

“SHITTY FIRST DRAFT”

Evidence-based medicine will never get anywhere until its practitioners can learn to weave evidence into a convincing story, and that requires four steps. The first is to uncover the motives and fears behind existing practices. “The more you say you don’t need that test or treatment, the more they’ll show you that they need it,” says Stein. “The answer to escalation is disarm. Instead of shouting louder, whisper. What are you afraid of?” says Stein.

“It’s often about fear and vulnerability and helplessness,” Stein says. The woman fighting for more mammograms may have felt helpless against cancer. “She thinks, I was once helpless and I will never be helpless again. I will prevent other women from ever feeling what I felt.” To explain the new guidelines to such women one needs to ask, “What have you been told before that has helped you deal with that fear? What can we tell you now that will address those fears?” says Stein.

Likewise, the runners who pop ibuprofen aren’t clinging to the drug out of loyalty, they’re taking it out of fear that without it they’ll be cobbled by pain and inflammation, and Nieman’s story about his results needs to speak to this concern.

Second, the story of new evidence must acknowledge the existing narrative. For supporters of the USPTF mammography guidelines, that means addressing head on the belief that mammograms are the best way to save lives. “When the USPSTF came out, they might have said, ‘we know that for years you’ve heard this, and the reason we’re changing course now is that we realize that there are harms associated with screening and we’re doing this because we care about you. We’re telling you the whole story now and it’s more complicated than we thought,’” says Schwartz. The task force needs to emphasize in its message that the guidelines have the same goal as the previous one—to save lives. “It sounds like such a different message.”

Instead of putting the answer first—researchers say do fewer mammograms—headlines about the mammogram guidelines should put the question front and center—researchers ask, how many mammograms provide the most benefits and fewest risks?—says Epstein.

Third, the evidence-based narrative must not only addresses existing concerns but offer a measure of comfort. “Medical uncertainty is very hard, so you need to find a way to reframe it so that you can say, the good thing about this is...,” says Elizabeth Rider, an assistant professor of Pediatrics at Harvard Medical School. For example, the person demanding an MRI to diagnose his back pain doesn’t just need to know that “the good news is...” that he can spare himself the hassle and potential harms from an MRI, he also needs reassurance that his back pain is very likely to get better soon, even if he opts not to do the scan right away. If the patient’s bias is toward doing *something*, this intention to help himself should be honored by giving him something tangible to do, such as exercise.

Lastly, new results must be put in the context of a mental model, and this model should be framed to emphasize the positive. In the case of mammograms, women need to be told, not just that the relentless progression model should be replaced by the uncertain future one, but that this new model contains a ray of hope. "There's good news here," says Susan Love, president of the Dr. Susan Love Research Foundation and author of *Dr. Susan Love's Breast Book*. While the uncertain future mental model doesn't offer the concrete certainty that "this mammogram will save your life" that the relentless progression model does, it means that not every cancer is scary. The evidence-based story says that you can have a cancer without disease, and that means we don't have to blast away every cancer cell, Love says.

But until an evidence-centered mind model becomes dominant, proponents of evidence-based medicine will continue to face pushbacks. "For truth to win, there has to be some shared conceptional scheme that allows people to recognize that truth has just emerged," says MacCoun. Finding that shared story must be evidence-based medicine's first goal.

SECOND DRAFT:

This is the conundrum facing those who seek to inject evidence-based medicine into health care reform—how do you convince doctors and patients to dump established, well-loved interventions when evidence shows they don't actually improve health?

The first step is to agree on a common goal, says MacCoun. “For truth to win, there has to be some shared conceptual scheme that allows people to recognize that truth has emerged,” he says. In lab experiments, researchers gave a brain teaser to groups of volunteers and told them to work together to solve it. “As soon as one person gets the answer, they should stop, but they don’t,” says MacCoun. “The answer is sitting right there on the table, but until the person who finds the solution gets at least one other person to back him up, no one recognizes that the problem has been solved.”

Similarly, those seeking to identify the most effective medical interventions must first establish agreement on what “effective” means. Should the efficacy of back pain treatments be measured by pain levels six months post-intervention, by cost, by provider profits or patient satisfaction? This isn't a scientific question, but a values judgment and different criteria yield different answers.

And then there's the question of what constitutes evidence. Proponents of comparative effectiveness research look for answers in large-scale trials, but these studies hinge on statistics about large groups of people, and such number crunching rarely convinces the public like personal anecdotes do.

“Studies have shown that powerful anecdotes trump data, we see that again and again,” says Nyhan. The runners who attended Nieman's talk were not moved by his study results, because the findings contradicted their own personal experience, which felt more true. When the problem is an emotion-charged one like breast cancer, personal anecdotes become even harder to overcome.

Women whose breast cancers were diagnosed with a mammogram will never be persuaded by the new mammography guidelines, says breast cancer advocate Brenner. “They all say, ‘if it weren't for that mammogram, I'd be dead right now,’ even though we know from the data that this wasn't the case for most of them.”

But science-based messages often lack compelling anecdotes. “Victims of overdiagnosis don’t say, look what the system did to me. They say, thank god the doctor saved me,” says Thomas B. Newman, a physician and narrative medicine expert at University of California, San Francisco. “Nobody can say I had an unnecessary mastectomy, and nobody would want to, it doesn't make a good story.”

For evidence-based medicine to make headway, its proponents must learn to tell an appealing story. Science works in data and statistics, but “Medicine is really made up of stories,” says Elizabeth Rider, an assistant professor of pediatrics at Harvard Medical

School. Narratives form the backbone of medicine—they're the way people make sense of the evidence. "We can all relate to stories. If somebody gives you a list of facts, you may remember some of them, but if somebody tells you a story, that's usually more memorable."

Howard F. Stein, a physician and medical anthropologist at the University of Oklahoma Health Sciences Center, tells the story of a farmer in Oklahoma who had come in for an appendectomy, but developed a type of rapid heartbeat that required treatment before surgeons could operate. "The cardiologist tried to explain supraventricular tachycardia to the family, but he might as well have been talking to a rock," says Stein. The family was very upset and couldn't understand why they were putting off the surgery. Finally, another doctor happened in and told the family, "His heart is shimmying like the front end of an old Chevy truck, and as long as it's shimmying we can't do the surgery." The tactic worked, says Stein. "He translated biomedical evidence into the kind of framework that would count as evidence in the patient's world. The doctor knew damn well that the patient's heart was not a pickup truck, but this story allowed the doctor and family to come to a common understanding without agreeing on cardiology 101."

New medical evidence must be framed in a convincing story, one that acknowledges the existing narrative. For supporters of the new mammography guidelines, that means addressing, head on, the widespread notion that breast cancer is a single, relentlessly progressive disease. "When the USPSTF came out, they might have said, 'We know that for years you've heard this, and the reason we're changing course now is that we realize that there are harms associated with screening, and we're changing our guidelines because we want to protect you,'" Schwartz says. The task force needed to emphasize in its message that the new guidelines have the same goal as the previous one — to save lives.

It's not enough to simply lay out the facts in a story. To take hold, evidence-based messages must also meet the human need for comfort. "Medical uncertainty is very hard, so you need to find a way to reframe it so that you can say, 'The good thing about this is...,'" says Elizabeth Rider, an assistant professor of pediatrics at Harvard Medical School. For example, the person demanding an MRI to diagnose his back pain doesn't just need to know that he can spare himself the hassle and potential harms from an MRI; he also needs reassurance that his back pain is almost certain to get better soon, even without an x-ray or surgery. And if a patient has a strong desire to do *something*, the story must offer something tangible to do.

Stories about the evidence must provide some measure of empowerment. Despite the evidence debunking it, the relentless progression model of breast cancer has persisted in part because it offers comfort and certainty by implying that every cancer can be cured, if women do the right thing. The breast cancer survivor fighting for more mammograms may have felt powerless against cancer, Stein says. "She thinks, 'I was once helpless and I will never be helpless again. I will prevent other women from ever feeling what I felt.'" For these women, mammograms offer a sense of empowerment and security, and

they are unlikely to accept the new guidelines unless they're presented in a way that addresses these needs.

Explanations that offer hope and empowerment will always hold more appeal than those that offer uncertainty or bad news, and when new evidence offers messy truths they must be framed in a positive light if they're to gain traction. You can ask people to give up ineffective interventions, but you must never ask them to abandon hope.

FINAL DRAFT

This is the conundrum facing those trying to inject evidence-based medicine into health care reform: How do you convince doctors and patients to dump established, well-loved interventions when evidence shows they don't actually improve health?

First, recognize that the facts alone are unlikely to change anyone's mind, University of Michigan political scientist Nyhan says. "People get defensive when you tell them they're wrong," he says. In one set of experiments, Nyhan took volunteers who believed that Saddam Hussein had weapons of mass destruction in Iraq and presented them with evidence that this belief was wrong. Instead of causing people to adjust their erroneous beliefs, the corrections often reinforced them. Presenting people with facts in conflict with their belief spurred them to re-examine all the reasons they'd held this belief in the first place, and this process of remembering served to reinforce the initial belief, despite the contrary evidence, Nyhan says.

Belief is a very difficult thing to overturn, especially when the belief is held by people with a vested interest in the old message. Sometimes these investments are monetary (back doctors make more money on procedures than on conservative treatment), but they can also be altruistic — breast cancer advocacy groups want to offer women something to protect themselves from a scary disease.

When the evidence presents a messy, unsatisfying picture, people are likely to take refuge in a more comforting story, even in the face of evidence that it's wrong. It comes down to something the satirist Stephen Colbert calls "truthiness," a term he coined in a 2005 episode of his Comedy Central show, *The Colbert Report*. "Truthiness is what you want the facts to be, as opposed to what the facts are," Colbert said. "It is the truth that is felt deep down, in the gut." The backlash against the new mammography guidelines stemmed in part from the truthiness of the message that mammography could prevent breast cancer. No matter that it wasn't true, it was what people wanted to believe.

For new evidence to overcome truthiness, it must be framed in an appealing story, one that acknowledges the existing narrative. For supporters of the new mammography guidelines, that means addressing, head on, the widespread notion that breast cancer is a single, relentlessly progressive disease. "When the [new screening guidelines] came out, they might have said, 'We know that for years you've heard this, and the reason we're changing course now is that we realize that there are harms associated with screening, and we're changing our guidelines because we want to protect you,'" Schwartz says. The task force needed to emphasize in its message that the new guidelines have the same goal as the previous one — to save lives.

For truth to win, stakeholders must also have a shared vision of what the problem is, so they can mutually recognize the correct solution once it's found, Berkeley psychologist MacCoun says. For those seeking to identify the most effective medical interventions,

that means establishing agreement on what “effective” means. Should the efficacy of back pain treatments be measured by pain levels six months post-intervention, by cost, by provider profits or by patient satisfaction? This isn’t a scientific question, but a value judgment, and different criteria yield different answers.

And then there’s the question of what constitutes evidence. Proponents of comparative effectiveness research look for answers in large-scale trials, but these studies hinge on statistics about large groups of people. Such number crunching rarely has the power of personal anecdote. “Studies have shown that powerful anecdotes trump data; we see that again and again,” Nyhan says. The runners who attended Nieman’s talk were not moved by his study results, because the findings contradicted their own personal experiences, which felt truer.

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Yet it’s not enough to weave the facts into a story. To take hold, evidence-based messages must also meet the human need for comfort and empowerment. “Medical uncertainty is very hard, so you need to find a way to reframe it so that you can say, ‘The

good thing about this is...,” Rider says. The relentless-progression model of breast cancer has persisted in part because it offers comfort and certainty by implying that every cancer can be cured, if only women do the right thing. This message about mammograms offers a sense of empowerment and security, and women are unlikely to accept the new guidelines unless they’re presented in a way that addresses these needs.

Explanations that offer hope and empowerment will always hold more appeal than those that offer uncertainty or bad news, and when new evidence offers messy truths, they must be framed in a positive light if they’re to gain traction. You can ask doctors to give up ineffective interventions, but you must never ask them or their patients to abandon hope.