# Providing the Gist of Medical Expertise in the Context of Laws, Rules, and Guidelines: Fuzzy-Trace Theory's Alternative Approach to Improve Patient Communication

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**Abstract**: Current guidelines and regulatory frameworks create a dilemma that threatens the effectiveness of much needed communication between patients and medical providers: How can patients be presented with detailed facts without creating cognitive "overload"? We explain how this is a false dichotomy and illustrate, using three examples, how fuzzy-trace theory offers a third way of informing patients.

Effective communication between medical providers and patients is a critical aspect of medical decision-making.[1] However, recent developments in laws, rules, and guidelines have converged to create what seem to be unavoidable dilemmas in patient communication. Here, we offer a theory-driven and evidence-based alternative to current recommendations.

Specifically, current guidelines and rules governing communication with patients emphasize (1) "providing balanced information about options" patients face in making medical decisions,[2] (2) giving patients immediate access to detailed medical results (Pub. L. No. 114-225), and (3) presenting alternative opposing frames of a decision equally.[3] Together, these examples illustrate a growing trend towards providing patients with detailed and specific facts to better inform them. As we explain, this approach creates an unintended dilemma: How can patients be presented with detailed facts without creating cognitive "overload"?[4]

Fortunately, viewing informing patients as a choice between overwhelming versus holding back information is a false dichotomy. Instead, research based on fuzzy-trace theory suggests that there is a promising third way of informing patients: Providing gist, or a bottom-line interpretation of facts in a way that makes sense (along with easy access to the details behind facts). Gist carefully navigates between patients struggling to interpret a confusing torrent of information — which produces overload — and paternalistic persuasion (patients blindly following providers' recommendations without understanding them), ultimately supporting patient decision-making.[5]

Our first example about "balanced information about options" comes from the International Patient Decision Aid Standards (IPDAS) collaboration.[6] The IPDAS collaboration is a group of researchers, practitioners, and stakeholders dedicated to improving the quality and effectiveness of patient decision-aids,[7] which are "evidence-based tools designed to help patients make specific and deliberated choices among healthcare options."[8] The most recent IPDAS guidelines state that "providing balanced information about options" is an important dimension of decision aid quality, and decision aids should show "the negative and positive features in a balanced and unbiased manner."[9] In contrast, we suggest that presenting a "balanced" view of

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positive and negative features of a decision (i.e., balanced benefits and harms) is misleading if these features are not in fact in balance.

For example, for approved medications in the U.S., the Food and Drug Administration (FDA) has determined that generally the benefits should outweigh the known or potential risks.[10] In particular, "for a new drug to be approved... the demonstration of safety requires a showing that the benefits of the drug outweigh its risks."[11] Accordingly, the Food, Drug, and Cosmetic Act as amended requires "a structured risk-benefit assessment framework in the new drug approval process."[12] Therefore, risk-benefit imbalance is expected (and presumably common) for approved drugs (e.g., vaccines), as stipulated by the Food and Drug Administration.

Consider the decision about whether to give a child the MMR (measles, mumps, rubella) vaccine.[13] A main gist about such vaccines is that the benefits tower over risks, which are nil.[14] (Note that gist is qualitative and interpretive, capturing the bottom-line meaning, not just simplistic.) However, instead of clearly communicating this gist message, a decision aid for such vaccination decisions contains nine pages full of detailed information and facts for parents to click through (e.g., "The first dose of MMR vaccine does not protect between 5 and 10 children out of every 100 from these diseases. After two doses of MMR-containing vaccine, only 1 child in 100 is still left unprotected.")[15]

The MMR decision aid also includes a bullet point list of "advantages" and "disadvantages" of getting the vaccine. Among the advantages, "My child will be better protected from the potentially serious complications of these diseases (e.g., encephalitis or death)" is listed, which is informative. However, perhaps in an effort to present the disadvantages "in balance" with the advantages per IPDAS, two bullet points are dedicated to the extraordinarily rare chance of experiencing serious side effects from the vaccine: "My child may be 1 in 1 million children who experience a serious complication such as a severe allergic reaction" and "If my child experiences a severe complication I may feel guilty or responsible because I had them vaccinated." Naturally, communicating the nonnegligible possibility of a terrible outcome should be mentioned for informed consent. However, dedicating more space to pointing out an extremely rare (1 in a million) and usually treatable disadvantage (along with suggesting guilt for parents) compared to the huge advantages of the vaccine obscures the key gist that getting the vaccine is the best way to protect children from catastrophic outcomes from these diseases (such as death, deafness, or intellectual disability).[16] If parents do not get the gist that the risks of the disease vastly overshadow the risks of the vaccine, they are not informed. Therefore, this is an example of how it is neither accurate nor helpful to present these benefits and harms "in balance" in a way that "does not favor one option over another" per IPDAS recommendations.

In addition, the decision aid provides a "side-by-side presentation of option attributes" in accord with IPDAS recommendations.[17] In particular, for each disease (measles, mumps, and rubella), the decision aid includes a figure presenting mild, moderate, and serious "complications" of (1) getting the disease on the left and (2) getting the MMR vaccine on the right, which is consistent with gist. However, comparing the number of children who have *symptoms* of each disease with the number of children who have *side effects* of receiving the MMR vaccine is problematic: A child experiencing mild pain at the injection site from the vaccine is not in the same category as a child experiencing measles who may later develop severe complications or pass the disease on to someone else who could die from it. Such "side-by-side" presentation, again aimed at presenting "balanced information," can obscure the key fact that side effects from a vaccine are categorically different from symptoms of a very serious childhood disease and, thus, that reality is imbalanced.

One might argue that it is appropriate for decision aids to provide "balanced information about options" because they are used in "preference-sensitive" decisions where "a single most appropriate option cannot be decided based on evidence or professional knowledge alone and may differ from patient to patient depending on the patients' preferences and life situation."[18] Indeed, one might conclude that in such cases, if there is no clear single appropriate option, it is best to present all options in a way that does not favor one over the other(s). However, shrinking from providing that concluding gist (that the options are balanced and why) may leave the patient still uninformed about the bottom line of the information. Research indicates that across a range of options, more and less balanced, providing a gist (digested by definition) is more effective than providing an unorganized list of option attributes.[19]

Moreover, regardless of whether options are balanced or imbalanced, medical decisions are preference-sensitive in that values, held to different degrees across individuals, inform preferences (e.g., religious and moral values), even when evidence-based medicine supports one option over others.[20] Vaccination decisions illustrate this preference-sensitivity and this sensitivity can influence choices even when patients appreciate the balance of medical evidence. To be clear, vaccination decisions are preference-sensitive and yet the medically "most appropriate option" should be presented to patients as such, and not on par with other less appropriate options.

Our second example involves changes to the handling of electronic medical records in response to the 21st Century Cures Act ("Cures Act"). This act prohibits "information blocking," which is interpreted in implementing regulations to include a practice that health care providers know is "unreasonable and is likely to interfere with access, exchange, or use of electronic health information."[21] These regulations have in turn been interpreted by the Office of the National Coordinator for Health Information Tech-

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nology as follows: "It would *likely* be considered an interference … if a health care provider established an organizational policy that, for example, imposed delays on the release of lab results for <u>any</u> period of time in order to allow an ordering clinician to review the results or in order to personally inform the patient of the results before a patient can electronically access such results."[22] In short, because of the Cures Act and its implementing regulations, a "vast array of data … including laboratory results, surgical reports, and doctors' notes" are now provided directly to patients through their electronic health portals.[23]

Without a doubt, being informed and having easy access to medical information are positive ambitions, but providing rapid access to neutral facts alone without a meaningful interpretation falls short of these aims. The detailed and specific IPDAS criteria (e.g., 44 "minimum" standards), place an undue emphasis on superficial qualities of decision aids (e.g., recent recommendations for "balanced information about options" and "loss and gain used equally") sometimes at the cost of clearly communicating the important points about medical decisions — the gist. Understanding the nature of gist interpretation, how the best gist can be selected, and how to communicate the gist to patients should be goals of future research to provide practical, policy-relevant alternatives to providing patients with uninterpreted facts.

Although increased transparency for patients is an important goal, the following scenario highlights one negative unintended consequence: Patients are provided with very detailed, specific information without adequate interpretation. For example, imagine a patient gets a blood test and receives a notification on Friday evening that their results are available on their electronic health portal. They view their results and see several "flags" indicating levels that are "low" or "high" according to the reference range. Although such evaluative labels can help patients understand their test results,[24] in practice many patients do not understand what these results mean.[25] Because this lab result was provided directly to the patient for the sake of transparency without any *meaningful* interpretive guidance from their provider, the patient is left to wonder about their abnormal health status while the doctor's office is closed over the weekend. Other than turning to "Dr. Google," the other main option for clarification is to send questions directly to the provider through an online messaging system. This example already plays out routinely in real life: At one hospital center, since the implementation of the Cures act, about 30% more test results were reviewed by patients prior to discussing them with their clinicians, with direct messages sent to clinicians within hours of viewing test results nearly doubling compared to before the act was implemented.[26]

To be clear, efforts to inform patients and increase ease of access to medical information are vitally important. Our point is that when informing patients and increasing transparency is interpreted literally as providing rapid access to information in the form of sterile facts and details prior to meaningful interpretation from a provider with expertise, this alone does not benefit patients and overwhelming patient messages can "burn out" providers.[27] We suggest that what would be beneficial would be to provide a gist interpretation vetted by rigorous research along with test results, as well as access to a human being who can answer questions.[28] Gist provides patients with the meaningful interpretative guidance they need to make sense of medical information, typically with access to the underlying detailed results.

A potential avenue for doing this may be for behavioral scientists with additional training on medical topics to consult with the person who ordered the test in the first place (thereby gleaning the context) and then disseminate the gist of the results to patients. Given limited resources, frequently occurring communications could also be distilled into a finite number of gist messages available with test results.

Given the regulatory burdens on medicine and other stressors to the system, many have argued for an increasing role for artificial intelligence (AI) that can answer medical questions.[29] However, AI differs from human intelligence in predictable ways, namely, it processes information in a literal verbatim way rather than getting the gist of information, incorporating the context.[30] Therefore, AI is predictably invalid when meaning and context matter, which is often. AI will slavishly adhere to guidelines, engaging in literal thinking, which will look good because it will be more consistent than humans. However, there is a predictably pernicious effect of this increase in reliability (i.e., lack of variability) — recommended decisions will not vary when they should vary. For example, a patient with a dynamic ST segment change of .5 mm on an ECG fits guidelines (in the sense of ruling out because the cutoff for elevation is 1 mm) but such elevation is potentially concerning in the context of other symptoms.[31] In short, there are always exceptions to rules, and a real expert recognizes that and "reads between the lines" of information.[32]

Our third example involves the IPDAS recommendation that patient decision aids "try to minimize framing" by presenting information in both loss and gain frames ("loss and gain used equally").[33] A main motivation behind this recommendation is to reduce risk of cognitive biases in patient decision aids. For example, classic framing effects demonstrate that people have inconsistent preferences when equivalent options are framed as a loss versus a gain (e.g., lives saved vs. lives lost).[34] However, presenting patients with both the gain and loss frame of a decision is likely to create decision conflict; it "kicks the can down the road" but does not resolve which way of presenting the information is helpful. From a practical standpoint, even the order of options within a gain or loss frame, respectively, let alone the order in which the gain and loss frames is presented, has been shown to influence preferences.[35] The IPDAS update further advocates "visual formats for event rates" as a way to "minimize bias from framing,"[36] although use of visual formats still generates framing effects.[37] These are just a few examples of how a neutral, cognitively unbiased presentation of information is simply not a practical reality — hence, framing presents a "dilemma" in the context of medical decision-making.[38] Instead, we advocate eliciting the gist of options from patients and providers who have extensive experience and deep knowledge of the specific decision (and its consequences), and presenting that gist to patients facing such a decision.[39]

More importantly, even if precise details could be presented in a truly unbiased way, neutral lists of such details would not be desirable by themselves. As discussed in depth in Reyna et al. (2022), providing patients with quantitative information (and/or a visual representation) on "both sides" of a decision without interpretive guidance on what the point of the information is (at the risk of introducing bias) is a disservice to patients. Apart from leaving patients without a clear sense of the key points about their medical decision, presenting information in this way is problematic because it shifts the burden onto the patient to sift through the facts to try to figure out what they really mean.[40]

As a clinician summarized to us, ultimately what patients want is not balanced information, immediately accessible, without framing but instead they want an expert to give them a professional recommendation, interpreting the known facts in a meaningful way, that respects their values and life situation. However, even after a clinician provides a gist, patients may still ask "Well what would you recommend doc?" or "What would you do if this was your child?" Fuzzy-trace theory distinguishes, on the one hand, the gist of options and patients' values, which together might point to one option rather than another when options are imbalanced, from, on the other hand, recommending one option over the other. When options are less one-sided, gist ought to convey that there are reasonably competing options amid uncertainty. Furthermore, options portrayed as balanced or near balanced are often not so, once the trivial is disentangled from the profound.

In summary, the three examples above illustrate the growing trend towards providing patients with detailed and specific factual information to achieve the goals of informing patients and increasing transparency. Without a doubt, being informed and having easy access to medical information are positive ambitions, but providing rapid access to neutral facts alone without a meaningful interpretation falls short of these aims. The detailed and specific IPDAS criteria (e.g., 44 "minimum" standards);[41] place an undue emphasis on superficial qualities of decision aids (e.g., recent recommendations for "balanced information about options" and "loss and gain used equally") sometimes at the cost of clearly communicating the important points about medical decisions — the gist. Understanding the nature of gist interpretation, how the best gist can be selected, and how to communicate the gist to patients should be goals of future research to provide practical, policy-relevant alternatives to providing patients with uninterpreted facts.

## Note

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