2; and sigmoidoscopy, 3-40) were either overestimates or underestimates of the risk reported in the current literature.[4,6,7] Eighty percent of all participants expressed the desire to be told about screening harms before undergoing the testing. Of 27 people who had received no cancer screening but had heard about the accompanying risk of overtreatment, 9 (34%) persons indicated that the possibility of overtreatment had been an argument against screening up to that point.

The tradeoff between the benefit of screening—life saved from cancer—and its harms—overdiagnosis and overtreatment—were systematically different for decisions on whether to start or continue cancer screening. Fifty-one percent of all participants were unprepared to start a screening that results in more than 1 overtreated person per 1 life saved from death due to cancer (**Figure**). However, 58.9% would continue cancer screening that they are receiving regularly even if they learned that the test results in 10 overtreated persons per 1 life saved from cancer death.

Discussion | Most participants in our sample who underwent routine cancer screening reported that their physicians did not tell them about overdiagnosis and overtreatment. The few who received information about overtreatment had unrealistic beliefs about the extent of that risk. The large number of uninformed patients might be explained by a large number of physicians who themselves know little about screening harms. When a national sample of 412 US primary care physicians, part of a larger project on physicians' understanding of cancer screening statistics,[8] was asked about the extent of overdiagnosis for mammography screening and PSA testing; only 33.9% and 42.9%, respectively, were able to provide a correct estimate.

The results of the present study indicate that physicians' counseling on screening does not meet patients' standards. Most individuals desired information about screening harms, which was not given, and attested that this knowledge would

matter to them: 69% of the sample indicated that they would not start screening if overdiagnosis was as high (ie, ≥10 cases per 1 life saved) as it is in mammography and PSA testing.[4,6]

Our results should prompt medical educators to improve the quality of teaching about screening and encourage medical journal editors to enforce clear reporting about overtreatment when publishing results on the effectiveness of cancer screening. These means may not be sufficient but would be a first step toward enhancing the number of physicians and patients who thoroughly understand the potential consequences of taking a cancer screening test.

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2.5. Overcoming the knowledge-behavior gap: The effect of evidence-based HPV vaccination leaflets on understanding, intention, and actual vaccination decision

Physicians can be one source for educating patients about the odds involved in cancer screening and prevention. An alternative option can be patient information leaflets. However, studies document that leaflets available to now on cancer screening[32,33] and cancer prevention[45,46] are not necessarily a better choice. Many of these leaflets use relative information for expressing the benefit, do not mention harms or downplay these either verbally or by using incorrect small-looking numbers, provide emotional anecdotes of how the screening or prevention saved somebody's life, and generally use persuasive language. All these means are intended to sway patients to do the "right thing" rather than encourage them to make an informed decision. The underlying belief is that most people are unable to make responsible decisions and therefore need to be nudged in the right direction by these who know better. How wrong this belief can be is documented by the studies of section 2.1. to 2.3., where medical professionals—often responsible for the content of leaflets—themselves do not understand basic health statistics and know little to nothing about the harms of cancer screening. Given the widespread lack of knowledge, it seems unlikely that professionals are much better at determining what is the "right thing" to do. Furthermore, because cancer screening and cancer prevention always entail treating asymptomatic people, they are highly preference-sensitive issues: Whether 1 woman saved from breast cancer counterbalances the 5-fold higher risk of being overtreated is something that no health professional can decide for individual women. Many women may feel that the risk is worth taking, but others may not; both groups have the right to decide according to their preferences.

Although the current quality of their information is not encouraging, leaflets still have the potential of becoming an educational tool for patients in the future if unbiased and transparent information turn into a standard.

The following study investigated whether transparent and sufficient information on the cervical cancer (HPV) vaccine helps people to make an informed decision on that vaccination. A sample of 225 girl–parent pairs coming from all districts of Berlin were presented with either an unbalanced or a balanced leaflet and then questioned on their knowledge about cervical cancer, their knowledge of the effectiveness of the vaccine, their vaccination intention, and their actual vaccination behavior. Because we could not guarantee representativeness of the sample and therefore could not assume equal states in knowledge and behavior, we studied all outcomes in a before –after design.

Wegwarth, O., Kurzenhäuser-Carstens, S., & Gigerenzer, G. (2014). Overcoming the knowledge-behavior gap: The effect of evidence-based HPV vaccination leaflets on understanding, intention, and actual vaccination decision. *Vaccine*, *32*, 1388-1393. doi:10.1016/j.vaccine.2013.12.038

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Overcoming the knowledge–behavior gap: The effect of evidence-based HPV vaccination leaflets on understanding, intention, and actual vaccination decision

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ABSTRACT

Objective: Informed decision making requires transparent and evidence-based (=balanced) information on the potential benefit and harms of medical preventions. An analysis of German HPV vaccination leaflets revealed, however, that none met the standards of balanced risk communication.

Methods: We surveyed a sample of 225 girl–parent pairs in a before–after design on the effects of balanced and unbalanced risk communication on participants' knowledge about cervical cancer and the HPV vaccination, their perceived risk, their intention to have the vaccine, and their actual vaccination decision.

Results: The balanced leaflet increased the number of participants who were correctly informed about cervical cancer and the HPV vaccine by 33 to 66 absolute percentage points. In contrast, the unbalanced leaflet decreased the number of participants who were correctly informed about these facts by 0 to 18 absolute percentage points. Whereas the actual uptake of the HPV vaccination 14 months after the initial study did not differ between the two groups (22% balanced leaflet vs. 23% unbalanced leaflet; $p = .93$, $r = .01$), the originally stated intention to have the vaccine reliably predicted the actual vaccination decision for the balanced leaflet group only (concordance between intention and actual uptake: 97% in the balanced leaflet group, $r_s = .92$, $p = .00$; 60% in the unbalanced leaflet group, $r_s = .37$, $p = .08$).

Conclusion: In contrast to a unbalanced leaflet, a balanced leaflet increased people's knowledge of the HPV vaccination, improved perceived risk judgments, and led to an actual vaccination uptake, which first was robustly predicted by people's intention and second did not differ from the uptake in the unbalanced leaflet group. These findings suggest that balanced reporting about HPV vaccination increases informed decisions about whether to be vaccinated and does not undermine actual uptake.

Wegwarth, O., Kurzenhäuser-Carstens, S., & Gigerenzer, G. (2014). Overcoming the knowledge-behavior gap: The effect of evidence-based HPV vaccination leaflets on understanding, intention, and actual vaccination decision. *Vaccine*, *32*, 1388-1393. doi:10.1016/j.vaccine.2013.12.038

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3. Discussion: Many physicians lack understanding of health statistics and leave their patients uniformed

Cancer screening is an increasingly central part of medical practice. Can patients expect to be competently counseled for it? Results of the three studies on physicians' understanding of health statistics that are presented in this habilitation thesis suggest that they cannot. The first study[39] documented that most gynecologists either did not know the numbers regarding the benefit and, particularly, harms or mostly failed to communicate this information transparently. The key problems identified in this study were the following:

(1) In response to the question of what the actual risk is of a 55-year old woman having breast cancer (prevalence; appr. 1.5%), gynecologists provided either qualitative information ("most common cancer") or information on lifetime incidence for women (estimates provided ranged from 10% to 25%).

(2) Most gynecologists expressed benefit and harms as verbal qualifiers rather than in numbers.

(3) If they did provide numbers for the benefit of screening, gynecologists used the misleading format of relative risk reduction (estimates provided ranged from 20% to 50%).

(4) None of the gynecologists mentioned the two greatest harms of mammography, overdiagnosis and overtreatment. In fact, the majority left the impression that the harms are "negligible."

(5) On the few occasions where gynecologists provided quantitative information on both benefit and harms, most used mismatched framing (relative risk information for benefits and absolute risk information for harms).

The second[13] (2.2) and third[40] (2.3.) study of this habilitation thesis illustrated that when evaluating the benefit of cancer screening (= reduction of at least cancer-specific mortality), the majority of primary care physicians in Germany and the US did not know which screening statistics provide valid or invalid evidence. In both studies, data on survival, mortality, incidence, and early-stage detection were obtained from epidemiological databases[47] and randomized controlled trials on prostate cancer screening[48]. Physicians were considerably more likely to recommend a screening test that was supported by invalid evidence—increased 5-year survival rate—than by valid evidence—reduced 5-year cancer mortality. In particular, the study with U.S. physicians[40] (2.3.) suggested that doctors mistakenly interpreted survival in the context of screening as if it were survival in the context of a treatment trial. After seeing only the survival rates, nearly half of the physicians who believed that "lives were saved" stated (in a fill-in-the-blank question) that there would be 300 to 310 fewer cancer deaths per 1,000 people screened—a result apparently obtained by subtracting the 5-year survival rates provided in the scenario (99% survival with screening minus 68% without screening = 31%). However, the 31% increase in 5-year survival corresponded with a real reduction in cancer mortality of about 0.4 in 1,000 within 5 years—an estimate that over 50% correctly provided when presented with cancer mortality rates in the second scenario.

Enthusiasm for screening in both studies was further increased by two other statistics, the percentage of stage I cancers detected and the cancer incidence. Neither statistics provides any information about a mortality benefit—the outcome that actually matters most for people considering cancer screening. For instance, in the U.S. study, after seeing information on the percentage of the detection of early-stage cancer and incidence, about 60% of the physicians were "more" or "much more" likely to recommend the

cancer screening than they were when seeing either survival or mortality data alone. Yet information on early detection provides little to no support that a screening is beneficial, given that even a harmful test can increase detection of early-stage cancer[43]. As for information on increased incidence in the screened group, if anything it only hints to the possibility of harm through overdiagnosis. But the enthusiasm that this statistic elicited suggests that most physicians had not considered the possibility of overdiagnosis; which is further indicated by an additional explanation on incidence that was endorsed by a large number of physicians. The study investigating German physicians' understanding of survival rates revealed a potential explanation of why incidence may be a decisive cue for physicians' recommendation behavior. What we called the *incidence-mortality fallacy*[13] is best illustrated by one of the physician's reasoning about increased incidence: "… mortality does more or less equate between groups; however, incidence of cancer is higher in the screened group. Thus, relatively fewer people die in the screening group."

In the U.S. study on survival rates, we also included explanatory notes during data presentation in order to see if these could diminish the confusion about increased survival rates and increased incidence. One note explained that higher survival or finding more stage I cancers with screening does not prove that screening saves lives and that such proof can only come from a randomized trial demonstrating lower cancer mortality. The other note highlighted the potential of overdiagnosis when incidence is increased in the screening group. Between 76% and 80% of physicians found the notes helpful, but both had ambiguous effects on their recommendation behavior.

In sum, a considerable number of physicians did not understand cancer statistics in our study and were not able to sufficiently and transparently communicate the benefit and harms of mammography screening. Past studies

found that physicians are susceptible to framing effects created by using relative versus absolute risk reduction formats[4,19-21,49] and have difficulty calculating the positive predictive value[22,23,25,39,50]. The studies on physicians' counseling and statistical understanding presented in this thesis made clear that the "old" problems stills exist and that there are further problems with other health statistics. Physicians' inability to understand health statistics have a visible effect on patients as documented by the fourth study[40] of this habilitation thesis, where we examined what a large national sample of 317 people at screening age (50 to 69 years) had learned about overdiagnosis and overtreatment in the context of screening from their physician. Most people in this sample (83%) underwent one or more routine cancer screening tests. However, only 9% of the whole sample indicated that their physician had informed them about the risk of overdiagnosis and overtreatment when discussing screening. The few who had been informed had unrealistic beliefs about the extent of the harms. The actual level of being informed was in stark contrast to the desire of being informed: 80% of the participants indicated that they wanted to be told about screening harms and this *before* being screened. Already Schwartz and colleagues[51] discovered more than a decade ago that only 6% of 479 U.S. women who attended mammography screening had ever heard of carcinoma in situ. Back then, the authors called upon clinicians to improve their counseling and to take more time to inform women having mammography about the existence of such carcinomas. Many years later, our study showed that their recommendation has not yet been followed. The reason behind the large number of uninformed patients is the large number of physicians who themselves know little about screening harms. Within the national sample of 412 U.S. primary care physicians[40] surveyed on cancer statistics, only 34 percent provided a correct estimate of the extent of overtreatment for mammography screening and 43 percent for PSA testing.

Information on overdiagnosis may, however, not necessarily alter people's screening decisions. The study showed that people's tradeoffs between the benefit of screening—lives saved from cancer death—and its harms—overdiagnosis and overtreatment—are systematically different for screening tests they have not yet attended and those they already attend regularly. Accordingly, 69% of all participants indicated that they were not prepared to start a new screening if as many as 10 or more persons were overdiagnosed per 1 life saved; which is in fact the case in mammography and PSA screening. However, 59% would continue their currently attended routine cancer screening even if they learned that it results in 10 overtreated persons per one life saved from cancer.

But physicians are not the only source of information for people seeking advice on whether to undergo screening or to consent to a cancer vaccine. Patient leaflets can be another potential source. However, studies on leaflets on screening[32,33,52] and on the HPV vaccination[45,46] against cervical cancer do not draw a very optimistic picture of the quality of information either. Most of the leaflets provide intransparent statistics on the actual risk of cancer and on the potential benefit of the screening/prevention, leave out information on harms, and use persuasive language in favor of the screening/prevention. The fifth study[53] in this habilitation thesis wanted to learn more about the effects of unbalanced reporting and revealed that it comes with the high price of keeping information-seeking people highly uninformed. The unbalanced leaflet used in the study has been publicly distributed by a German cancer charity, which provided annual incidence of and mortality figures for cervical cancer without setting these in context to the whole female population. Furthermore, its authors drew on results of retrospective studies when describing the relation of HP viruses and cervical cancer development, and selectively reported results of the approval studies.

In contrast, the balanced leaflet provided incidence and mortality information in absolute numbers and gave information on the reference class; it also reported actual results of the approval studies of the vaccine concerning potential reduction of cervical cancer (measured by the surrogate marker of a reduction of precancerous lesions). Between 86% and 95% of the participants who received and read the unbalanced leaflet either overestimated the risk of cervical cancer and the effectiveness of HPV vaccination by at least an order of magnitude or could not answer these questions. Even worse, reading this leaflet actually reduced the number of people who correctly knew the answers before. Furthermore, subjective perceptions of the risk of getting cervical cancer increased unrealistically; an effect of incidence numbers being given without the underlying reference group. These findings add to the evidence that unbalanced reporting seriously misinforms and misleads people (e.g., [39,54,55,56]). Not surprisingly, the increase in risk perception and in overestimating the effectiveness of the vaccine resulted in an increase in the reported intention to become vaccinated. The balanced leaflet, in contrast, improved people's knowledge for each of the investigated dimensions by 22 to 66 percentage points and reduced unrealistic subjective risk judgments of getting cervical cancer, which resulted in a reduced intention to become vaccinated. Because prevention by vaccination is an important means of improving health care, the difference in intention might be a potential source of concern. However, the study found no grounds for this concern. Although the unbalanced leaflet increased vaccination intention and the balanced leaflet decreased it, the two groups did not differ in their actual vaccination behavior, investigated 14 months later: 22% in the balanced group and 23% in the unbalanced group reported that their daughters had been vaccinated against HPV in the meantime. In this regard, the study showed another important effect: The balanced leaflet induced a vaccination intention that

robustly predicted people's actual vaccination behavior. For 97% of people in the balanced group, we found a concordance between their reported vaccination intention and their actual vaccination behavior, while this was the case for only 60% in the unbalanced group. Thus, as we concluded from this study, informing people transparently does not undermine their preventive behavior, whereas intransparent information may undermine their trust in health information from public health authorities in the long run.

4. Conclusion: The need to overcome the educational blind spot on statistical literacy

Efficient health care requires informed doctors *and* patients[57]. Our health care system falls short on both counts. The studies presented in this habilitation thesis illustrate the extent of the problem. Why is risk literacy so limited in health care?

One frequently discussed answer assumes that people suffer from cognitive shortcomings that make them basically hopeless at dealing with risks[58]. Yet the fact that even 4th-graders can understand the positive predictive value if information is presented in "natural frequencies"[59] shows that the problem does not lie in stable cognitive deficits but in *how* information is presented to physicians and patients. This includes biased reporting in medical journals, brochures, and the media, which use relative risks and other misleading statistics that do not promote informed physicians and patients due to conflicts of interest and defensive medicine[60].

What can be done? If we can change the one key factor and turn statistical illiteracy into literacy, some other obstacles might fall like dominos. Every medical school should teach their students how to understand evidence in general and health statistics in particular, and statistical literacy should be assessed in continuing medical education (CME). To evaluate and communicate risk sufficiently, medical students need to learn that they should use numbers rather than merely verbal descriptions, absolute risks instead of relative risks, and mortality rates instead of survival rates in the context of screening. They also need to know that when evaluating the posterior probability of a test, they would fare better with the use of natural frequencies than with conditional probabilities. But statistical literacy also demands rethinking the teaching of statistics at medical schools. Instead of making

statistics a mathematical procedure in itself, it should be taught as a useful tool for solving clinically relevant problems by using concrete examples. One great disappointment of motivated medical students is when their statistics curriculum has little to do with their own world of counseling.

Breast Cancer Early Detection
by mammography screening

HARDING CENTER FOR
RISK LITERACY

Numbers for women aged 50 years or older who participated in screening for >10 years.		
Benefits	**1,000 women without screening**	**1,000 women with screening**
How many women died from breast cancer?	5	4
How many women died from all types of cancer?	21	21
Harms		
How frequent were false diagnoses, often associated with months of waiting for all-clear?	–	100
How many women were additionally diagnosed and operated** for breast cancer?	–	5

* This means that about 5 out of 2,000 women (40+ years of age) with screening died from breast cancer within 10 years – one less than without screening.
** Complete or partial breast removal

Source: [1] Gøtzsche, PC, Jorgensen, KJ (2013). *Cochrane database of systematic reviews* (1): CD001877.pub5 [2] Leitlinienprogramm Onkologie (Juli, 2012). Interdisziplinäre S3-Leitlinie für die Diagnostik, Therapie und Nachsorge des Mammakarzinoms. http://www.awmf.org/uploads/tx_szleitlinien/032-045OL_l_S3__Brustkrebs_Mammakarzinom_Diagnostik_Therapie_Nachsorge_2012-07.pdf

Figure 4. *Screening fact box on mammography. Fact boxes can help structure the conversation about screening's benefit and harms as it gives data side by side and on equal weights.*

To cultivate informed patients who do not simply request unneeded treatments and tests, elementary and high schools should start teaching the mathematics of uncertainty – statistical thinking – rather than only the mathematics of certainty. And once physicians master the basics of statistical thinking, the next step is to provide patients with transparent numbers. Contrary to the popular belief, most patients prefer numbers and facts about their care[61,62]. A "screening/drug fact box" (see **Figure 4**) is a simple tool that can help structure consultations with patients about the performance of a

medical treatment as a fact box provides data on benefit and harms side by side and weighted equally. Studies[63,64] have demonstrated that even people with lower educational attainment like fact boxes, find the data valuable, and, most importantly, can understand the information presented in them. Of course, a critical mass of informed citizens will not resolve all health care problems, but it can constitute a major triggering factor for better care. Informed patients will ask questions that require doctors to become better informed, who in turn will more easily see through biased reporting and attempts to create undue hopes and fears.

Guidelines on complete and transparent reporting in journals, brochures, and the media need to be better enforced, and legal systems need to be changed in order to protect patients and doctors alike against the practice of defensive medicine, instead of encouraging doctors to do more than needed.[57]

However, even if statistical literacy increases in the citizenship and even if reporting in journals and brochures changes, physicians and health care providers will quite likely (and should) remain the most important sources of health information for a patient. Thus, also in the future, the responsibility for helping patients understand the potential benefits and harms of medical prevention and intervention will continue to fall largely upon doctors. Ensuring future patients receive the counseling they should receive is not only the responsibility of medical educators, who undoubtedly need to improve the quality of teaching medical statistics. It also remains the responsibility of all medical students and all licensed physicians to stay curious about statistical issues that they have not yet understood and to insist on a proper statistical education from their medical schools and organizations, for the best of their patients.

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6. Appendices to studies

6.1   Wegwarth, O. & Gigerenzer, G. "There is nothing to worry about": Gynecologists' counseling on mammography, *Patient Education and Counseling*, 08/2011, 251-256, *84* (2).   IF: 2.59

6.2   Wegwarth, O., Gaissmaier, W., & Gigerenzer, G. Deceiving numbers: Survival rates and their impact on doctors' risk communication, *Medical Decision Making*, 05/2011, 386-394, *31* (3).   IF: 2.69

6.3   Wegwarth, O., Schwartz, L. M., Woloshin, S., Gaissmaier, W., & Gigerenzer, G. Do physicians understand cancer screening statistics? A national survey of primary care physicians in the United States, *Annals of Internal Medicine*, 03/2012, 340-349, *156* (5).   IF: 16.01

6.4   Wegwarth, O., & Gigerenzer, G. Overdiagnosis and overtreatment: Evaluation of what physicians tell patients about screening harms, *JAMA Internal Medicine*, 12/2013, 2086-2087, *173 (22).*   IF: 13.25

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6.1 Appendix: "There is nothing to worry about": Gynecologists' counseling on mammography.

Coding scheme for information gathered during telephone counseling (Note: this coding scheme is a translated version of the German original.)

1) **Risk of having cancer at mother's age:**
   ☐ No information
   ☐ Verbal qualifier:

   _____

   _____

   ☐ Numerical information:
       ☐ Lifetime incidence (numbers ≈ 10%)
       ☐ Prevalence (numbers ≈ 1% and 2%, 1 to 2 in 100)
       ☐ Other numbers: _____

   Further remarks:

   _____

2) **Benefits of mammography:**
   a. Reduction of disease-specific mortality
   ☐ No information
   ☐ Verbal qualifier:

   _____

   _____

   ☐ Numerical information:
       ☐ Absolute risk reduction (numbers ≈ 1 in 1,000, also 5 to 4 in
          1,000, 4 to 3 in 1,000, 11 to 10 in 2,000, 0.1%)
       ☐ Relative risk reduction (numbers ≈ 25%, 20%, 10%)
   ☐ Other number: _____

   Further remarks:

   _____

   b. Reduction of overall mortality

☐ No information

☐ Verbal qualifier:

_____

_____

☐ Numerical information:

    ☐ Absolute risk reduction (numbers ≈ 0 in 1,000; no more life is saved)

    ☐ Other number: _____

Further remarks:

_____

3) Risks of mammography screening:

☐ *Risk of false alarms*

    ☐ No information

    ☐ Verbal qualifier:

_____

    ☐ Numerical information:

_____

☐ *Risk of misses*

    ☐ No information

    ☐ Verbal qualifier:

_____

    ☐ Numerical information:

_____

☐ *Risk of overdiagnosis and overtreatment*

    ☐ No information

    ☐ Verbal qualifier:

_____

    ☐ Numerical information:

_____

☐ *Risk of X-rays*

    ☐ No information

    ☐ Verbal qualifier:

_____

☐ Numerical information:

_____

Further remarks:

_____

6.2   Appendix: Deceiving numbers: Survival rates and their impact on doctors' risk communication.

Conditions of the survey versions: "group" and "time"
(Note, this is a translation of the German surveys)

Preface to the study (displayed in both versions "group" and "time")
For all screenings mentioned in the following questionnaire, please assume the following: They are noninvasive, and they detect tumors for which several treatment options such as surgery, chemotherapy, and radiotherapy exist. Furthermore, each of the respective screenings commenced being routinely used at the beginning of the 1990s.

Conditions of version "group"

1) Condition 5Y
A 55-year-old healthy patient of yours has come to see you today because s/he is seeking advice on whether to attend screening for tumor E. You know that the screening began to be routinely used at the beginning of the 1990s. Based on data from a randomized trial you know the following:

- The 5-year survival rate after diagnosis is 82% for the unscreened group.
- The 5-year survival rate after diagnosis is 98% for the screened group.

A) Based on this data, would you recommend undergoing screening to your patient?

Yes, I would.   ☐
No, I would not.   ☐
I can't decide.   ☐

Why?_____

B) Based on this data, do you think screening will reduce the number of people who will die from tumor E?

 Yes.   ☐

If yes, out of 1,000 people, how many fewer will die of tumor E if they regularly attend screening?   _____of 1,000

No.   ☐

2) Condition 5YM
A 55-year-old healthy patient […]

- The 5-year survival rate after diagnosis is 67% for the unscreened group.
- The 5-year survival rate after diagnosis is 80% for the screened group.

- The disease-specific mortality rate for the unscreened group is 12.5 out of 100,000 persons.
- The disease-specific mortality rate for the screened group is 13 out of 100,000 persons.

A) Based on this data, would you recommend […]

3) Condition M
A 55-year-old healthy patient […]

- The disease-specific mortality rate for the unscreened group is 18 out of 100,000 persons.
- The disease-specific mortality rate for the screened group is 18 out of 100,000 persons.

A) Based on this data, would you recommend […]

4) Condition 5YMI
A 55-year-old healthy patient […]

- The 5-year survival rate after diagnosis is 75% for the unscreened group.
- The 5-year survival rate after diagnosis is 89% for the screened group.

- The disease-specific mortality rate for the unscreened group is 14.2 out of 100,000 persons.
- The disease-specific mortality rate for the screened group is 14.5 out of 100,000 persons.

- The incidence for the unscreened group is 51 out of 100,000 persons.
- The incidence for the screened group is 97 out of 100,000 persons.

A) Based on this data, would you recommend […]

Conditions of version "time"

1) Condition 5Y

A 55-year-old healthy patient of yours has come to see you today because s/he is seeking advice on whether to attend screening for tumor A. You know that the screening began to be routinely used at the beginning of the 1990s. Based on data of the SEER Program of the NCI you know the following:

- The 5-year survival rate after diagnosis was 67% in 1975.
- In 2004, the 5-year survival rate had increased up to 98%.

A) Based on this data, would you recommend undergoing screening to your patient?

Yes, I would.	☐
No, I would not.	☐
I can't decide.	☐

Why?_____

B) Based on this data, do you think screening will reduce the number of people who will die from tumor A?

Yes. ☐

If yes, out of 1,000 people, how many fewer will die of tumor A if they regularly attend screening?   _____of 1,000

No. ☐

2) Condition 5YM

A 55-year-old healthy patient […]

- The 5-year survival rate after diagnosis was 55% in 1975.

- In 2004, the 5-year survival rate had increased up to 80%.

- The disease-specific mortality rate was 25 out of 100,000 persons in 1975.
- In 2004, it was 26 out of 100,000 persons.

A) Based on this data, would you recommend […]

3) Condition M
A 55-year-old healthy patient […]

- The disease-specific mortality rate was 37 out of 100,000 persons in 1975.
- In 2004, it was 37.3 out of 100,000 persons.

A) Based on this data, would you recommend […]

4) Condition 5YMI
A 55-year-old healthy patient […]

- The 5-year survival rate after diagnosis was 61% in 1975.
- In 2004, the 5-year survival rate had increased up to 89%.

- The disease-specific mortality rate was 28.2 out of 100,000 persons in 1975.
- In 2004, it was 28.7 out of 100,000 persons.

- The incidence was 103 out of 100,000 persons in 1975.
- In 2004, it was 194 out of 100,000 persons.

A) Based on this data, would you recommend […]

6.3 Appendix: Do physicians understand cancer screening statistics? A national survey of primary care physicians in the United States.

(The following questions were preceded by two survey screener questions—the first on primary specialty, the second on divided clinical time—and information about this survey).
(Note, this transcript of a survey, which was originally presented as an interactive online survey)

1. Which of the following prove that a cancer screening test "saves lives" from cancer?

		Proves screening saves lives	Does not prove screening saves lives	Don't know
a.	Screen-detected cancers have better 5-year survival rates than cancers detected because of symptoms.	☐	☐	☐
b.	More cancers are detected in screened populations than in unscreened populations.	☐	☐	☐
c.	Mortality rates are lower among screened persons than unscreened persons in a randomized trial.	☐	☐	☐

We are now going to ask you about a screening for **Cancer X** in more detail.

In the following, please assume that

- the screening is noninvasive
- it is free
- and it detects a cancer for which treatment, such as surgery, radiotherapy, etc., is available.

2. Imagine that a 55-year-old healthy patient asks you about a screening for **Cancer X**.

Please answer the following questions based on data for patients age 50 to 69 (in the table below), which come from a large trial of U.S. adults that lasted about 10 years.

	Without screening test	With screening test
5-year survival rate	68%	99%

Please choose <u>one</u> answer for each question.

2a. Would you recommend this screening test to your patient?

☐ Definitely yes
☐ Probably yes
☐ Probably no
☐ Definitely no
☐ Can't decide

Why?_____

2b. Do you think this screening test saves lives from **Cancer X**?

☐ Yes
☐ No
☐ Can't tell

(if "yes" participants were directed to 2c, otherwise to 3)

2c. How would you describe the mortality benefit of screening for **Cancer X**?

☐ Very large
☐ Large
☐ Moderate
☐ Small
☐ Very small

2d. If 1000 people age 50 to 69 were screened regularly over the next 5 years, approximately how many fewer would die of **Cancer X** than if they were not screened?

_____ out of 1000   ☐ Given the data I can't tell

3. Now, next to the information you already received, consider an additional piece of information from the same trial on screening for **Cancer X**.

	Without screening test	With screening test
5-year survival rate	68%	99%
Percent of cancer X detected at stage I (early cancers)	36%	54%

3a. How does the stage information affect your recommendation about the screening?

☐ Much more likely to recommend screening
☐ More likely to recommend screening
☐ No change
☐ Less likely to recommend screening
☐ Much less likely to recommend screening

3b. After having received the additional information, do you expect the screening to save more lives from **Cancer X** than you thought without this information?

☐ Yes

☐ No
☐ Can't tell

We are now going to ask you about another screening in more detail, this time for **Cancer Z**. Again, please assume in the following that
- the screening is noninvasive
- it is free
- and it detects a cancer for which treatment, such as surgery, radiotherapy, etc., is available.

4. Imagine that your 55-year-old healthy patient also asks about a screening for **Cancer Z**.

Please answer the following questions based on data for patients age 50 to 69 (in the table below), which come from a large trial of U.S. adults that lasted about 10 years.

	Without screening test	With screening test
Mortality Risk of dying from **Cancer Z** over 5 years	2.0 deaths per 1000 people	1.6 deaths per 1000 people

Please choose <u>one</u> answer for each question.

4a. Would you recommend this screening test to your patient?

☐ Definitely yes
☐ Probably yes
☐ Probably no
☐ Definitely no
☐ Can't decide

Why?_____

4b. Do you think this screening saves lives from **Cancer Z**?

☐ Yes
☐ No

☐ Can't tell

(if "yes" participants were directed to 4c, otherwise to 5)

4c. How would you describe the mortality benefit of screening for **Cancer Z**?

☐ Very large
☐ Large
☐ Moderate
☐ Small
☐ Very small

4d. If 1000 people age 50 to 69 were screened regularly over the next 5 years, approximately how many fewer would die of **Cancer Z** than if they were not screened?

_____ out of 1000   ☐ Given the data I can't tell

5. Now, next to the information you already received, consider an additional piece of information from the same trial on screening for **Cancer Z.**

	Without screening test	With screening test
Mortality Risk of dying from **Cancer Z** over **5** years	2.0 deaths per 1000 people	1.6 deaths per 1000 people
Incidence Risk of diagnosis of **Cancer Z** over **5** years	27 cancers per 1000 people	46 cancers per 1000 people

5a. How does the additional information on incidence affect your recommendation about the screening?

☐ Much more likely to recommend screening
☐ More likely to recommend screening

☐ No change
☐ Less likely to recommend screening
☐ Much less likely to recommend screening

5b. After having received the additional information, do you expect the screening to save more lives from Cancer Z than you thought without this information?

☐ Yes
☐ No
☐ Can't tell

	Without screening test	With screening test
Mortality Risk of dying from **Cancer Z** over **5 years**	2.0 deaths per 1000 people	1.6 deaths per 1000 people
Incidence Risk of diagnosis of **Cancer Z** over **5 years**	27 cancers per 1000 people	46 cancers per 1000 people

5c. Do you think the following statements about the incidence and mortality
data in the table (above) are true or false?

	True	False	Don't know
People in the screened group must have had more Cancer Z risk factors than people in the unscreened group did.	☐	☐	☐
For every death prevented by screening, some people are diagnosed with and treated for Cancer Z unnecessarily.	☐	☐	☐
The decreased mortality is all the more impressive given the higher incidence of cancer with screening.	☐	☐	☐

6. Some professional organizations have suggested including EDUCATIONAL
notes to help doctors interpret screening information.

Please consider the following EDUCATIONAL note about Cancer Z in
addition to the data you have already seen.

	Without screening test	With screening test
Mortality Risk of dying from Cancer Z over 5 years	2.0 deaths per 1000 people	1.6 deaths per 1000 people
Incidence Risk of diagnosis of Cancer Z over 5 years	27 cancers per 1000 people	46 cancers per 1000 people

NOTE: To prevent one death from Cancer Z, as many as 47 additional
people would be diagnosed with Cancer Z and treated (e.g., with surgery
or radiotherapy) unnecessarily.

6a. How does the information in the note affect your recommendation about the screening compared to the information you already had about **Cancer Z**?

☐ Much more likely to recommend screening
☐ More likely to recommend screening
☐ No change
☐ Less likely to recommend screening
☐ Much less likely to recommend screening

6b. What did you think of this educational note about **Cancer Z**?

☐ Extremely helpful
☐ Somewhat helpful
☐ Nothing new
☐ Confusing

7. Let's go back to **Cancer X**.

Also for **Cancer X**, some professional organizations have suggested including EDUCATIONAL notes to help doctors interpret screening information.

Please consider the following EDUCATIONAL note about **Cancer X** in addition to the data you have already seen.

	Without screening test	With screening test
5-year survival rate	68%	99%
Percent of cancer X detected at stage I (early cancers)	36%	54%

NOTE:

Higher 5-year survival rates (or finding more early-stage cancers) with screening do not prove that screening saves lives, due to biases such as lead-time bias.

The only way to know if screening saves lives is when a study or randomized trial demonstrates that **Cancer X** mortality is lower in the screening group compared to the non-screening group.

7a. How does the information in the note affect your recommendation about the screening compared to the information you already had about **Cancer X**?

☐ Much more likely to recommend screening
☐ More likely to recommend screening
☐ No change
☐ Less likely to recommend screening
☐ Much less likely to recommend screening

7b.   What did you think of this educational note about **Cancer X**?

☐ Extremely helpful
☐ Somewhat helpful
☐ Nothing new
☐ Confusing

Thank you very much for completing the survey!

6.4   Appendix: Overdiagnosis and overtreatment: Evaluation of what physicians tell patients about screening harms.

(Note, this transcript of a survey, which was originally presented as an interactive online survey)

Survey

---Explanation of overdiagnosis and overtreatment---

In the next paragraph, we are going explain the most common harms associated with

cancer screening: overdiagnosis and overtreatment. Your understanding of these

harms is important as you will be asked for your opinion on them afterward.

Cancer screening results in some degree of overdiagnosis, which means the

detection of "pseudocancer." Pseudocancers are screen-detected cell abnormalities

that meet the pathological definition of cancer but will never progress to a cancer

that will threaten your life or cause you any symptoms during your lifetime.

Pathologically, these pseudocancers are hard to distinguish from real (progressive

and threatening) cancers. So if you tested positive your doctor would not always

know for certain whether the cell abnormality is progressive (real cancer) or not

(pseudocancer). Most of the pseudocancers will be ruled out by further testing.

However, no cancer screening test is 100% certain, which is why you cannot reduce

the risk of being overdiagnosed with a pseudocancer to zero. Thus, some people

remain overdiagnosed even after further testing. As a consequence, those who do

not actually have a "real" cancer will nonetheless be treated for a "real" cancer by

therapies such as chemotherapy, surgery, and radiation. This is called overtreatment.

Overtreated people do not profit in any physical way from the treatment but, on the contrary, may only suffer some of the various side effects from cancer treatment.

---Start survey----

1) Imagine you are considering a cancer screening that saves 1 person per 1,000 screened people from dying from the cancer. However, this cancer screening also results in some degree of overdiagnosis and thereby in overtreatment, such as unnecessary surgery and radiation. Please indicate by ticking one of the boxes below what number of overdiagnosed people among these 1,000 you would find tolerable while still being prepared to do the screening:

0 people	☐
Up to 1 person	☐
Up to 5 people	☐
Up to 10 people	☐
Up to 20 people	☐
Up to 50 people	☐
Up to 100 people	☐

2) Have you ever had routine cancer screening?

☐ YES

    Which of the following screening tests do/did you routinely attend?

    ☐ Mammography

    ☐ Papanicolaou test (pap smear test)

    ☐ PSA test

    ☐ Sigmoidoscopy or colonoscopy

☐ others

(participants were directed to question 3)

☐ NO

(participants were directed to question 4)

3) Did your physicians tell you about the possibility of being overdiagnosed and/or overtreated if having the cancer screening test?

☐ YES

> *Did your physicians quantify the risk of being overdiagnosed/overtreated, that is, provide you with a number of the risk?*
>
> ☐ *yes*
>
> *For what cancer screening test did your doctor tell you the risk of overdiagnosis/overtreatment in numbers?*
>
> | | |
> |---|---|
> | ☐ *Mammography* | *What was the number: _____* |
> | ☐ *Papanicolaou test (pap smear test)* | *What was the number: _____* |
> | ☐ *PSA test* | *What was the number: _____* |
> | ☐ *Sigmoidoscopy or colonoscopy* | *What was the number: _____* |
> | ☐ *others _____* | *What was the number: _____* |
>
> *If you learned that one of the screening tests you are doing on a regular basis would result in about 10 overdiagnosed people per one life saved from cancer, would you continue to have that screening test?*
>
> ☐ *yes*
>
> ☐ *probably yes*
>
> ☐ *probably no*
>
> ☐ *no*
>
> *("thank you" page)*
>
> ☐ *no*
>
> > *Would you have liked to receive the estimate of the risk of being overdiagnosed/overtreated?*
> >
> > ☐ *yes*
> >
> > ☐ *no*

If you learned that one of the screening tests you are doing on a regular basis would result in about 10 overdiagnosed people per one life saved from cancer, would you continue to have that screening test?

☐ *yes*

☐ *probably yes*

☐ *probably no*

☐ *no*

("thank you" page)

☐ NO

Would you have liked to be told about the risk of overdiagnosis and overtreatment by your physician before being tested?

☐ *yes*

☐ *no*

If you learned that one of the screening tests you are doing on a regular basis would result in about 10 overdiagnosed people per one life saved from cancer, would you continue to have that screening test?

☐ *yes*

☐ *probably yes*

☐ *probably no*

☐ *no*

("thank you" page)

4) Have you ever heard of the possibility of being overdiagnosed and overtreated?

☐ YES

How did you hear about it?

☐ *from the media*

☐ *from my doctor*

☐ *from friends/family members*

☐ *from health-related Web sites/health agencies*

☐ *other resources*

(If not "from my doctor"): Would you have liked to be told about the risk of overdiagnosis and overtreatment by your physician?

❑ *yes*

❑ *no*

If you learned that one of the cancer screening tests you may consider in the future would result in about 10 overdiagnosed people per one life saved from cancer, would this screening test still be an option for you?

❑ *yes*

❑ *probably yes*

❑ *probably no*

❑ *no*

So far, you haven't had any cancer screening test. Is the possibility of being overdiagnosed part of this decision?

❑ *yes*

❑ *no*

("thank you" page)

❑ NO

Would you like to be told about the risk of overdiagnosis and overtreatment by your physician before being tested?

❑ *yes*

❑ *no*

If you learned that one of the cancer screening tests you may consider in the future would results in about 10 overdiagnosed people per one life saved from cancer, would this screening test still be an option for you?

❑ *yes*

❑ *probably yes*

❑ *probably no*

❑ *no*

("thank you" page)

6.5   Appendix: Overcoming the knowledge-behavior gap: The effect of evidence-based HPV vaccination leaflets on understanding, intention, and actual vaccination decision.

Part 1

Before getting started with the questionnaire, we would like to ask you to provide the following information so that we can assign your responses an anonymous code.

Code:
- First and second letter of your mother's first name:

    _____

- Day of birth (indicate the day only: for instance, May 15th, 1998 = 15):

    _____

- Second and third letter of your first name:

    _____

Question 1:
Have you ever heard about the HPV vaccine (also called the cervical cancer vaccine) for girls aged 12 to 17 years?
☐ Yes
If YES, please continue with *Question 2*.

☐ No
If NO, please take the leaflet and read it carefully. Take as much time as you need. Once you have finished, take the second part of the questionnaire to hand and continue with **question 8.**

Question 2:
Judging on what you have heard about the vaccine so far, do you think that you would also like to have it?
☐ Yes, I want to have the vaccine.
☐ No, I do not want to have the vaccine.
☐ I am not sure, whether I want to have the vaccine.

Question 3:
The vaccine is often referred to as the "cervical cancer vaccine." What do you think how risky is it to develop cervical cancer WITHOUT having the vaccine?
My risk is:

Not risky	Not very risky	Somewhat risky	Very risky	Highly risky

Question 4:
What has the HPV vaccine been shown to prevent?

☐ Preliminary forms of cervical cancer.
☐ Cervical cancer.
☐ I don't know.

Question 5:
For every 100,000 women in Germany, how many do you think _develop_ cervical cancer each year?
☐ Up to 10 out of every 100,000 women.
☐ Up to 100 out of every 100,000 women.
☐ Up to 1,000 out of every 100,000 women.
☐ More than 1,000 out of every 100,000 women.
☐ I don't know.

Question 6:
For every 100,000 women in Germany, how many do you think _die_ of cervical cancer each year?
☐ Up to 10 out of every 100,000 women.
☐ Up to 100 out of every 100,000 women.
☐ Up to 1,000 out of every 100,000 women.
☐ More than 1,000 out of every 100,000 women.
☐ I don't know.

Question 7:
Within 100,000 women, how many of these _deaths_ do you think _could potentially be prevented by the HPV vaccination_?
☐ Approximately 1 death.
☐ Up to 10 deaths.
☐ Up to 100 deaths.
☐ Up to 1,000 deaths.
☐ I don't know.

PLEASE READ THE LEAFLET BEFORE ANSWERING THE FOLLOWING QUESTIONS.

Part 2

!!! The purpose of the study is to learn how to improve leaflets on medical matters. It is thus very important to us that you answer the following questions WITHOUT using the leaflet. If you do not know an answer, just check what you consider to be right or probable!!!

Question 8:
What has the HPV vaccine been shown to prevent?
☐ Precancerous forms of cervical cancer

☐ Cervical cancer
☐ I don't know.

Question 9:
For every 100,000 women in Germany, how many do you think _develop_ cervical cancer each year?
    ☐ Up to 10 out of every 100,000 women.
    ☐ Up to 100 out of every 100,000 women.
    ☐ Up to 1,000 out of every 100,000 women.
    ☐ More than 1,000 out of every 100,000 women.
    ☐ I don't know.

Question 10:
For every 100,000 women in Germany, how many do you think _die_ of cervical cancer each year?
    ☐ Up to 10 out of every 100,000 women.
    ☐ Up to 100 out of every 100,000 women.
    ☐ Up to 1,000 out of every 100,000 women.
    ☐ More than 1,000 out of every 100,000 women.
    ☐ I don't know.

Question 11:
Within 100,000 women, how many of these _deaths_ do you think _could potentially be prevented by HPV vaccination_?
    ☐ Approximately 1 death.
    ☐ Up to 10 deaths.
    ☐ Up to 100 deaths.
    ☐ Up to 1,000 deaths.
    ☐ I don't know.

Question 12:
Please tick all of the following listed harms, which you think are associated with the HPV vaccination:
    ☐ Infertility
    ☐ Issues at the injection site, e.g..; swelling, redness, pain
    ☐ Shortness in breath, breathing trouble
    ☐ Unspecific pain or problems with the joints (arthritis)
    ☐ Hallucinations
    ☐ None of these.

Question 13:
Judging on what you now know about the HPV vaccine, do you think that you would like to have it?
    ☐ Yes, I want to have the vaccine.
    ☐ No, I do not want to have the vaccine.
    ☐ I am not sure, whether I want to have the vaccine.

Question 14:
After reading the brochure, what do you think how risky is it to develop cervical cancer without having the HPV vaccination? My risk is:

Not risky	Not very risky	Somewhat risky	Very risky	Highly risky

Congratulations, you made it!

Thank you very much for taking the time to help with our project
„HPV vaccination? Know your chances!".

Acknowledgements

Erklärung
§ 4 Abs. 3 (k) der HabOMed der Charité

Hiermit erkläre ich, dass

- weder früher noch gleichzeitig ein Habilitationsverfahren durchgeführt oder angemeldet wurde,
- die vorgelegte Habilitationsschrift ohne fremde Hilfe verfasst, die beschriebenen Ergebnisse selbst gewonnen sowie die verwendeten Hilfsmittel, die Zusammenarbeit mit anderen Wissenschaftlern/Wissenschaftlerinnen und mit technischen Hilfskräften sowie die verwendete Literatur vollständig in der Habilitationsschrift angegeben wurden,
- mir die geltende Habilitationsordnung bekannt ist.

Ich erkläre ferner, dass mir die Satzung der Charité – Universitätsmedizin Berlin zur Sicherung Guter Wissenschaftlicher Praxis bekannt ist und ich mich zur Einhaltung dieser Satzung verpflichte.

………………………………….   ……………………………..
Datum   Unterschrift