

**Rudy Owens**  
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**Learning Objective:** How do we change recommendations and have stakeholders respond appropriately.

**Changing Health Recommendations on Controversial Procedures Requires a Careful Consideration of the Public's Interests Prior to Rolling out New Guidelines**

**ABSTRACT:** *A major challenge for health professionals is translating epidemiological concepts of health risks into common language so individuals can use the information to make educated personal decisions. That challenge is further complicated with controversial topics, such as how to best use mammography to detect breast cancer, as seen when recommendations for routine mammograms were recently changed based on a review of data and risks. The strong reaction critical of the U.S. Preventive Services Task Force's (USPSTF) breast cancer screening recommendations from November 2009 highlights the perils medical and scientific professionals face in a 24-hour news cycle and in a media-saturated communications environment. Independent scientific panels cannot operate in a media vacuum and must be responsible to the public when communicating risk information concerning health topics of great interest.*

**Communicating Health Risks:** Communicating health risks and revising risk recommendations is decentralized and often driven by media outlets that do not have an understanding of science.<sup>1</sup> No one party controls the full message. In fact, most public health messages operate in a contested environment with conflicting, even hostile messages.<sup>2</sup> Instead, multiple parties, such as panels like the USPSTF, health advocacy groups, elected officials, professional medical organizations, and medical and scientific publications each convey information with a goal of influencing outcomes and health behaviors. As seen with the November 2009 revisions to the USPSTF's 2002 breast cancer screening recommendations, changes to health guidelines can lead to debates that can further confuse the public. This controversy is not surprising, given breast cancer is the most frequently diagnosed cancer among women and the second-leading cause of cancer deaths among women in the United States, claiming the lives of an estimated 39,840 women in 2010.<sup>3</sup> State health administrators, as seen in our case, then face the confusing task of interpreting conflicting health messages and determining whether to cover annual mammography for all women ages 40-50 enrolled in the state's Healthy Options Program.

Health communications are critical to disease prevention and health promotion.<sup>4</sup> They overlap with patient-provider relations, individual's adherence to clinical recommendations, the development of public health message campaigns, and the education

of consumers. At the individual level, they can help raise awareness of health risks and solutions. The Healthy People 2010 report notes healthy communications must be: accurate, available, balanced, consistent, culturally relevant, evidence-based, reliable, repetitive, timely, and understandable.<sup>4</sup> The U.S. Centers for Disease Control and Prevention, only as recent as 1993, formally integrated health communications into prevention programs with the goal of influencing behavior to promote individual and community health.<sup>5</sup>

However, the communication process is dynamic. It involves a complex interaction of those sharing and receiving the message, requiring that risk information be presented with care. Thus any communication of health risks to the public also needs to take into account<sup>6</sup>:

- the perceived control over an illness by individuals and society,
- the dread or fear of a disease—in the case of breast cancer, its delayed effects,
- the public's general understanding of risk,
- media interest in the topic, and
- trust in the organizations or institutions.

Those communicating risks must be sure they are developing clear and consistent messages for the news media, as risk perceptions, when linked to media portrayals of risk, are highly contingent upon how messages are framed and communicated and who communicates them.<sup>1</sup>

In the practice of clinical medicine and epidemiology, the concept of risk is critical to understanding a disease and its prevention. Generally, risk is conveyed as a statistical measurement as a degree of association between characteristics or conditions of a disease in a given population.<sup>7</sup> But lay people's ability to translate scientific knowledge into useful concepts is problematic. The lay audience does not think the same way about risks as public health professionals and scientists.<sup>6</sup> People can misunderstand scientific or probabilistic data. Rare risks are often overrated and more common risks are underrated, and individuals' own preconceptions greatly impact how they interpret risk information.<sup>7</sup> Lay people also have problems understanding cumulative risk. Finally, it is the perception of risk, not actual risk, that determines how people respond to potential hazards.<sup>1</sup>

For instance, saying someone has a 1.3 chance in 10,000 of getting ill compared to the population's chance of 1.0 in 10,000 is not meaningful to many people, but saying that an individual's risk is 30 percent higher than the general population's is seen as "riskier,"

though these are equivalent.<sup>7</sup> What's more, some people may personally view health risks pessimistically, while optimists believe that diseases "can't happen to me." Control over one's environment and life also impacts personal perception. Those with familial history of cancer do not interpret risk hypothetically; they see it as a reality with personal and familial meaning.<sup>7</sup> The situation is further complicated by the emergence of new research, which needs to be evaluated against existing health guidelines.

Each year, patients and doctors receive hundreds of cancer screening messages, leading to confusion, even among experts. According to a survey by the National Cancer Institute, more than two-thirds of those surveyed responded that there were so many recommendations on cancer prevention that it was difficult to determine what to follow.<sup>8</sup> A Canadian study on cancer screening recommendations found physicians did not adhere to such guidelines backed by good evidence and that many physicians had performed cancer screening procedures (routine mammograms for women ages 40-49) that were not recommended by the Canadian equivalent of the USPSTF.<sup>9</sup>

**Who Updates Guidelines and Why They Do It:** The group at the center of the mammography controversy in this case, the USPSTF, was created by the U.S. Public Health Service in 1984. It remains an independent panel of medical experts that assesses the benefits and harms of preventive services in people asymptomatic for diseases and makes recommendations for preventive services that should be used in primary care practices.<sup>10</sup> Its evidence-based recommendations are intended for health care providers, which reportedly allows clinicians to make informed decisions for patients. The body meets three times a year. Each USPSTF recommendation is given a grade (A, B, C, D, I) based on the strength of the evidence about the benefits and risk of a preventive service. Grades of **A** and **B** are recommendations for the service, with a high certainty of benefit. A grade of **C**—the grade given by the panel in November 2009 for women to start regular, biennial screening mammography before the age of 50 years—is a recommendation against routinely offering the service and moderate certainty the benefit is small. Grade **D** recommends against the service, and grade **I** means insufficient evidence to make a determination.<sup>11</sup>

The USPSTF is now allowing public comments on its draft recommendation statements prior to their publication. The USPSTF claims it is taking this new step "to keep its work and methods clear to the public it serves." Based on the panel's web site, this new practice

only began in 2010, after the controversy erupted surrounding its revisions to its previous breast cancer screening recommendations.<sup>12</sup>

Other prominent health organizations have protocols for communicating cancer risks, some different than the USPSTF's. The American Cancer Society (ACS), since 2000, has published an annual summary of recommendations for early cancer detection, guidance about testing for early detection for cancers where mass screening is not recommended, emerging issues, and current data on cancer screening rates for adults. Guidelines are reviewed and revised at least every 5 years, but may be changed earlier if evidence warrants a new recommendation to health professionals and the public.<sup>13</sup> There is no time-specific mandate for new guidelines; those are driven by the emergence of new data from researchers.

**Misunderstanding or Poor Communications:** On Nov. 16, 2009, the USPSTF ignited a media firestorm by revising its 2002 breast cancer screening guidelines for the general population, even though it offered nearly the same recommendation in 1989. The panel updated its statement that women age 40 and over have a mammogram every 1-2 years. The body first publicly communicated "against routine screening mammography in women aged 40 to 49 years," leading to confusion. That sentence was later dropped, and the final message said the "decision to start regular biennial screening mammography before the age of 50 years should be an individual one and take into account patient context, including the patient's values regarding specific benefit and harms"(see summary table).<sup>11,14</sup> The USPSTF also recommended against teaching breast self-examination (BSE) and concluded the current evidence was insufficient to assess the additional benefits and harms of clinical breast exams (CBEs) beyond screening mammography for women ages 50-74.<sup>11</sup> Immediately, the American Cancer Society, the National Cancer Institute, and the American College of Obstetricians and Gynecologists attacked the panel's conclusion and said they would not change their guidelines and would continue to urge women ages 40-49 to undergo the tests.<sup>15</sup>

**Summary of USPSTF Screening Mammography Guidelines: 2002 and 2009<sup>11,16</sup>**

New USPSTF Guidelines (Nov. 2009)			USPSTF Guidelines 2002-2009	American Cancer Society Guidelines
Mammo-	Before	-No routine screening	Age 40+: routine	Age 40+, annual

grams	age 50	-Mammograms to be given on case-by-case basis after assessing risk factors	screening every 1-2 years.	mammograms
	Age 50-74	Mammograms every 2 years		
	Age 75+	No recommendations		
Self-exam		Recommends against physicians teaching patients how to do this	No recommendations	Recommends but does not specify time interval
Clinical breast exam		No recommendations	No recommendations	-Age 40+ annual -Age 20-39, every 3 years

The debate over changes to the panel’s previous mammography guidelines were driven by pronounced public concerns over breast cancer itself. For instance, the USPSTF ‘s 2008 recommendations against men age 75 and older getting prostate-specific antigen (PSA) blood test for prostate cancer did not generate widespread coverage.<sup>17</sup> The controversy also was fueled by its timing amid an intense national debate over health-care reforms proposed by the Obama administration and by critics of the new recommendations, who stoked fears of medical rationing.<sup>16</sup> The concerns were not unwarranted, as it was reported the 16-member panel’s conclusions, under the proposed health reforms, would set standards for services insurance plans would be required to cover at little or no cost in the reforms. In late 2009, 39 million U.S. women were receiving mammograms each year costing about \$5 billion.<sup>16</sup>

By November 2009, distrust of government also had grown because of the economic crisis and partisan differences over the size and role of government. National polling in 2009 found trust in the federal government had shrunk—6 in 10 Americans said their confidence had fallen from the previous year.<sup>18</sup> Messaging from any quasi-government panel likely would be compromised in this climate. The public’s level of trust can determine if communications are able to lead to changes in behavior or adoptions of self-protective actions.<sup>6,19</sup> What’s more, trust can be further eroded when there are contradictory communications from experts or groups of experts, as occurred in this mammography guidelines dispute.<sup>19</sup>

Finally, the dispute also demonstrated that health recommendations by scientific bodies can be turned into controversies by 24/7 news programming, talk radio, blogs, and misinformation offered by reporters, pundits, and politicians.<sup>14</sup> Daniel Kopans, radiology

professor at Harvard Medical School, was quoted saying: “Tens of thousands of lives are being saved by mammography screening, and these idiots want to do away with it. It’s crazy – unethical, really.”<sup>16</sup> Clinicians have noted the communication of highly charged health guidelines needs to be attuned to public sensitivities, and that independent bodies need to be immune from political intimidation to preserve their integrity.<sup>14</sup> But achieving this balancing act, in the United States and in other countries debating mammography guidelines, appears impossible because opposing camps have created lobbies promoting their own interpretation of breast cancer research.<sup>20</sup> Dr. Lisa Swarz of Dartmouth characterized breast cancer screening guidelines since the 1990s as “one-sided messages from doctors and advocacy groups, in essence, telling them they were crazy if they didn’t get screened.” She claims the members of the medical community, particular doctors, since the late 1990s have not accurately communicated risk and harms of mammography, preventing women from making informed decisions to do mammograms in their 40s.<sup>17</sup>

**Back to the Case/Questions:** In addition to being the No. 2 cancer killer among U.S. women, breast cancer is also a U.S. cultural phenomenon, with corporate branding, official color designation, and “Race for the Cure” events that attract 1 million persons annually.<sup>21</sup> Social amplification theory suggests that events can interact with psychological, social, and institutional factors in ways that intensify risk perceptions.<sup>1</sup> Given the prevalence and awareness of breast cancer in the United States, the debate triggered by the USPSTF’s announcement was not surprising. What is less clear from this incident is if the USPSTF will exercise self-censorship when it considers its next recommendations on a controversial preventive service and whether health administrators, such as the State of Washington’s Department of Health, can make an informed decision to cover mammograms for women ages 40-49 if the USPSTF recommendation is in conflict with other prominent bodies’ guidelines for screening mammography for that same group.

- 1. Why did the public not erupt in fury when the USPSTF recommended against men age 75 and older getting a PSA blood test for prostate cancer?**
- 2. How will the new health care reform law passed by Congress impact how insurance companies cover routine annual mammography screening?**

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