DISREGARDING UNCERTAINTY, MARGINALIZING PATIENTS

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What does it mean to "trust the science"? The phrase is often used to suggest that scientific knowledge is static and that the public can treat current recommendations as eternal verities. The medical community is not omniscient, however. Indeed, some illnesses are characterized by uncertainty: it is not clear with what frequency the associated symptoms occur or whether they are a manifestation of a psychological disorder or a physiological disease. The medical field is no stranger to such challenges, labeling such illnesses as "contested." The communication of uncertainty surrounding these illnesses, however, presents a troubling dynamic. Rather than engaging in constructive dialogue that moves scientific understanding forward, viewpoints become entrenched, points of disagreement are obscured, and professionals retaliate against one another. In the best case scenario, patients are merely left to sort through dense medical concepts on their own; in the worst case, they are targeted by predatory providers. Patients suffer, trust in science declines.

Drawing on insights from the economics literature, this Article presents a theoretical framework for approaching the uncertainty inherent in contested illnesses. The framework discusses the pattern of evidence accumulation that accompanies an uncertain illness, distinct from that of a disease where uncertainty is substantially resolved. Applying these insights to the communication of uncertainty surrounding contested illnesses, the Article notes that null results in the presence of well-designed studies should be weighed differently than null results in the presence of case studies or small sample studies. If an illness is truly uncertain, the framework highlights the potential benefits of additional caution in approaching irreversible actions, such as prematurely communicating the resolution of uncertainty (which can lead to the development of patient mistrust). This careful communication of uncertainty is vital to prevent patient marginalization and to clarify the often-inscrutable information landscape in these contexts. Current regulations for medical providers and public figures are insufficient, however, to incentivize such careful communication. This Article proposes a government-coordinated informational digest that weighs existing evidence based on the rigor of study design and imputes null results to missing results of completed studies. The agency coordinating the digest will provide incentives for studies that fill gaps in the literature and which incorporate input from patient advocate groups into the design. In doing so, it will enable the medical community to both better handle existing uncertainty and to take important steps toward resolving it. More importantly, however, this transparent process educates the public about how scientific beliefs should evolve and prevents the irreversible harm of patient marginalization.

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INTRODUCTION

Attempting to preserve public trust in science has perversely—but predictably—led to its decline. Medical professionals and officials—concerned about maintaining trust in the medical community—gloss over unknowns, prematurely communicating certainty in describing new illnesses.[1] Patients whose experiences do not match these initial predictions are told that there is no evidence to support their story.[2] As more data is collected, scientific knowledge updates, and certainty rises.[3] For fear of garnering public mistrust—and bound by their prior statements—officials scramble to justify their initial statements.[4] People puzzle over the inconsistencies, and the now-marginalized patients lose faith.[5] Medical professionals' fears are a self-fulfilling prophecy, and the next cycle repeats on a more distrustful audience.

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1. *See infra* Section I.A.
2. *Id.*
3. *See infra* Section II.A.
4. *See* Andrew Selsky, *Explainer: What's with the Confusion Over Masks?*, AP (Nov. 18, 2020), https://apnews.com/article/ap-explains-confusion-over-masks-74a67cc33e65721fe4cdf45fbdeb78e5 [https://perma.cc/A3VU-G2RZ] (describing the confusion over mask guidance over the pandemic).
5. *See infra* Section I.A.

While underlying scientific realities are constant, they are rarely known with any precision in the context of emerging diseases. This fact has been clearly demonstrated by the discussion surrounding long COVID. "Long COVID," defined as enduring symptoms and complications following acute COVID infection, is currently the subject of ever-evolving science.[6] While few contest that patients suffer symptoms outside of the acute infection period, there is considerable uncertainty as to which symptoms are causally linked to the original infection and to their frequency.

This is not a new problem: the maladies from which patients suffer often are not well-defined, and the field of medicine is rife with uncertainty.[7] This Article focuses on illnesses that are characterized by uncertainty, either regarding their classification as a physiological disease[8]—a disease relating to the body rather than solely the mind—or the symptoms with which they are associated. These ailments have sometimes been referred to as "contested illnesses" by the medical community.[9]

While there are many potentially expensive implications of officially recognizing a new disease, this Article examines an oft-overlooked, but no less fundamental, policy decision: the obligation to accurately acknowledge and communicate uncertainty surrounding contested illnesses. Poor communication of uncertainty in the context of contested illness results in two special harms. First, it perpetuates rather than resolves uncertainty by failing to differentiate between areas with and without well-designed studies. Second, it creates a potentially irreversible harm of eroding trust in science and marginalizing patient communities. This Article notes that past experience with contested illnesses and patient communities demonstrate that such marginalization can be difficult or impossible to reverse. Applying insights from the economics

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6. Alice Burns, *Long COVID: What Do the Latest Data Show?*, KFF (Jan. 26, 2023), https://www.kff.org/policy-watch/long-covid-what-do-latest-data-show/ [https://perma.cc/NG77-U596].

7. Technically, there has been considerable debate in the economics literature on how to characterize uncertainty. *See, e.g.*, Mark J. Machina & Marciano Siniscalchi, *Ambiguity and Ambiguity Aversion*, in THE HANDBOOK OF THE ECONOMICS OF RISK AND UNCERTAINTY, (Mark J. Machina & W. Kip Viscusi, eds., 2014). For the purposes of this Article, uncertainty refers to uncertain risks, or the phenomenon where risks are not precisely known. This concept has also been called ambiguity. However, for the sake of linguistic simplicity, this Article will just use the term "uncertainty."

8. This Article uses "physiological" to denote a mechanism that is not purely psychological. *Physiological vs. Psychological*, DICTIONARY.COM (June 1, 2023), https://www.dictionary.com/compare-words/physiological-vs-psychological [https://perma.cc/67AN-NX64]. ("In medicine, the terms *physiological* and *psychological* are often used in contrast to each other. *Physiological* relates to the physical and chemical processes of the body, and may be used to describe physical diseases or disorders. *Psychological* relates to the processes of the mind, and may be used to describe mental illnesses."). Admittedly, these terms are difficult to disentangle in practice: even psychological ailments can have biological predicates. This term is meant merely to track the discussion patient communities have about whether an ailment can be considered mainly a mental illness or if there is a physical mechanism causing most symptoms.

9. Jaime Ducharme, *Have We Been Thinking About Long-Haul Coronavirus All Wrong?*, TIME MAG. (Oct. 16, 2020), https://time.com/5897992/long-haul-coronavirus-me-cfs/ [https://perma.cc/WKQ4-YZMQ].

literature to the context of contested illnesses, the Article argues that careful framing of uncertainty can help identify when uncertainty is significantly resolved and prevent the irreversible harm of patient marginalization.

Despite this clear prescription, such careful framing of uncertainty does not—and will not—happen, as current legal obligations are insufficient to incentivize this behavior. Usual liability levers of the standard of care, the doctrine of informed consent, and medical board discipline are particularly ill-suited to incentivizing providers to communicate uncertainty carefully. Physicians, researchers, and patient advocates engaging in broad public health communications similarly do not face sufficient obligations to correctly assess and communicate uncertainty.

In order to prevent the dual dangers of confusion and marginalization, this Article proposes a government-coordinated informational digest that summarizes existing evidence and assigns an uncertainty score based on the current data. This infrastructure can further be used to address issues of publication bias through the use of clinical trial registration data and to provide incentives for researchers to conduct studies that will fill remaining gaps. Additional incentives are provided for studies that incorporate patient advocate feedback on study design, providing an appropriate venue for patients to influence research. This approach boasts many informational benefits, including explicitly acknowledging—rather than pointedly ignoring—where uncertainty exists. Most importantly, however, the transparency in the way the digest updates its ratings will educate the public (and potentially medical providers) on how the scientific process works in the presence of uncertainty. The transparent incorporation of new information—and subsequent updating of recommendations—undermines the harmful narrative of an omniscient scientist, boosting confidence in the scientific community.

This Article proceeds as follows: Part One discusses the history and challenges associated with several contested illnesses. Part Two introduces a framework for exploiting uncertainty to make the best dynamic decision in the context of contested illnesses. This framework, adapted from the economics literature, acknowledges both the probative value of null results (depending on context) and the effect that irreversible choices—here, prematurely pronouncing the uncertainty associated with contested illness resolved—have on dynamic decision-making. It also shows that patient marginalization can be the result of such premature communications; based on the framework presented, special caution might be necessary to prevent such marginalization. Part Three proposes an informational intervention: a government-coordinated informational digest that summarizes current evidence and assigns an uncertainty rating. The disclosure of raw data (studies) and the provision of a summary rating helps patients and providers be aware of the current state of the literature. The continual updating of this list and rating provides transparent and nuanced discussion of the evolution of scientific beliefs about uncertain illnesses. The agency implementing the digest would identify gaps in the literature and provide

incentives for studies that fill them. Part Four argues that not only is the digest beneficial, it is essential, as current legal obligations are often inadequate to make physicians' and public figures' communications sufficiently nuanced to accurately identify uncertain risks and to prevent patient marginalization. Moreover, the explicit and transparent updating of evidence on this platform additionally is a powerful example to the public that revising beliefs in response to new evidence is not a betrayal of the scientific process, but a faithful execution of it.

I. MEDICINE'S COMPLICATED RELATIONSHIP WITH CONTESTED ILLNESSES

In medicine, almost nothing is known with complete certainty. Particular illnesses, however, are *defined* by uncertainty.[10] This uncertainty coincides with—but is not fully described by—the uncertainty over a treatment's benefits. The uncertainty associated with contested illnesses can be characterized in at least two ways. First, there can be uncertainty that the disease exists at all. Second, there can be uncertainty as to how the disease is characterized (i.e., the causal mechanism or the prevalence of symptoms). While these two options appear distinct, upon closer examination they are remarkably similar. When people say a disease "doesn't exist," this often means that the very real distress the patient feels is psychological rather than physical.[11] It could also mean that the symptoms are not associated with a sufficiently systematic set of causal mechanisms. For example, a series of headaches may have different, idiosyncratic causes, not one unified mechanism. This is similar to having an incorrectly specified causal mechanism or believing that the observed symptoms are attributable to other illnesses, particularly psychological disorders.

In approaching a cluster of symptoms, the source of which is unknown, a policymaker may erroneously ignore an actual illness or erroneously identify a nonexistent one. Ignoring an illness may take the form of focusing on unrelated ailments (like obesity) or treating the ailment as purely psychological.[12] Conversely, physicians can erroneously identify an ailment by labeling an uncommon presentation of a common illness as a new illness or by identifying idiosyncratic ailments as systematic.[13] The history of contested illnesses

10. *See infra* section I.A.

11. *See, e.g.*, Joe Gough, *The Mind Does Not Exist*, AEON (Aug. 30, 2021), https://aeon.co/essays/why-theres-no-such-thing-as-the-mind-and-nothing-is-mental [https://perma.cc/L3YH-VQFR]. To denote an illness as psychological rather than physiological is not to undermine its seriousness. Indeed, part of the current contested illness dynamic seems to be driven in part by the stigma and doubt surrounding psychological ailments. Correcting this discourse is one way to undermine this problematic dynamic.

12. Julia Naftulin & Anna Medaris, *Patients are Calling Out 'Medical Gaslighting,' Saying Doctors Deny Their Symptoms and Misdiagnose Serious Illnesses*, INSIDER (Apr. 2, 2022, 1:55 PM), https://www.insider.com/medical-gaslighting-patients-say-doctors-deny-symptoms-misdiagnose-2022-4 [https://perma.cc/KKM9-8F6A].

13. Reed Abelson, *E.R. Doctors Misdiagnose Patients with Unusual Symptoms*, N.Y. TIMES (Dec. 15, 2022), https://www.nytimes.com/2022/12/15/health/medical-errors-emergency-rooms.html [https://perma.cc/V849-6AZA].

provides examples of each error, along with the consequences of such mistakes.

A. A Bleak History

This Part provides an overview of chronic Lyme, Morgellons, and chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). While these three illnesses are by no means the census of contested illnesses, they are some of the most prominent. Some of these illnesses are well-accepted by the medical community as having physiological (but unknown) causes, while others are broadly considered psychological disorders. Discovery of such illnesses are not confined solely to the past, however. This Part also notes that long COVID shares many characteristics of prior contested illnesses. Accordingly, communicating the implications of such uncertainty becomes increasingly important.

1. Chronic Lyme Disease.—Chronic Lyme disease is alleged to be a complication of a newly discovered[14] but generally accepted acute infection: Lyme disease. Transmitted through bites of infected ticks, Lyme disease is characterized by a bulls-eye-shaped rash called the erythema migrans rash.[15] This rash does not appear in all infected individuals, however, and sometimes presents in an alternate form.[16] In the absence of a rash, "fever, chills, headache, fatigues, muscle and joint aches, and swollen lymph nodes" may appear.[17] These fairly common symptoms make diagnosis difficult; compounding this is the poor sensitivity and specificity[18] of the extant diagnostic tests.[19]

A subset of patients, however, believe that they suffer from a chronic version of the disease ("chronic Lyme disease"). This group attributes their ongoing symptoms—including chronic inflammation, dizziness and shortness

14. Indeed, Lyme disease was only recognized in the mid-1970s. Its rise to prominence is attributed to patient Polly Murray, who complained of an unknown illness characterized by headaches, swollen joints, and listlessness. Doctor after doctor was unable to help her, despite her reporting that her condition was spreading to her friends and neighbors. Dr. Allen Steere, a physician who had spent two years researching unknown outbreaks at the Center for Disease Control (CDC), however, identified her ailment as a tick-borne illness. The disease was later named Lyme, after the town where it was discovered. David Grann, *Stalking Dr. Steere*, N.Y. TIMES MAG. (June 17, 2001), https://www.nytimes.com/2001/06/17/magazine/stalking-dr-steere.html [https://perma.cc/9AMZ-2XAT].

15. *Lyme Disease: Signs and Symptoms of Untreated Lyme Disease*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/lyme/signs_symptoms/index.html [https://perma.cc/HXB9-A4EL] (last visited Aug. 23, 2022).

16. *Id.*

17. *Id.*

18. Sensitivity refers to the likelihood that a test correctly identifies a true positive, while specificity refers to the likelihood of correctly identifying a true negative. Rajul Prikh, et al., *Understanding and Using Sensitivity, Specificity, and Predictive Values*, 56 INDIAN J. OPHTHALMOLOGY 45, 46 (2008).

19. *See, e.g.*, *Lyme Disease: Diagnosis and Testing*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/lyme/diagnosistesting/index.html [https://perma.cc/4WG8-VBL5] (last visited Aug. 23, 2022).

of breath, heart palpitations, seizures, and hallucinations[20]—to an active infection. Believing that the bacteria causing the disease evade detection and remain in the body long after the prescribed weeks of antibiotics regimes, these groups advocate for long-term antibiotic use.[21] While mainstream physicians acknowledge that patients experience ongoing symptoms past the acute infection, they believe that the infection ends after short-term antibiotic treatment.[22] All remaining symptoms they attribute to enduring damage from the now-resolved infection.[23] Continued antibiotic use would, accordingly, not be helpful.[24] Given the potential complications of long-term antibiotic use—including gastric complications and the development of antibiotic-resistant bacteria—they view this course of action as actively harmful.[25]

2. Morgellons.—Morgellons is a particularly harrowing example of a contested illness. Patients with Morgellons perceive multicolored filaments and fibers sprouting from underneath the skin.[26] Patients with Morgellons often have extensive scarring from where the fibers have been believed to sprout (and from where patients have picked at their skin).[27]

Like chronic Lyme, the movement behind this disease was relatively recent. In 2002, former medical researcher Mary Leitao observed her son complaining that he felt bugs crawling under his skin.[28] Upon closer inspection, Leitao found colored fibers emerging from her son's skin.[29] Looking for answers, Leitao joined a community of patients already claiming to have suffered from this disease, which Leitao ultimately named Morgellons.[30] She founded the Morgellons Research Foundation in 2004.[31] Mainstream medicine has characterized Morgellons as a delusion of parasitosis ("DOP").[32]

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20. *What Are the Symptoms of Chronic Lyme Disease?*, IGENEX INC., https://igenex.com/tick-talk/what-are-the-symptoms-of-chronic-lyme-disease/ [https://perma.cc/9WC2-7V3T] (last visited Sept. 3, 2023).

21. Grann, *supra* note 14; Paul G. Auwaerter et al., *Antiscience and Ethical Concerns Associated with Advocacy of Lyme Disease*, 11 LANCET INFECTIOUS DISEASE 713 (2011).

22. Auwaerter et al., *supra* note 21, at 717.

23. *Id.*

24. *Id.*

25. *Id.*

26. *CDC Releases Results of Morgellons Disease Investigation*, CBSNEWS (Jan. 26, 2012, 4:16 PM), https://www.cbsnews.com/dfw/news/cdc-releases-results-of-morgellons-disease-investigation/ [https://perma.cc/CT25-9MYA].

27. Will Storr, *Morgellons: A Hidden Epidemic or Mass Hysteria?*, GUARDIAN (May 6, 2011, 7:03 PM), https://www.theguardian.com/lifeandstyle/2011/may/07/morgellons-mysterious-illness [https://perma.cc/4MPM-CYKA].

28. Chico Harlan, *Mom Fights for Answers on What's Wrong With Her Son*, PITTSBURGH POST-GAZETTE (July 23, 2006), https://www.post-gazette.com/news/health/2006/07/23/Mom-fights-for-answers-on-what-s-wrong-with-her-son/stories/200607230221 [https://perma.cc/VZ3B-YH4C].

29. *Id.*

30. This name came from a disease noted by Sir Thomas Browne in 1674. Caroline S. Koblenzer, *The Challenge of Morgellons Disease*, 55 J. AM. ACAD. DERMATOLOGY 920 (2005).

31. Harlan, *supra* note 28.

32. *Id.*

3. Chronic Fatigue Syndrome/Myalgic Encephalomyelitis.—Chronic fatigue syndrome/myalgic encephalomyelitis ("CFS/ME") is one of the most famous contested illnesses, more relevant today than ever. Patients suffering from CFS/ME experience severe fatigue and cognitive disfunction; most importantly, small exertions can leave them debilitated.[33] In 2015, the IOM proposed that the condition be renamed systemic exertion intolerance disease (SEID),[34] a new diagnostic criteria which requires 1) "profound fatigue," 2) a "[s]ubstantial decrease in function," 3) that "[p]ersists for at least [six] months," 4) with "[p]ost-exertional malaise and unrefreshing sleep," and 5) "[c]ognitive impairment and/or orthostatic intolerance."[35] The effects of the illness are not mild: the Institute of Medicine ("IOM") reports that at least 25% of patients with CFS/ME have been bedbound or housebound at some point in their lives.[36]

While the CDC has recognized CFS/ME since 1988, there is no known cause of the ailment.[37] The scientific community originally considered this condition primarily a psychological disorder; however, more recent studies have identified numerous physiological differences in patients with CFS/ME.[38] While this does not amount to a causal diagnosis, it provides a starting point for more unifying pathophysiology models.[39] As the Institute of Medicine notes, it is suspected that CFS/ME is triggered by the Epstein-Barr virus or another unspecified infection.[40] Indeed, some have hypothesized that some symptoms associated with long COVID are attributable to CFS/ME.[41] In 2017, the NIH awarded a total of $7 million per year to research efforts concentrated on CFS/ME.[42]

Controversy over treatment of CFS/ME is considerable. Graded exercise (GE) and cognitive behavioral therapy (CBT) were initially proposed as potential solutions; indeed, a very expensive, long-term study was conducted to

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33. COMM. ON THE DIAGNOSTIC CRITERIA FOR MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME, BD. OF THE HEALTH OF SELECT POPULATIONS, INST. OF MED., BEYOND MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME: REDEFINING AN ILLNESS (2015) [hereinafter BEYOND MYALGIC ENCEPHALOMYELITIS].

34. *Id.* at 11.

35. *Id.* at 7.

36. *Id.* at 2.

37. Gary P. Holmes et al., *Chronic Fatigue Syndrome: A Working Case Definition*, 108 ANNALS INTERNAL MED. 387 (1988).

38. Anthony L. Komaroff, *Advances in Understanding the Pathophysiology of Chronic Fatigue Syndrome*, 322 J. AM. MED. ASS'N 499 (2019).

39. *Id.*

40. BEYOND MYALGIC ENCEPHALOMYELITIS, *supra* note 33, at 162.

41. Ross Douthat, *Long-Haul Covid and the Chronic Illness Debate*, N.Y. TIMES (Feb. 2, 2021), https://www.nytimes.com/2021/02/02/opinion/long-covid-lyme-disease.html [https://perma.cc/G4X4-B9F4].

42. *ME/CFS Research*, NAT'L INSTS. OF HEALTH, https://www.nih.gov/mecfs/research [https://perma.cc/DMK2-LG6U] (last visited Aug. 23, 2022).

evaluate their benefits.[43] Patient advocacy groups were hostile to this course of treatment, however, feeling that it fed into the narrative that CFS/ME patients were lazy or mentally disturbed.[44]

These experiences illustrate the difficulties patients face in navigating novel ailments. Due to the complexity of such biological processes, patients are ill-equipped to assess, much less resolve, this uncertainty. The medical controversy surrounding contested illnesses often depends on relatively obscure scientific points. Attempting to identify and understand the points of disagreement between divergent lines of literature requires considerable time and scientific expertise that most patients do not have. Accordingly, it falls to specialists to describe and characterize the uncertainty.

It is particularly difficult to weigh the merits of two rival viewpoints when each view refuses to address the other. Moreover, precisely because these lines of literature often do not speak to one another, there are few primers on the points of departure. Patients are often lost in trying to navigate this informational terrain.

A prime example of this is the discourse over chronic Lyme disease. While the rhetoric between chronic Lyme advocates and skeptics can be incendiary and broad, the main point of disagreement comes down to whether ongoing symptoms are attributable to an active infection or to residual damage after the infection has cleared.[45] Mainstream medicine, represented by the professional organization Infectious Diseases Society of America (IDSA), does not deny that chronic Lyme patients are suffering real physiological pain; instead, it acknowledges that symptoms remain.[46] IDSA merely rejects the idea that there is an active infection that requires continual use of antibiotics.[47] To support this conclusion, it points to 3 randomized, double-blind controlled studies that found minimal or no improvement in symptoms with additional antibiotic use.[48] The considerable side effects of antibiotics—as well as the social danger associated with antibiotic overuse—make such ineffective treatment particularly costly for

43. Peter D. White et al., *Comparison of Adaptive Pacing Therapy, Cognitive Behaviour Therapy, Graded Exercise Therapy, and Specialist Medical Care for Chronic Fatigue Syndrome (PACE): A Randomised Trial*, 377 LANCET 823 (2011).

44. The back-and-forth over this study is discussed in detail in Part II.A.

45. Grann, *supra* note 14; Auwaerter et al., *supra* note 21, at 717.

46. Molly Fischer, *Maybe It's Lyme: What Happens When Illness Becomes an Identity?*, THE CUT (July 24, 2019), https://www.thecut.com/2019/07/what-happens-when-lyme-disease-becomes-an-identity.html [https://perma.cc/WGS2-5VTT].

47. *Id.*

48. Mark S. Klempner et al., *Two Controlled Trials of Antibiotic Treatment in Patients with Persistent Symptoms and a History of Lyme Disease*, 345 N. ENGL. J. MED. 85 (2001); L.B. Krupp et al., *Study and Treatment of Post Lyme Disease (STOP-LD): A Randomized Double Masked Clinical Trial*. 60 NEUROLOGY 1923 (2003); R.F. Kaplan et al., *Cognitive Function in Post-Treatment Lyme Disease: Do Additional Antibiotics Help?*, 60 NEUROLOGY 1916 (2003).

patients' health.[49]

The literature on Morgellons is equally murky. A CDC-sponsored population study found no evidence of infectious agents being associated with the symptoms experienced by Morgellons sufferers.[50] Years after this study, a group of other researchers presented evidence of Morgellons sufferers testing positive for *Borrelia* spirochetes.[51] The number of Morgellons sufferers documented with *Borrelia* was remarkably small (4 in the first study, 24 in the second).[52] The only researchers interacting with this set of results are the researchers associated with the original project.[53] Accordingly, it is very difficult to understand whether mainstream physicians accept this view or are still skeptical. This disagreement is far from purely academic: if accepted, Morgellons patients would likely be treated with antibiotics. Because unnecessary use of antibiotics is (as noted above) particularly risky, this is an important point to clarify.

The aforementioned examples demonstrate the difficulty in addressing the inherent uncertainty of contested illnesses. The emergence of such illnesses, however, is not confined to the past: long COVID—and other future complications—may involve similar considerations as past contested illnesses.

B. A (Less) Bleak Future?

In the wake of a global pandemic, many people who survived the initial COVID-19 infection began to realize that they faced a further danger of enduring symptoms weeks after the primary infection.[54] These symptoms varied broadly, including anxiety, anosmia, fatigue, and cardiovascular effects.[55] Preliminary data suggested that such symptoms are more common in women, people with lower socioeconomic status, smokers, and minorities.[56] The post-infection experience of symptoms is broadly referred to as post-COVID

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49. Auwaerter et al., *supra* note 21, at 713. The ethnographic evolution of chronic Lyme disease has been well-documented by Abigail Dumes. ABIGAIL A. DUMES, DIVIDED BODIES (2020); Henry M. Feder, Jr. et al., *A Critical Appraisal of "Chronic Lyme Disease,"* 357 N. ENGL. J. MED. 1422, 1428 (2007).

50. Marianne J. Middelveen et al., *Association of Spirochetal Infection with Morgellons Disease*, F1000RESEARCH 1, 8 (2013) [hereinafter Middelveen I].

51. *Id*.; Marianne J. Middelveen et al., *Exploring the Association Between Morgellons Disease and Lyme Disease: Identification of* Borrelia Burgdorferi *in Morgellons Disease Patients*, 15 BMC DERMATOLOGY 1, 9 (2015) [hereinafter Middelveen II].

52. Middelveen I, *supra* note 50, at 1. The study describes the sample as "randomly-selected patients who met the key clinical criterion for MD." Middelveen II, *supra* note 51.

53. Middelveen I, *supra* note 50; Middelveen II, *supra* note 51.

54. Nikki Nabavi, *Long Covid: How to Define It and How to Manage It*, BMJ (Sept. 7, 2020), https://www.bmj.com/content/370/bmj.m3489 [https://perma.cc/JA4M-FUKT].

55. *Id.*

56. Anuradhaa Subramanian et al., *Symptoms and Risk Factors for Long COVID in Non-Hospitalised Adults*, 28 NATURE MED. 1706, 1710 (2022).

syndrome or "long COVID."[57]

This comprehensive label masks considerable heterogeneity in not only the duration of experience and severity of symptoms, but also the mechanism by which harm actualized. Scientists have suggested there are at least 3 types of long COVID: the first involves ongoing symptoms caused by direct cell damage inflicted from the virus.[58] The second refers to ongoing effects from extended hospitalization, such as muscle weakness and brain dysfunction.[59] The third category involves symptoms that appear after recovery.[60] While all causally link back to the original infection, the mechanism by which each occur invokes different public health concerns and treatment options.

Uncertainty over what symptoms characterize long COVID—and with what prevalence—has been a main difficulty in assessing optimal COVID-19 responses.[61] Investments to prevent the original infection may be more valuable if brain fog accompanies 40% of long COVID-19 cases than if it only affects 1% of cases (or if the brain fog lasts years rather than days).

Discussing long COVID in the context of contested illness may seem jarring, but is not meant to discount the experiences of people suffering from ongoing complications of COVID-19. In terms of uncertainty, however, the similarities between long COVID and prior contested illnesses are numerous. One can argue that, unlike currently classified contested illnesses, long COVID has a clear mechanism: infection with the COVID-19 virus. This, however, is no different from the experiences of other contested illnesses. Many of the prior contested illness ailments have a definite predicate; the uncertainty is over which symptoms causally relate to the predicate. Others dispute the nature of the chronic symptoms following an acute infection: are the symptoms caused by an ongoing infection or merely byproducts of damage done by the original (now inactive) infection?[62] Still others seek to discern whether physical symptoms are manifestations of psychological disorders caused by another medical experience.[63]

Within the context of contested illnesses, however, long COVID is somewhat unique because multitudes of people became at risk in a relatively short period. This difference potentially has three effects. First, there may be

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57. There are multiple names for this syndrome, including "post-COVID-19 condition, post-acute COVID-19 syndrome, post-acute sequelae of COVID-19 (PASC)." *Id.* at 1706. This Article will refer to the syndrome as "long COVID."

58. Sara Berg, *What Doctors Wish Patients Knew About Long COVID*, AM. MED. ASS'N. (Mar. 11, 2022), https://www.ama-assn.org/delivering-care/public-health/what-doctors-wish-patients-knew-about-long-covid [https://perma.cc/8ERW-544D].

59. *Id.*

60. *Id.*

61. Further work is currently being done to better characterize the symptoms of long COVID. Tanayott Thaweethai et al., *Development of a Definition of Postacute Sequelae of SARS-CoV-2 Infection*, 329 JAMA 1934, 1935 (2023).

62. *See generally* Grann, *supra* note 14, *and* Auwaerter et al., *supra* note 21.

63. *See generally* Storr, *supra* note 27, *and* White et al., *supra* note 43.

more people to study.[64] Secondly, it is difficult to discount patient experiences, since everyone knows someone affected by COVID-19.[65] Finally, the high level of uncertainty experienced in the pandemic,[66] may have prompted people to give the benefit of the doubt to the widespread effects of COVID-19. While these differences may save long COVID from some of the dysfunctional dynamics noted in this section, only time will tell. In light of this potential, it is worth turning to the economic literature to understand how to best assess and manage the uncertainty inherent in contested illnesses.

II. A FRAMEWORK FOR APPROACHING CONTESTED ILLNESSES

In light of the special concerns that contested illnesses pose, this Part discusses how to identify contexts where uncertainty is significant and—in contexts where it persists—how to make decisions despite incomplete information. While the framework can be used to analyze other examples of decision-making under uncertainty, this Part will discuss the decision to communicate to patients that their symptoms are not due to a physiological cause.

This Article uses the term uncertainty to refer to uncertain risks: while risk refers to a probability associated with an outcome, uncertainty characterizes a scenario when risk is not precisely known.[67] A risky illness might be associated with a high probability of harm, but an uncertain illness is associated with an *unknown* probability of harm. Part II.A. describes how to differentiate illnesses for which significant uncertainty still exists and those for which it been largely resolved. For circumstances where uncertainty persists, Part II.B. discusses the considerations governing the decision to make an irreversible statement about the nature of the illness.

A. Identifying Which Illnesses Are Still Contested

No risk is known with total precision. Some risks, however, are particularly uncertain. Consider an ailment which either has a purely psychological or partly physiological cause (or equivalently, an ailment for which the risk posed by the

64. Notably, however, even with a larger population to study, studies must be well-designed to avoid the types of issues that arise with observational study. *See infra* Part II.A.

65. Deidre McPhillips, *It Seems Like Everyone has Covid-19. Here's Why This Wave is Probably Worse than Official Data Suggests*, CNN (Sept. 1, 2023, 9:56 AM), https://www.cnn.com/2023/09/01/health/covid-case-data-wave/index.html [https://perma.cc/E7ER-9VKR]; Ross Douthat, *Long-Haul Covid and the Chronic Illness Debate*, N.Y. TIMES (Feb. 2, 2021), https://www.nytimes.com/2021/02/02/opinion/long-covid-lyme-disease.html [https://perma.cc/8NJR-GBFT].

66. *See infra* Section II.B.; Jonathan Koffman, Jamie Gross, Simon Noah Etkind, & Lucy Selman, *Uncertainty and COVID-19: How are We to Respond?*, 113 J. ROYAL SOC'Y MED. 211 (2020).

67. *See* footnote discussion, *supra* note 8. Technically, uncertain risks are described as probability distributions over probabilities. For example, there may be a 50% chance the risk is 0% and a 50% chance the risk is 25%.

physical mechanism is unknown).[68] Because society does not know the true risk of a physical mechanism causing the illness, we conduct studies to create estimates of the true risk. We may track people affected by the physical mechanism and compare health outcomes with a control group of people unaffected by the physical mechanism. Controlling for lifestyle conditions, socioeconomic confounders such as nutrition, and other behaviors, the resulting difference in symptom prevalence should be informative.[69] As we perform more studies, we expect a distribution of estimates of the underlying risk.

Insofar as mainstream science acknowledges a contested illness, it often notes that there is insufficient evidence to support a physical mechanism. While this is a very accurate scientific statement, it does not distinguish between circumstances in which rigorous studies find no evidence and circumstances in which rigorous studies have not been undertaken. Null results produced by well-designed studies are not equivalent to the absence of such studies. The inference of the absence of physical mechanism is much stronger when data from well-designed studies fail to establish a link than if no studies—or only poorly designed studies—are conducted.

Not all studies are created equal, however. Case studies or anecdotes simply are not as probative as randomized double-blind controlled studies because they are less able to distinguish the connection between a physical cause and symptoms from confounders such as prior health issues, socio-economic factors, other co-morbidities, or selection into treatment.[70] Failing to account for these differences in evidentiary value[71] needlessly perpetuates uncertainty.

As new data is created, it is normal for risk beliefs to update.[72] New estimates are used to revise the original beliefs about the risk through a process known as Bayesian updating,[73] allowing the updated estimate of risk to converge to the true value. The specter of new information should not paralyze decision

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68. Another way uncertainty impacts contested illnesses is imprecision in the prevalence with which a particular symptom is associated with an illness. It makes a great difference if brain fog is associated with 70% of afflicted patients (vs. 1%). For simplicity, this section will focus on the physiological/psychological distinction, but expansion to the above question is straightforward. In both these cases, the relevant risk (either the likelihood that a physical mechanism causes the symptoms or that a particular symptom will develop in the presence of the illness) is not precisely known.

69. This is not a straightforward process, and much of the existing scientific evidence can be criticized for failing to adjust for such behavioral factors. These details are discussed more rigorously in Elissa Philip Gentry, *Damned Causation*, 54 ARIZ. ST. L.J. 419, 431 (2022). Abstracting away from these details, this paper discusses what we should do with these idealized estimates.

70. *See generally id.*

71. *Infra* Part IV.A.2.b.

72. Replication is important to better understand risk. The other statistical concept at play here, however, is consistency: with more data, the estimator converges to the population average. The law of large numbers, accordingly, notes that as sample size converges to infinity, the sample mean converges to the population mean. GEORGE CASELLA & ROGER L. BERGER, STATISTICAL INFERENCE 235 (Carolyn Crockett et al. eds., 2nd ed. 2002). Essentially, this means that as studies have larger samples, the more likely the resulting estimates approach the true population average.

73. Technically, the "original" probability is known as the "prior" probability and the "updated" probability is a "posterior" probability. *Id.* at 324.

makers, however, because the value of additional data is highest when less information currently exists.

To see this, consider example Figures 1 and 2. Each dot represents an estimate from a different study, each with the same methodological rigor and variance, with the vertical axis indicating the number of studies with a given estimate. The vertical line indicates the average effect represented by the plotted estimates.[74] In Figure 1, only three estimates are plotted, the average of which is 0. Because there are so few observations, the addition of one additional estimate—either appearing as 3 in Figure 1b or -3 in Figure 1c—changes the average considerably.

74. Assuming equal study rigor—and equal variance for the estimates—the average converges to the posterior mean, which is the best estimate of the true risk based on the evidence. *Id.* at 235.

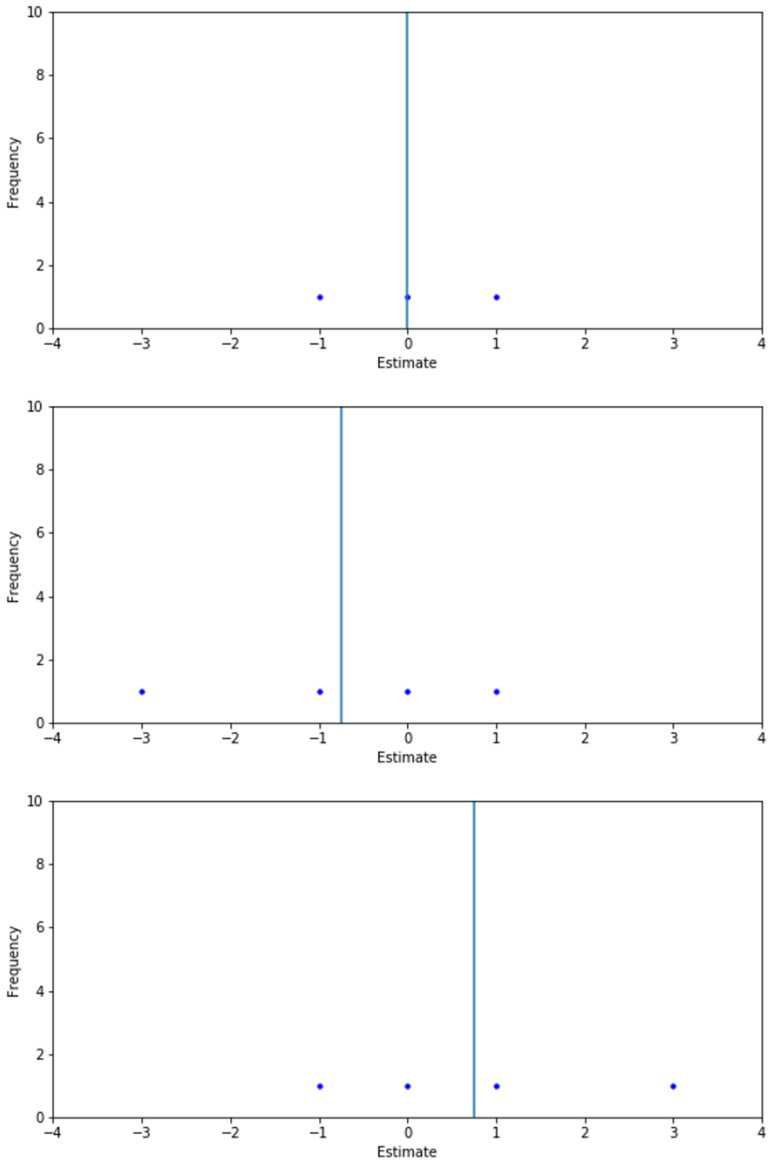

Figure 1. The top figure (Figure 1a) shows the original three estimates. The middle figure (Figure 1b) adds an estimate of -3 and the last figure (Figure 1c) an estimate of 3. The vertical line indicates the average effect of the displayed values.

For Figure 2, the average effect is roughly the same as in Figure 1. However, because of the number of existing studies, the addition of one extreme estimate does not shift the average value by much (Figure 2b and Figure 2c). Accordingly, people should expect beliefs to change in the beginning, with confidence in the updated estimates eventually rising.

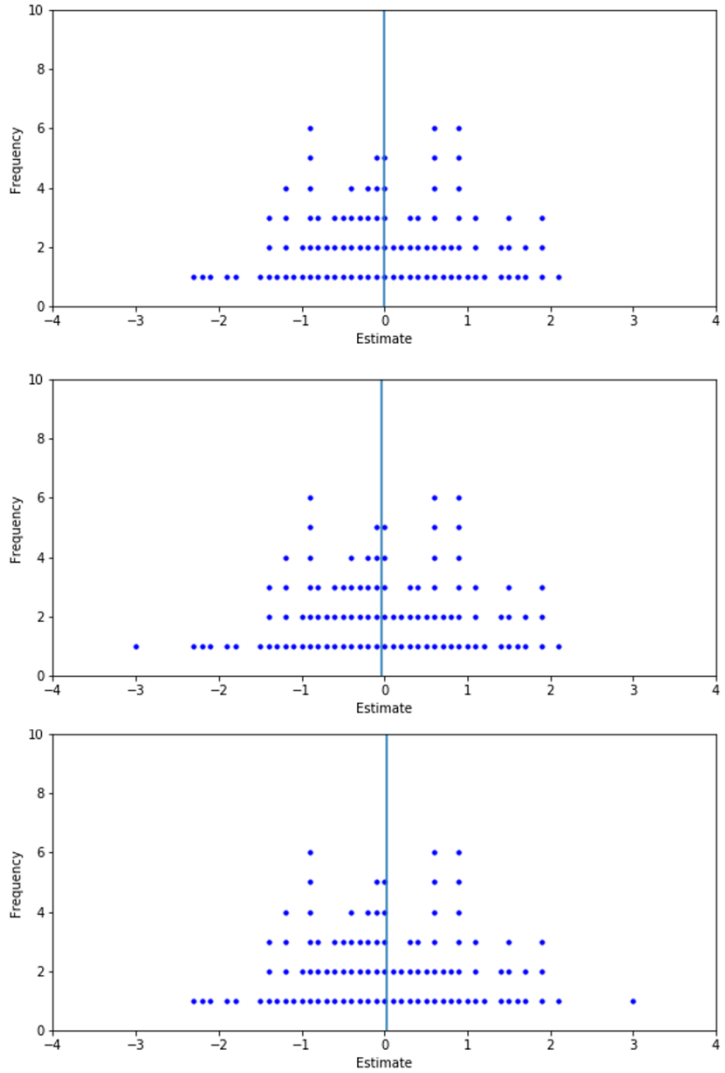

Figure 2. The top figure (Figure 2a) shows the original one hundred estimates. The middle figure (Figure 2b) adds an estimate of -3 and the last figure (Figure 2c) an estimate of 3. The vertical line indicates the average effect of the displayed values.

The difference in evidentiary value between well-designed studies that produce null results and the absence of well-designed studies has not been reflected in the experience of contested illnesses. One of the unfortunate legacies of these contested illnesses is that, despite some well-designed—often expensive—studies in Morgellons, CFS/ME, and chronic Lyme, there is no ascertainable effect on the level of perceived uncertainty.

1. Morgellons.—Given its increasing recognition—with high-profile figures like Joni Mitchell claiming to suffer from the illness—other researchers

began to be interested in Morgellons.[75] Spurred on by this interest, the CDC began the first large scale, $600,000 population-based study of Morgellons in 2008.[76] The study followed 115 people within the Kaiser Permanente Northern California program,[77] and performed detailed epidemiological tests, clinical evaluations, and material tests.[78] In 2012, the study results were published, concluding that there was no environmental or infectious source.[79] The filaments were largely cellulose, probably of cotton origin, not unidentified materials as previously claimed.[80] It could not determine whether the condition was a new condition or an expansion of "an existing condition such as delusional infestation."[81] The study was relatively guarded in its conclusions: it took great pains to note that it could not answer whether the illness was purely psychological.[82] Instead, it merely noted that it failed to find any infectious cause and that their affected population had coexisting conditions for which other treatments were available; it suggested that treating those conditions first may benefit patients.[83]

Despite this relatively well-designed, systematic study,[84] patient advocacy groups still rejected the findings.[85] One leader of the Charles E. Holman Morgellons Disease Foundation issued a statement criticizing the CDC as selecting the wrong population for their study.[86] Morgellons research has continued, both ignoring and criticizing the CDC study as non-responsive.[87] Oklahoma State University professor Dr. Randy Wymore was a prominent participant.[88] Certain he could match these fibers to an external source, he

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75. Storr, *supra* note 27.

76. Michele L. Pearson et al., *Clinical, Epidemiologic, Histopathologic and Molecular Features of an Unexplained Dermopathy*, 7 PLOS ONE (2012); *Federal Study of Morgellons Yields No Answers*, CBS NEWS (Jan. 25, 2012, 10:51 PM), https://www.cbsnews.com/news/federal-study-of-morgellons-yields-no-answers/ [https://perma.cc/H7XF-FAY7].

77. Pearson et al., *supra* note 76, at 1.

78. *Id.*

79. *Id.*

80. *Id.*

81. *Id.* at 11.

82. *Id.*

83. *Id.* (noting "[W]e did find among our study population co-existing conditions for which there are currently available therapies . . . . In the absence of an established cause or treatment, patients with this unexplained dermopathy may benefit from receipt of standard therapies for co-existing medical conditions and/or those recommended for similar conditions such [as] delusions [of] infestation.").

84. While this was not an experiment—experiments are often unavailable in these contexts—relative to the existing data on Morgellons, this study was an improvement.

85. Cindy Casey, *Response from Cindy Casey, Morgellons Patient and Founder of the Charles E. Holman Foundation* (2012), https://assets1.cbsnewsstatic.com/i/cbslocal/wp-content/uploads/sites/15909545/2012/01/response-from-cindy-casey.pdf [https://perma.cc/SN66-2DQM].

86. *Id.* ("The study is flawed from the very beginning in the method of patient selections. Only one of these patients was familiar to me and was known to have the symptoms and manifestations we identify as Morgellons Disease.").

87. *See, e.g.*, Marianne J. Middelveen et al., *History of Morgellons Disease: From Delusion to Definition*, 11 CLINICAL, COSM. & INVESTIGATIONAL DERMATOLOGY 71, 79 (2018).

88. Storr, *supra* note 27.

requested samples of fibers from sufferers.[89] He then compared these samples to a variety of fibers from different sources and was unable to find a match.[90] After experiencing difficulty in finding a lab willing to assess a potential Morgellons fiber, he found an independent lab to assess the sufferers' fibers.[91] The lab found the fibers to be "nylon; cotton; a blond human hair; a fungal fibre; a rodent hair; and down, most likely from geese or ducks."[92] Wymore did not consider this to be dispositive,[93] however, and continued his research, establishing a lab dedicated to Morgellons research.[94] Wymore is joined by a few other researchers in the field.[95] Virginia Savely is a nurse practitioner that claims to have treated more than 500 Morgellons patients[96] and has published numerous studies on Morgellons.[97] Researchers Marianne Middelveen and coauthors posit a connection between Lyme disease and Morgellons.[98] Their evidence relies on the examination of four Morgellons patients, who had evidence of "spirochetes."[99] Following up on this evidence, Middelveen looks at a "larger group of 25" patients, 24 of which had detectable levels of Borrelia spirochetes.[100] Middelveen described this study as "show[ing] the somatic nature of the disease and put the final nail in the coffin of delusional infestation."[101] Very few scholars outside of the initial team of Marianne Middelveen (veterinary microbiologist, MA), Raphael Stricker (MD), Virginia Savely (NP), and Melissa Fessler (NP) publish on this topic, making it difficult to know how the broader scientific community perceives this theory.[102]

2. Chronic Fatigue Syndrome.—While the cause of CFS is still unknown,

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89. *Id.*

90. *Id.*

91. *Id.*

92. *Id.*

93. *Id.*

94. TULSA AREA BIOSCIENCE EDUCATION & RESEARCH CONSORTIUM, https://taberc.com/index.php/resources-for-investigators/andy-wymore-laboratory.html [https://perma.cc/EHU5-TWHZ] (last visited Sept. 23, 2023).

95. *Id.*

96. Storr, *supra* note 27.

97. *See, e.g.*, Virginia Savely, *Delusions May Not Always Be Delusions*, 24 ARCHIVES PSYCHIATRIC NURSING 215 (2010); Virginia Savely, Mary Leitao, & Raphael Stricker et al., *The Mystery of Morgellons Disease: Infection or Delusion*, 7 AM. J. CLINICAL DERMATOLOGY 1 (2006); Virginia Savely & Raphael Stricker, *Morgellons Disease: Analysis of a Population with Clinically Confirmed Microscopic Subcutaneous Fibers of Unknown Etiology*, 3 CLINICAL, COSM. & INVESTIGATIONAL DERMATOLOGY 67 (2010).

98. Middelveen I, *supra* note 50.

99. *Id.* The study describes the sample as "randomly-selected patients who met the key clinical criterion for MD." *Id.*

100. Middelveen II, supra note 51.

101. The Charles E. Holman Foundation, *Charles E. Holman Foundation Announces Publication of New, Significant Medical Paper on Morgellons Disease*, CISION (Feb. 17, 2015), https://www.prweb.com/releases/2015/02/prweb12522467.htm [https://perma.cc/B9GC-X9EJ].

102. The Carlat Psychiarty Podcast, *Morgellons: A Tiny Bug or a Big Delusion?* (Sept. 16, 2020), https://www.thecarlatreport.com/blog/morgellons-a-tiny-bug-or-a-big-delusion/ [https://perma.cc/DL3R-A6X8].

proposed treatment[103] options became a litmus test of how to characterize the illness. Patients with CFS/ME have been derided as lazy and their symptoms attributed to deconditioning.[104] This initial reaction led to a complicated relationship with proposed treatment of graded exercise therapy (GET) and cognitive behavioral therapy (CBT).[105] Patients viewed these options with skepticism: the implication of using GET and CBT, patients felt, was that their symptoms were caused by laziness and mental instability.[106] In light of this skepticism, the UK Medical Research Council funded the PACE trial, a large-scale study into the potential effects of graded exercise on CFS.[107] The original published results suggested that a combination of cognitive behavioral therapy and graded exercise was associated with alleviation of CFS symptoms.[108]

Soon after publication, however, the results were called into question. Several data scientists alleged that the authors redefined their endpoints mid-study, and a team of scientists reanalyzed the data with its original endpoints, finding more modest results, which some believe are purely a function of placebo effects.[109] Several organizations have updated their guidance to discount the study's findings,[110] while others, like the Cochrane Reports, have

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103. While the focus of this Article is not on the uncertain treatment but on uncertain illnesses, the distinction is nuanced. In practice, for many of these diseases, the characterization of the disease informs the prescribed treatment. For chronic Lyme disease, mainstream experts believe that the ongoing symptoms experienced by patients might have been caused by the original infection. They do not believe, however, that the symptoms are caused by an ongoing infection requiring long-term antibiotics. Accordingly, their characterization of the symptoms follows other medically unexplained sicknesses such as chronic fatigue syndrome. "Lyme literate doctors," conversely, have concrete treatment plans (namely, long-term antibiotic usage).

104. Steven Lubet & David Tuller, *The Medical Community is Changing its Mind on Chronic Fatigue Syndrome. Why Aren't Insurers?*, STAT (July 19, 2018), https://news.yahoo.com/opinion-medical-community-changing-mind-084555746.html [https://perma.cc/KSP5-3YDF].

105. Kate Kelland, *Online Activists are Silencing Us, Scientists Say*, REUTERS (MAR. 13, 2019, 11:00 AM) https://www.reuters.com/investigates/special-report/science-socialmedia/ [https://perma.cc/835L-MRM5].

106. *Id.*

107. Peter D. White et al., *Protocol For The PACE Trial: A Randomised Controlled Trial of Adaptive Pacing, Cognitive Behaviour Therapy, and Graded Exercise as Supplements to Standardised Specialist Medical Care Versus Standardised Specialist Medical Care Alone for Patients with the Chronic Fatigue Syndrome/Myalgic Encephalomyelitis or Encephalopathy*, 7 BMC NEUROLOGY 1 (2007) (describing the study's protocol); White et al., *supra* note 43.

108. *Id.*

109. *See* Carolyn E. Wilshire et al., *Rethinking the Treatment of Chronic Fatigue Syndrome—A Reanalysis and Evaluation of Findings from a Recent Major Trial of Graded Exercise and CBT*, 6 BMC PSYCHOLOGY 1 (2018); *see also Expert Reaction to Reanalysis of the PACE Trial for Chronic Fatigue Syndrome (CFS) Treatments*, SCI. MEDIA CTR. (Mar. 22, 2018), https://www.sciencemediacentre.org/expert-reaction-to-reanalysis-of-the-pace-trial-for-chronic-fatigue-syndrome-cfs-treatments/ [https://perma.cc/TUX9-DLLT].

110. NAT'L INST. FOR HEALTH & CARE EXCELLENCE, MYALGIC ENCEPHALOMYELITIS (OR ENCEPHALOPATHY)/CHRONIC FATIGUE SYNDROME: DIAGNOSIS AND MANAGEMENT 93 (2021), https://www.nice.org.uk/guidance/ng206/resources/myalgic-encephalomyelitis-or-encephalopathychronic-fatigue-syndrome-diagnosis-and-management-pdf-66143718094021 [https://perma.cc/KN7G-JY74].

been slower to adapt.[111]

Outside of scientific critique of the findings, however, the results were hotly contested[112] by the patient advocate community, concerned that the study would be used to suggest that their PEM was mostly due to laziness. In response to an organization not sufficiently adjusting their recommendations regarding GET, patient advocacy group #MEAction issued a statement saying that "we must immediately emphasize that #MEAction does not support graded exercise therapy due to serious risk of harms to people with ME," despite acknowledging that "there is not systematic evidence regarding the harms of exercise therapies."[113] This outcome-based criticism is similarly unscientific and not sensitive to new evidence.

3. Chronic Lyme Disease.—Similarly, for chronic Lyme disease, IDSA supports its skepticism of continued antibiotic regimines with evidence from double-blind studies that found no significant improvement with antibiotic treatment and documented significant adverse effects of such long-term use.[114] The publication of these results did not seem to change the chronic Lyme advocates'minds, despite the rigorous research design and replication.[115]

These examples demonstrate how broken the scientific marketplace appears. While ongoing uncertainties need not be fully resolved,[116] the inability to move even marginally toward a scientific consensus is disappointing. Moreover, given the animosity between these lines of research, there is no real communication between the two camps, resulting in research silos.

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111. David Tuller, *Trial By Error: What's Up With Cochrane's Exercise Review?*, VIROLOGY BLOG (Sept. 24, 2019), https://www.virology.ws/2019/09/24/whats-up-with-cochranes-exercise-review/ [https://perma.cc/42KZ-BCAL]; Lillebeht Larun et al., *Exercise Therapy For Chronic Fatigue Syndrome*, COCHRANE LIBR. (Oct. 2, 2019), https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD003200.pub8/full#CD003200-sec-0046 [https://perma.cc/RJ6V-WVCB].

112. *See, e.g.*, Andrew Anthony, *ME and the Perils of Internet Activism*, GUARDIAN (July 28, 2019), https://www.theguardian.com/society/2019/jul/28/me-perils-internet-activism-michael-sharpe-myalgic-encephalomyelitis-chronic-fatigue-pace-trial [https://perma.cc/7ACF-W4JY] (noting the backlash the Pace authors received after publication of results).

113. *Cochrane Releases Problematic Review on ME/CFS*, #MEACTION (Oct. 2, 2019), https://www.meaction.net/2019/10/02/cochrane-review-releases-problematic-review-on-me-cfs/ [https://perma.cc/8SDH-6LET].

114. B.A. Fallon et al., *A Randomized, Placebo-Controlled Trial Of Repeated IV Antibiotic Therapy For Lyme Encephalopath*y, 70 NEUROLOGY 992 (2008); Klempner et al., *supra* note 48, at 85; Krupp et al., *supra* note 48, at 1923; Gary P. Wormser, *Duration of Antibiotic Therapy for Early Lyme Disease: A Randomized, Double-Blind, Placebo-Controlled Trial*, 138 ANNALS INTERNAL MED. 697 (2003); J. Oksi, *Duration of Antibiotic Treatment in Disseminated Lyme Borreliosis: A Double-Blind, Randomized, Placebo-Controlled Multicenter Clinical Study*, 26 EUR. J. MICROBIOLOGICAL INFECTIOUS DISEASES 571 (2007).

115. *See Leading Research*, INT'L LYME & ASSOCIATED DISEASES SOC'Y, https://www.ilads.org/research-literature/leading-research/ [https://perma.cc/2VZY-6VRC] (last visited Aug. 26, 2022).

116. As an example, for chronic Lyme, ongoing discussions involve the correct diagnostic test (some are too conservative, some too liberal) as well as the clinical significance of a negative test. Judy Stone, *The Lyme Wars, Part 2: Which Way Should We Treat?*, FORBES (Aug. 3, 2019), https://www.forbes.com/sites/judystone/2019/08/03/the-lyme-wars-part-2-which-way-should-we-treat/?sh=1a4345681d92 [https://perma.cc/7Z85-H595].

Ideally, beliefs about emerging disease would update smoothly with new information, based on the rigorous design of the study and strength of the results. Once battle lines are drawn, however, research lines seem to develop independently. Rather than reduce uncertainty, rhetoric becomes more polarized and difficult to parse.[117]

It is tempting to interpret the dismal histories of contested illnesses as demonstrating the futility of interrupting this dynamic. To the contrary, however, these histories demonstrate the importance of not allowing such deep divisions to form in the first place. The following section discusses the potential harm created by making irreversible choices (e.g., prematurely declaring uncertainty resolved) and contexts in which it is best to wait.

B. Making Irreversible Choices Under Uncertainty

If uncertainty regarding whether an illness is purely psychological is found to persist, how should it be handled? The rest of this Part demonstrates that, while excessive caution can often be harmful to the public, delaying a policy that is effectively irreversible (such as designating a disease as purely psychological) can sometimes be warranted.

Because uncertain risks are associated with a range of probabilities and outcomes, the decision on how to characterize an uncertain risk is consequential. Even in the early stages of data accumulation, when the degree of confidence in the estimates is low and we know that the current estimate will likely change with new information, it is best to characterize a risk using its "updated" estimate (provided that the existing studies are well-designed[118]). While exercising additional caution feels intuitively safer, this is not generally the case. Consider the following example: out of a population of 100 people, 40 patients experience a set of symptoms, referred to as Illness X. While the harm associated with Illness X is very real (and approximately $100 per affected person), it is uncertain if the mechanism is caused by a physical stimulus (for example, exposure to bacteria) or is purely psychological. The government currently believes that there is a 70% chance that Illness X is purely psychological and a 30% chance that these 40 patients have a physiological disease. In other words, there is a 70% chance that the physical mechanism poses a 0% population risk and a 30% chance it poses a 40% population risk. [119]

Suppose that a policymaker is deciding whether to invest in medication meant to address the proposed physical cause of Illness X. If there is a physical

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117. *See id.*

118. This matters in order for the estimate to be an unbiased signal of the whole body of potential evidence. Unbiasedness is a technical statistical term, meaning that the expected value of the estimator is the population average. CASELLA & BERGER, *supra* note 72, at 330. Practically, this means that while any individual draw of this estimator might not equal the population average, the likelihood that the estimator overestimates the effect is the same as it underestimating the effect.

119. Nominal numbers (as in the previous sentence) are more intuitive to work with, but this example can be phrased as uncertainty over population risk of Illness X from a physical stimulus.

cause of Illness X, the medication reduces its prevalence by 5 percentage points. If the mechanism is psychological, however, there will be no benefit. How much the policymaker is willing to invest depends on how they asses the probability that Illness X has a physical rather than purely psychological cause.

A common approach to such uncertainty is to "put a thumb on the scale" and characterize the uncertain risk by its highest estimate. Treating the illness as *definitely* having a physical cause, a policymaker will be willing to invest up to $500 for a population of 100[120] to reduce the prevalence of Illness X. On average, however, treating this uncertain risk as definite will make society worse off.[121] In the event that there is no physical cause (which occurs with 30%), the intervention is useless. Choosing a higher (or lower) probability to characterize the uncertain risk will warrant systematically over- (under-) investing in safety.

Excessive protection can be harmful: spending money on an intervention where, on average, benefits are relatively low prevents money from being allocated to other purposes. If spending is private, other purposes can include rent, nutrition, and other medical care. If spending is public, other purposes include housing initiatives, nutrition programs, or enhancing medical benefits. Indeed, one study found that income losses from regulation can also result in loss of life.[122] Because of this, negative net benefits[123] not only have monetary but physical costs as well.

If instead the physical risk of Illness X is characterized by a probability-weighted average ("expected value") of the risk, the estimate correctly takes into account likely values and unlikely values of the risk, discounting appropriately when there is a very low probability that the risk takes a certain value.[124] Over the potential states of the world, society is better off using the unbiased estimate to determine the value of interventions to prevent emerging diseases. This remains true even when there is low confidence in the estimate.[125]

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120. Reducing the risk of contracting Illness X from 40% to 35% creates $500 in benefits: $(0.40 \times 100 \times 100) - (0.35 \times 100 \times 100) = 500$.

121. To see this, there is a 30% chance that the net benefits are positive and 70% chance that net benefits are negative. Suppose an intervention costs $400. While the payoff from this investment will be positive if the true risk is 40%, the payoff is negative if true risk is 0%. On average, the net benefit from the investment is -$250, indicating that society is worse off than if it had done nothing.

On average, this investment will have negative payoffs: $[0.30 \times \{((0.40 - 0.35) \times (100 \times \$100)) - \$400\}] + [0.70 * \{((0.0 - 0.0) \times (100 \times \$100)) - \$400\}] = \$30 + -\$280 = -\$250 < 0.$

122. *See* W. Kip Viscusi, *Risk-Risk Analysis*, 8 J. RISK & UNCERTAINTY 5 (1994).

123. Net benefits represent the value of benefits minus costs.

124. With this value, the policymaker will only spend $150 to reduce the potential bacterial vector of Illness X by 5 percentage points $(0.30 \times 0.05 \times 100 \times 100) + (0.70 \times 0.00 \times 100 \times 100) = \$150$.

125. This is not to suggest that there are not issues with implementing cost-benefit analysis in the context of "uncertain futures," where, *inter alia*, there are potentially irreversible changes and the likelihood of catastrophic outcomes is unknown. Susan Dudley notes some of these issues, such as dealing with uncertain probabilities, assessing interrelated risks, and valuing irreversible harm. Susan Dudley, *Dynamic Benefit-Cost Analysis for Uncertain Futures*, 10 J. BENEFIT-COST ANALYSIS 206, 209 (2019). To address these issues, Dudley advocates a more flexible form of decision-making, where policymakers incorporate current learning to flexibly adjust strategy. *Id.* at 216; *see also* W. Kip Viscusi, Joel Huber, &

While characterizing an uncertain risk by its highest estimate may generally be harmful, there may nevertheless be good reason to postpone irreversible choices in the presence of uncertainty. Irreversible choices here can be thought of as choices that restrict the potential policy tools available in a subsequent period.[126] For example, in the beginning of a pandemic, a government may either take no action or institute minor measures (such as mandated masking) in order to keep the exponential growth rate of infection low. If it chooses the former, and the growth rate skyrockets, the option to use minor measures will no longer be sufficient to control the growth rate. Considerably more resources would be necessary to reduce the growth. Because the same policy option—minor measures to keep the exponential rate low—is no longer available once the rate soars, the choice to do nothing is said to be irreversible.

In our context, classifying an illness as purely psychological—or, alternatively, nonexistent—can be viewed as an irreversible choice that marginalizes patient communities. Simply reversing a broad statement about the nonexistence of a disease is not a feasible policy option because trust is not easily regained. Patients may continue to experience harm, either through seeking ineffective or unsafe treatments from predatory physicians, not adopting future beneficial treatments, and feeling disbelieved. Moreover, for a policymaker, the ability to be believed in the future declines for a subset of the population as well, reducing the number of viable policy tools.

Patients who are ignored can become siloed away from the traditional medical community, eroding trust in the medical community more generally. This dynamic can be both a push and a pull. Patients who feel that their experiences are not believed may distance themselves from the mainstream medical community. Dr. Almudena Alameda Cuesta and coauthors present evidence from a series of interviews of patients with contested illnesses, specifically fibromyalgia, CFS/ME, and multiple chemical sensitivities.[127] The patients highlight the conflict inherent in the patient-provider relationship, with one noting that their doctor felt "contempt" for them for two reasons: "firstly, [the patient] make[s] [the physician] uncomfortable, because [the physician is] baffled by the disease. Secondly, because they think [the patient is] probably malingering."[128] The stigma perceived by these patients by their healthcare providers creates a barrier between patient and provider.[129] The authors believe that this leads to a "decrease in the demand for health care," i.e., a decreased desire to receive medical attention.[130] In turning away from the mainstream

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Jason Bell, *Responsible Precautions for Uncertain Environmental Risks*, 10 J. BENEFIT-COST ANALYSIS 296, 309 (2019). These recommendations are entirely compatible with the proposed framework.

126. *See, e.g.*, Christian Gollier & Nicholas Treich, *Decision-Making Under Scientific Uncertainty: The Economics Of The Precautionary Principle*, 27 J. RISK & UNCERTAINTY 77 (2003).

127. Almudena Alameda Cuesta et al., *Fibromyalgia, Chronic Fatigue Syndrome, and Multiple Chemical Sensitivity: Illness Experiences*, 30 CLINICAL NURSING RSCH. 32 (2021).

128. *Id.* at 37.

129. *Id.*

130. *Id.*

medical community, patients often look to patient support groups, facilitated by the Internet.[131] In a study of an electronic support group for fibromyalgia, *Fibro Spot*, sociologist Kristin Barker analyzed communications exchanged on the (virtual) open bulletin board.[132] Barker notes the fraught relationship participants describe with their medical providers.[133] Participants exhibited "skeptical dependency" on medical providers, in which participants criticize the ignorance of their physicians but also felt helpless to address their own symptoms.[134] In assessing medical providers' opinions, participants also prioritized lived experience over medical expertise.[135] This dynamic, in which these statements are validated by fellow patients, can lead to eroding trust in the medical community.

Simultaneously, the promise of answers from more "literate" physicians may push patients into riskier treatments. Indeed, as one researcher notes, "[e]xplaining that there is no medication, such as an antibiotic, to cure the condition is one of the most difficult aspects of caring for such patients. Nevertheless, failure to do so in clear and empathetic language leaves the patient susceptible to those who would offer unproven[136] and potentially dangerous therapies."[137]

This marginalization is mirrored by the siloed research lines that develop. For chronic Lyme, the animosity between International Lyme and Associated Diseases Society (ILADS)—which argues an ongoing infection causes current symptoms—and the Infectious Diseases Society of America (IDSA)—which

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131. Michael Murphy et al., *Electronic Support Groups: An Open Line of Communication in Contested Illness*, 57 PSYCHOSOMATICS 547, 549 (2016).

132. Kristin K. Barker, *Electronic Support Groups, Patient-Consumers, and Medicalization: The Case of Contested Illness*, 49 J. HEALTH & SOC. BEHAV. 20, 24 (2008).

133. *Id.* at 28.

134. *Id.*

135. *Id.* at 28-29.

136. In addition to having a higher likelihood of being ineffective or unsafe, treatment is often quite expensive. Part of this expense is due to the lack of insurance coverage; however, this is not a straightforward issue. Many alternative practitioners affirmatively refuse to take insurance. *See, e.g.*, Ginger Savely, DNP, *Frequently Asked Questions*, https://gingersavely.com/faq/ [https://perma.cc/68VT-AR2N] (last accessed Oct. 20, 2023); Fran Zell & Tom Boswell, *Wisconsin Lyme Doctor Gets Reprieve*, WISCOMMUNITY (Jan. 29, 2012), https://www.wis.community/blogarticle/wisconsin-lyme-doctor-gets-reprieve [https://perma.cc/73AK-ZU6M] (noting that a chronic Lyme doctor refused to take public or private insurance because he did not want to be investigated for "doing 'what I know is right for patients.'"). Those physicians argue that accepting insurance places a target on their backs, as insurance companies often report physicians for their prescription practices. *Id.* Whatever the reason, the price of such treatment to patients is often exorbitant. The price for an initial consultation with some of these practitioners is $500 out of pocket. *See, e.g.*, Zhen Wang, *Doctors Debate, Patients Suffer: The Fight Over Chronic Lyme Disease In Wisconsin*, WIS. PUB. RADIO (Mar. 13, 2022), https://www.wpr.org/doctors-debate-patients-suffer-fight-over-chronic-lyme-disease-wisconsin [https://perma.cc/RCF3-CSHS]; The Carlat Psychiatry Podcast, *supra* note 102.

137. Feder, Jr. et al., *supra* note 49, at 1428. Notably, ILADS' website provides a portal for patients to search for Lyme "literate" physicians—physicians who are aware of the need for ongoing treatment—in their area. *Provider Search*, INT'L LYME & ASSOCIATED DISEASES SOC'Y, https://www.ilads.org/patient-care/provider-search/ [https://perma.cc/B9G6-7GTF] (last visited Nov. 14, 2023).

believes the symptoms result from enduring damage from a now-resolved infection—is jarring.[138] The animosity extends to the development of scientific evidence. IDSA points to numerous double-blind studies that failed to find significant improvement with antibiotics, many demonstrating adverse effects associated with long-term antibiotic use.[139] Currently, chronic Lyme advocates' research builds upon itself and largely ignores the competing results of mainstream physicians.[140] ILAD and IDSA promulgate competing guidelines for the treatment of Lyme,[141] and the interactions between the two groups are particularly contentious.

For Morgellons, a small group of researchers (Stricker, Middelveen, Wymore, and Savely) present one side of the debate. The contrary side is no longer active, as mainstream science has basically concluded that the inquiry is over. For CFS/ME, the camps originally consisted of patient advocacy groups and researchers.[142] Currently, the camps seem less divided, as scientific evidence has trended toward a physiological explanation.[143] Debate over the efficacy of GE and CBT, however, is still quite contentious.[144] These divisive camps can serve as impediments to resolving uncertainty. Rather than an entire field working together to methodically design and implement studies that can rigorously elucidate the characteristics of a disease, divided research efforts are placed in competition with one another. Once a viewpoint is assigned, the neutrality (and perceived unbiasedness) of the study is threatened. Patients are left to reconcile the often-contradictory scientific conclusions on their own, a task that they are ill-suited to tackle.

It is also not clear that this marginalization only occurs on a disease-by-disease basis. Patient advocates for one contested illness often advocate for other such illnesses. Raphael Stricker, one of the leaders in chronic Lyme

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138. The physician largely responsible for much of the information on acute Lyme infection, Dr. Steere, suspected that many patients who believed that they had chronic Lyme actually experienced ongoing symptoms due to lasting damage from the original infection or other illnesses like fibromyalgia and chronic fatigue syndrome. After testifying in front of the Senate Labor and Human Resources Committee to this effect, Dr. Steere began receiving death threats, after which he retired from the public eye. Grann, *supra* note 14.

139. *See supra* footnote 114 and accompanying sources.

140. *See Leading Research*, INT'L LYME & ASSOCIATED DISEASES SOC'Y, https://www.ilads.org/research-literature/leading-research/ [https://perma.cc/2VZY-6VRC] (last visited Aug. 26, 2022).

141. Paul M. Lantos et al., *Clinical Practice Guidelines by the Infectious Diseases Society of America (IDSA), American Academy of Neurology (AAN), and American College of Rheumatology (ACR): 2020 Guidelines for the Prevention, Diagnosis and Treatment of Lyme Disease*, 72 CLINICAL INFECTIOUS DISEASES e1 (2021); Daniel J. Cameron, Lorraine B. Johnson, & Elizabeth L. Maloney, *Evidence Assessments and Guideline Recommendations in Lyme Disease: The Clinical Management of Known Tick Bites, Erythema Migrans Rashes and Persistent Disease*, 12 EXPERT REV. ANTI-INFECTIVE THERAPY 1103 (2014).

142. *See, e.g.*, #MEACTION, https://www.meaction.net/ [https://perma.cc/LV5Q-G5FG] (last visited Sept. 2, 2023).

143. Komaroff, *supra* note 38, at 499.

144. *See* White et al., *supra* note 43.

research, is also one of the leading names for Morgellons research.[145] Indeed, Marianne Middelveen was treated for Lyme by Stricker before joining forces to understand Morgellons.[146] Similarly, singer Dana Parish—who partnered with physician Steven Phillips to write a book about, *inter alia*, chronic Lyme disease—has advocated for both Lyme and long COVID-19,[147] with her Twitter feed expressing concern over suppression of information from leading experts.[148] This is suggestive that alienation from mainstream medicine extends beyond the original point of contention. This would be intuitive if a group believed that mainstream science erroneously found resolution of uncertainty where there should not be. This poor judgment may lead groups to mistrust judgment in other contexts. This ultimately means, however, that patient marginalization would not be confined to a narrow diagnostic context but may become a broader phenomenon.

For these reasons, if patient marginalization is indeed irreversible (as suggested above), there may be reason to *delay* statements prematurely calling a disease discredited or purely psychological, depending on the likelihood that better information will be created in the next period.[149] Crucially, this may be true even in cases in which there are one-period expected benefits to classifying a disease as purely psychological. As W. Kip Viscusi and coauthors note in such circumstances, "the optimal strategy often involves holding off from expensive or irreversible actions and instead learning about the risk based on experience, and considering adaptive behavior that involves switching to other policies if the outcomes with the uncertain choice are sufficiently unfavorable."[150]

Building on the logic of decision-making with irreversibility described by Nicholas Treich and Christian Gollier,[151] suppose that the government must

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145. Laurie Saloman, *Morgellons Found to Be Closely Linked with Lyme Disease*, CONTAGION LIVE (Nov. 1, 2016), https://www.contagionlive.com/view/morgellons-found-to-be-closely-linked-with-lyme-disease [https://perma.cc/Y7T4-Q6SL].

146. *See, e.g.*, Marianne J. Middelveen et. al., *Dermatological and Genital Manifestations of Lyme Disease Including Morgellons Disease*, 14 CLINICAL, COSM. & INVESTIGATIONAL DERMATOLOGY 425 (2021).

147. Bay Area Lyme Foundation, *Ticktective with Dana Parish: From Long Covid to Long Lyme: Persistent Infections Drive Chronic Illness*, https://www.bayarealyme.org/videos/ticktective-with-dana-parish-from-long-covid-to-long-lyme-persistent-infections-drive-chronic-illness/ [https://perma.cc/Z27C-H6RD] (last visited Sept. 23, 2023).

148. *See* Dana Parish (@danaparish), X, https://twitter.com/danaparish [https://perma.cc/4GJC-DWEY] (last visited Sept. 2, 2023) (X is formerly known as Twitter).

149. *See* Gollier & Treich, *supra* note 126, at 77.

150. Viscusi, Huber, & Bell, *supra* note 125, at 309.

151. Formally, Gollier and Treich's example involves a level of investment, I, a discount factor, b, and a benefit amount P. While I do not use a model of investment, the option value intuition from their model translates. Gollier & Treich, *supra* note 126, at 82-83. While there have been other recommendations for more dynamic decision-making under uncertainty, *see* Peter Molk & Arden Rowell, *Reregulation and the Regulatory Timelines*, 101 IOWA L. REV. 1497, 1498 (2016); Yoon-Ho Alex Lee, *An Options Approach to Agency Rulemaking*, 65 ADMIN. L. REV. 881, 883 (2013); Dudley, *supra* note 125, this Part discusses a context in which decisions are irreversible due to patient marginalization. Accordingly,

decide between making a statement noting that Illness X is purely psychological or abstaining from such a statement. The statement has ramifications for the provision of care. In the case that Illness X is purely psychological and the government does not issue the statement, patients continue to receive non-psychiatric care, which may not address their illness and may cause other side effects (net benefits of -$100 per affected patient). Conversely, if the government erroneously issues the statement, patients will also not be correctly treated (net benefits of -$100 per affected patient). This harm can be either medically harmful treatment, ineffective treatment, or the harms associated with losing trust in medicine: self-treatment, predatory physicians, and reduced likelihood to adopt other health recommendations.[152] If the government properly refrains from issuing or properly issues the statement, patients receive proper care (net benefits of $100 per patient).

To assess the value of making the statement that Illness X is purely psychological, we must consider the two potential outcomes: (1) the government is correct that Illness X is purely psychological, and (2) the government is incorrect in its assessment and there is a physiological mechanism. If the government were to issue the statement, the expected net benefits for one period would be

$$(1)\ [0.70 * \{40 * (100)\}] + [0.30 * \{40 * (-100)\}] = 1600.$$

In this expression, the first bracket refers to the state of the world in which Illness X is purely psychological, where the government correctly issues the statement, and everyone receives the correct treatment (worth $100). By best estimates, this state occurs with 70% probability. Meanwhile, the second bracket corresponds to the state where the government incorrectly issues the statement, and everyone receives incorrect treatment (worth -$100) occurring, by best estimates, with 30% probability.

Because the choice to issue a statement is not reversible, patients receive these net benefits in perpetuity. Accordingly, we must calculate the net present value (the present value for infinite periods) of these net benefits.[153] Based on a reasonable discount factor, equation (1) becomes:

$$(2)\left\{0.70 * \frac{[40*(100)]}{.08}\right\} + \left\{0.30 * \frac{[40*(-100)]}{.08}\right\} = 20{,}000 > 0$$

This means that, considered in isolation, making the statement in the first period is better than never making the statement. As shown in the above equation, the state of the world where the statement would produce positive net benefits is more probable than the alternative.

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built-in options to alter regulatory course—which are important in contexts where it is possible—are not applicable here.

152. As will be noted in Part II.B., this harm may be asymmetric: patients erroneously told that an illness is psychological may experience more marginalization than patients erroneously told that an illness is physiological. This example conservatively treats these two harms as equivalent, but the extension is straightforward.

153. The net present value of infinite periods is calculated as follows, where b is a discount factor. In the above calculations, b=0.92 for $\frac{1}{1-b} * V = NPV$.

Rather than acting irreversibly in period 1, however, the government could instead wait until more information about the disease is revealed. Suppose, for simplicity, that the government expects to know with certainty whether Illness X is purely psychological in period 2. Should the government act in the first period or wait until the second period, when the uncertainty resolves? Instead of taking irreversible action in period one—before uncertainty is resolved—postponing irreversible action *may* be more beneficial. Conservatively assuming that all patients make the wrong decision in period 1, equation (3) calculates the expected net benefits from waiting until period 2 to issue the statement

$$(3)\ \{40 * (-100)\} + \left\{0.70 * 0.92 * \frac{[40*(100)]}{.08}\right\} + \left\{0.30 * 0.92 * \frac{[40 * (100)]}{.08}\right\} = 42{,}000 > 0$$

Delaying the decision to make a statement has potential costs. First, optimal treatment is delayed[154] until period 2 because the government has not issued the statement. This cost is reflected in the first brace. From period 2 onward, however, the government has the benefit of knowing which state of the world it is in, instead of guessing. It will decide to make a statement only in the case that it knows Illness X is psychological. In period 1, this state of the world is expected to arise with 70% probability (and is reflected in the second brace). The government will refrain from making the statement if it knows that Illness X is physiological. In period 1, this happens with 30% probability (and is reflected in the third brace).

Here, the net benefits are roughly double the benefits of acting irreversibly in the first period. Because the government cannot reverse its initial choice, waiting has considerable benefits. Rather than guess the right decision and take the expected value over different states of the world, the government can preserve its decision until after uncertainty is resolved, thereby minimize harm. Notably, the same pattern can hold when uncertainty is not fully resolved, but merely lessened in the second period.[155]

This is merely a numerical example and, as such, is not intended to suggest that a particular policy is always optimal. Crucially, however, the examples demonstrate the pressure created by irreversible choices: the option value of waiting for better information might postpone irreversibly calling a contested

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154. To account for this, we simply multiply the prior net present values by a discount factor, denoted b.

155. For example, suppose the government believes with 90% probability that it will have evidence that Illness X is 80% likely psychological in period 2 (and 20% likely physiological)). With 10% probability, the government expects that no new evidence will be discovered, such that the probability that Illness X is psychological remains at 70%. The benefits of waiting a period before issuing the statement are lower than when certainty is resolved but still greater than acting in the first period. The formula for calculating this is $(40 * (-100)) + 0.92 \times \left\{\left\{0.9 \times \left\{\left\{0.80 \times \frac{[40*(100)]}{.08}\right\} + \left\{0.20 \times \frac{[40 * (-100)]}{.08}\right\}\right\}\right\} + \left\{0.1 \times \left\{\left\{0.70 \times \frac{[40*(100)]}{.08}\right\} + \left\{0.30 \times \frac{[40 * (-100)]}{.08}\right\}\right\}\right\}\right\} = 22{,}680$. Indeed, this is an underestimate of the benefits, as the government would have the option to continue delaying the decision in period 2.

illness resolved. Unlike characterizing a risk by its highest estimate (as criticized earlier in this section), however, the risk is characterized by its probability-weighted average, and the decision to wait depends on the expected value of additional data (which, as noted in Part II.A, declines with level of existing data).[156]

The additional caution to rule out contested illnesses, however, should not be misunderstood to suggest that policymakers should automatically make statements affirming them. Indeed, in the interim, physicians should explicitly acknowledge when little is known about a disease. They should solicit and acknowledge patient experiences early and become more restrictive in their allowance as time/research goes on.[157] Rather than artificially pretending to know the unknown, hearing patients' narratives and considering alternatives early has additional benefits. Explicit acknowledgment—and communication—of this evolution to patients help prepare them for the natural process of updating beliefs. It also keeps them from being (unnecessarily) dismissed in the period in which uncertainty is high, mitigating the danger of marginalization.

Glossing over areas of uncertainty is often justified by not wanting to spook patients/society and create even higher ambient uncertainty. However, in the context of contested illnesses, this communication takes place when a patient is already experiencing a very real, uncomfortable health event. A candid acknowledgment of uncertainty often feels better than the alternative: a dismissive platitude.

Despite the social benefits of communicating uncertainty carefully, past histories demonstrate that current communication falls considerably short. The following Part proposes a new informational intervention to summarize the current level of uncertainty in the data and to provide incentives to gradually move science toward resolving it.

III. AN INFORMATIONAL INTERVENTION: A GOVERNMENT-COORDINATED DIGEST

In light of the dangers of poorly communicating uncertainty, the explicit acknowledgment—and nuanced description—of uncertainty is paramount. The history of contested illnesses discussed in Part II demonstrates not only that such careful communication has not been the norm in the past but also the resulting legacy of long-lasting harms. The specter of emerging uncertain risks, including

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156. As an example, if the government believes that there is only a 50% chance that it will learn more about Illness X in the second period (i.e., a 50% chance that period 2 will make them believe that 80% likely that Illness X is purely psychological), waiting will make society worse off. The option value of waiting for new information is too low. $(40 * (-100)) + 0.92 \times \left\{\left\{0.5 \times \left\{\left\{0.80 \times \frac{[40*(100)]}{.08}\right\} + \left\{0.20 \times \frac{[40 * (-100)]}{.08}\right\}\right\}\right\} + \left\{0.5 \times \left\{\left\{0.70 \times \frac{[40*(100)]}{.08}\right\} + \left\{0.30 \times \frac{[40 * (-100)]}{.08}\right\}\right\}\right\}\right\} = 19{,}000.$

157. A caveat to this idea is if advances in technology suddenly make previously unobservable effects observable (or if circumstances change).

the risk of long COVID, requires society to find a better way to ensure that uncertain risks are better communicated.

This Article proposes a government-coordinated digest that would perform two functions. First, the digest would summarize the current evidence underlying the contested illness and assign a rating corresponding to the strength of the evidence as to whether the illness remains uncertain.[158] In assessing the strength of the data, the digest will weigh studies based on the level of methodological rigor and leverage study registrations on ClinicalTrials.gov to address the issue of publication bias. This rating—and its transparent and public updating—serves to guide providers and patients in circumstances when uncertainty remains unresolved. Second, the digest would create recommendations and incentives for study designs/interventions that are necessary to begin to resolve uncertainty. By summarizing the literature, gaps in the literature and outstanding questions become clear. Indeed, as emphasized in Part IV.A.2, there is potentially a gap between the types of studies that are privately rewarding for researchers and types that are socially beneficial. Articulating those gaps and connecting them to existing research incentive mechanisms (such as grant funding) can help the evolution of scientific inquiry be less biased and more constructive.

In true meta-analysis fashion, the report would disclose the studies done to date, the criteria for inclusion in the assessment, and the weighting formula. The list of current studies itself is important, alerting the public (and professionals) to the sometimes-obscure pieces of data. While exclusion of certain studies would currently be imperceptible, researchers or practitioners who ignore a subset of the data would be obligated to provide a compelling reason to do so. Using the tools of meta-analysis, the agency will additionally produce a rating corresponding to the degree of confidence in understanding the illness's proposed mechanism. The mechanism may be entirely psychological or physiological (or a mixture of the two)—the rating merely summarizes the level of certainty in the articulated mechanism.

Summarizing existing literature into an easily understood rating is not a trivial task, but the transparent process will shift disagreements into more fruitful territory. While some weighting criteria will be relatively straightforward (for example, differences in methodology provide a strong reason for weighing results differently), judgment calls are inevitable in characterizing a body of evidence. The explicit discussion of the assumptions used moves the scientific discourse into a more productive conversation. For actors who are not interested or who do not have the technical skills to assess the detailed information, reports of raw data will be overwhelming. The addition of the rating provides an easy figure to communicate the strength of the evidence. For actors willing and able to grapple with the data, the digest's

158. Similar ratings systems are used in drug digests such as DRUGDEX. *See Drugdex System*, DRUG DISCOVERY ONLINE, https://www.drugdiscoveryonline.com/doc/drugdex-system-0001 [https://perma.cc/8XBJ-T3AJ] (last visited Sept. 23, 2023).

provision of raw estimates allows them to reanalyze the data with different criteria. Ratings that are disproportionately sensitive to controversial assumptions will be correctly flagged by critics.

While the rating itself is helpful, the paradigm shift in how society discusses contested illnesses is more important—by taking them seriously rather than dismissing them out of hand and removing the stigma of not knowing the mechanism with certainty. This shift interrupts the cycle of immediately dismissing a new disease, reversing the dismissal, and then pretending as though the truth should have been known from the beginning.

In addition to incorporating existing published work, the government digest would go further by addressing publication bias. Publication bias is the phenomenon in which published results are not representative of the full body of results, with statistically significant results being more likely to be published.[159] To account for this, the digest would incorporate data from ClinicalTrials.gov to track studies initiated but not completed (or for which results have not been reported). Most medical journals require that studies be preregistered on ClinicalTrial.gov in order for the results to be eventually published.[160] Technically, the site must also be updated to include any results; however, empirical studies have noted that this is often not the case.[161] By imputing unreported results as null results, the government digest will be able to present a more unbiased signal of the state of the evidence.

Finally, not only would the digest provide a comprehensive rating, but it would also identify gaps in the literature and provide incentives for researchers to create studies to fill these gaps. Often, the uncertainty associated with contested illnesses is a function of too many small-sample, poorly designed studies with contradictory results.[162] For reasons summarized in Part IV.A.2, researchers may not be fully incentivized to conduct studies that are necessary to help resolve uncertainty. Replication studies are very important in empirically establishing an effect; however, the reputational gains of conducting a replication study are not always high.[163] Moreover, while a large-scale study with a rigorous methodology produces more credible results, it is also quite expensive. Publishing interesting findings from small samples or case studies

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159. *See* Kassiani Nikolopoulou, *What is Publication Bias? | Definition & Examples*, SCRIBBR (Oct. 29, 2022), https://www.scribbr.com/research-bias/publication-bias/ [https://perma.cc/ZH4F-25PC].

160. *See Clinical Trials*, INT'L COMM. MED. J. ED., https://www.icmje.org/recommendations/browse/publishing-and-editorial-issues/clinical-trial-registration.html [https://perma.cc/RGY7-FE8S] (last visited Aug. 26, 2022) (recommending that medical journal editors require public registration of clinical trials as a condition for submission for publication).

161. *See* Jennifer Kao, *Information Disclosure in the Presence of Competition: Evidence from the Pharmaceutical Industry*, SSRN (Apr. 16, 2022), https://ssrn.com/abstract=4081398 [https://perma.cc/XU67-KEUL].

162. *See* David Scales, *What I've Learned Reporting about Lyme Disease, a Contested Illness*, COLUM. JOURNALISM REV. (Dec. 18, 2018), https://www.cjr.org/analysis/lyme-disease-contested-illness-empathy.php [https://perma.cc/65FE-7NQ4].

163. Jorn H. Block et al., *Replication Studies in Top Management Journals: An Empirical Investigation of Prevalence, Types, Outcomes, and Impact*, 73 MGMT. REV. Q. 1109, 1110 (2022).

may be more rewarding for individual researchers. Priority in grant funding can be given to fill the gaps in contested illness funding, topics that would otherwise not be considered sufficiently intellectually interesting (with insufficient publication potential) to be undertaken. Moreover, given the importance of properly timed patient feedback,[164] designs that incorporate patient feedback may qualify for additional incentives.

While this seems like an ambitious endeavor, many of these functions (in particular, the summarization of findings) are similar to current efforts in related contexts; however, the digest goes further in its breadth, publicity, and incentives. The National Center for Complementary and Integrative Health (NCCIH) publishes digests on complementary and alternative treatments for illnesses.[165] It summarizes evidence on different alternative treatments in plain English, noting both the likely safety and efficacy of each.[166] It even funds specific research efforts. However, as noted above, uncertain treatments are distinct from uncertain illnesses.[167] The NCCIH does not focus on treatments for many of the aforementioned contested illnesses.[168] This is understandable, as their goal is not to discuss contested illnesses but alternative treatments to recognized illnesses.[169] Moreover, the extent of disclosure would be greater, including the foundations for the recommendations (e.g., lists of studies and estimates and assumptions in addition to the plain English recommendations).

Similar efforts include the Patient-Centered Outcomes Research Institute (PCORI), which focuses on comparative clinical effectiveness research,[170] and the Agency for Healthcare Research and Quality (ARHQ), which creates reports on various health topics.[171] The latter may be a particularly intuitive manager for the digest, but none of their current efforts go as far as proposed in this Article. The digest would go further in extending review to contested illnesses in its disclosure and rating requirements (with imputations for publication bias). Moreover, coupling its recommendations with incentives makes efficient use of government resources already dedicated to research.

Insofar as a digest has come close to performing these functions, the

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164. *See* discussion *infra* Part IV.A.2.

165. *See, e.g.*, *Alzheimer's Disease at a Glance*, NAT'L CTR FOR COMPLEMENTARY & INTEGRATIVE HEALTH (June 2019), https://www.nccih.nih.gov/health/alzheimers-disease-at-a-glance [https://perma.cc/FPM8-PEH6].

166. *See, e.g.*, *id.*

167. *See, e.g.*, *id.*

168. *See generally*, *Health Topics A-Z*, NAT'L CTR FOR COMPLEMENTARY & INTEGRATIVE HEALTH, https://www.nccih.nih.gov/health/atoz#linkM [https://perma.cc/Z6BE-Q2G7] (last visited Sept. 23, 2023).

169. *See About NCCIH*, NAT'L CTR FOR COMPLEMENTARY & INTEGRATIVE HEALTH, https://www.nccih.nih.gov/about [https://perma.cc/ZP7R-KDWJ] (last visited Sept. 23, 2023).

170. *About Us*, PATIENT-CENTERED OUTCOMES RSCH. INST., https://www.pcori.org/about/about-pcori [https://perma.cc/2VKB-46UW] (last visited Sept. 2, 2023).

171. *Mission and Budget*, AGENCY FOR HEALTHCARE RSCH. & QUALITY, https://www.ahrq.gov/cpi/about/mission/index.html [https://perma.cc/9FKD-E3QF] (last visited Sept. 2, 2023).

Cochrane[172] reports are a great example. Cochrane periodically issues reports on the efficacy of various treatments.[173] Cochrane is funded by "national governments, international governmental and non-governmental organizations, universities, hospitals, private foundations, and personal donations worldwide," as well as from income from the purchase of their informational products.[174] Unlike Cochrane reports, however, which are more periodic, the proposed digest would allow patients to monitor the status of a particular illness over time. Similarly, the digest would provide incentives to coordinate research efforts that would work toward resolving uncertainty.

While public funding[175] for such a digest would be new, the whole intervention may indeed reduce costs overall. The increased confidence in scientific ratings will likely lead to greater adherence to public health directives (e.g., vaccines and preventative measures) that will save on health costs. Insofar as this rating can prevent spending on unnecessary (and indeed, potentially dangerous) treatments, health costs are further reduced.

Finally, relative to the existing set of tools, the government-coordinated digest would make the process of updating scientific beliefs about contested illnesses public and transparent. Because the existing reports are generally periodic, they are not continually referenced as a resource in public communications. For this reason, they poorly accomplish the educational function of the digest, which is the key to undermining patient marginalization.

While some segments of society distrust the government, the reason for the distrust matters. It is difficult to claim that extant distrust in the government is not in some ways attributable to the prior dynamic of poorly acknowledging or communicating uncertainty. Strong intervention to prevent further erosion of public trust through such transparency will become even more important. Insofar as society worries that multiple private sources may be more informative than one government source, this intervention does not restrict any information. It merely requires one source to provide a comprehensive review of the information. Other entities are free to conduct their own meta-analyses. Nothing but persuasiveness affects another entity's ability to make statements to the contrary or reassess the disclosed raw data under new criteria. Even if people

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172. *See Our Evidence*, COCHRANE, https://www.cochrane.org/evidence [https://perma.cc/CYU8-6977] (last visited Aug. 26, 2022).

173. *See id.*

174. *Our Funders and Partners*, COCHRANE, https://www.cochrane.org/about-us/our-funders-and-partners [https://perma.cc/93PY-9XGE] (last visited Aug. 26, 2022). As seen in the PACE trial scandal, however, concern remains about private influence in issuing such reports. This is not to suggest that government reports will be immune from such critiques; however, there would be a lot more transparency in the process of creating and updating the records.

175. While establishing this digest under a government entity would require resources, the majority of the start-up expenses would be the fixed cost of creating the infrastructure. There would likely be a lag as the digest catches up on existing contested illnesses, and a triage system would need to be established. However, this is no worse than our current state, where no information is being organized. *See generally*, TRUST FOR AMERICA'S HEALTH, THE IMPACT OF CHRONIC UNDERFUNDING ON AMERICA'S PUBLIC HEALTH SYSTEM: TRENDS, RISKS, AND RECOMMENDATIONS, 2022 (2022).

disagree with the way the information is weighed, the government digest will create awareness of the relevant pieces of data that should be considered. Insofar as this distrust is prompted by lack of awareness of public funding, a look at the alternatives helps. Academic centers are not independently incentivized to accomplish this task. Insofar as government funding provides these incentives—just as much of current basic research is actually funded by the federal government—funding alone is inferior to the procedural safeguards and transparency of an agency creating these ratings. The general tools of public disclosure and access allow the public to assess the rationales given for study inclusion.

IV. NECESSITY OF A GOVERNMENT DIGEST

Insofar as critics suggest that such a revolutionary informational intervention is unnecessary to prevent patient marginalization, existing levers of liability or public obligation provide insufficient incentives to prompt such nuanced communications. The following Part reviews the incentives currently available for medical providers and public figures to implement the recommendations of this framework and argues that not only is the government digest necessary to fill this gap, but it creates additional benefits that improve society's understanding—and implementation—of the scientific process.

A. Current Incentives for Communicating Uncertainty Are Inadequate

In considering the actors who communicate the nature of emerging illnesses to patients and the public writ large, two major categories emerge. Medical providers—physicians, nurse practitioners, physician assistants, etc.—perform a crucial function within the patient-provider relationship. Their ability to communicate uncertainty to a patient within the context of their treatment plan is paramount; this Part notes, however, that despite the fiduciary duty owed to patients, incentives to communicate uncertainty correctly are largely inadequate. Second, public figures engaged in health communications to the general public—including medical providers, researchers, and patient advocates—are both bound by fewer explicit duties and are poorly positioned to address the level of uncertainty for a particular illness. Because these collective incentives leave much to be desired, a broader educational intervention—in the form of a government-coordinated informational digest—is necessary.

1. Incentives for Medical Providers.—The current legal system does not provide sufficient incentive for physicians to adequately communicate uncertainty within the physician-patient relationship. This Article argues that adequately communicating uncertainty is one of the most important functions, both for enhancing patient welfare and for maintaining public trust in science.

Malpractice claims, duties of informed consent, and disciplinary actions are

the obvious levers for incentivizing physicians to pursue their patients' interests. These avenues, however, are woefully inadequate in the context of uncertain risks of emerging illnesses.

a. Informed consent.—One basis of liability for not communicating uncertainty accurately may be the breach of the duty of informed consent. One of the duties flowing from the fiduciary relationship between physician and patient is to obtain informed consent in treatment.[176] Courts vary in the tests they employ to assess whether an issue is within the scope of informed consent; however, there are two main tests. A physician-centered test asks whether a reasonable physician would have disclosed a particular risk.[177] Reasoning that the informed consent doctrine exists to preserve patient bodily autonomy, other courts employ a patient-centered test, focusing on what a reasonable patient would find to be material.[178]

The physician-focused test is particularly vulnerable to the emerging illness context because a "reasonable" physician may not disclose the uncertainty surrounding the illness (much like the issue with defining the standard of care). Even the patient-centered test, however, is potentially tenuous here. Physicians would point to evidence regarding whether patients respond positively to physicians' expressions of uncertainty. Prior evidence on how patients reward acknowledgements of uncertainty is mixed. Dr. Geoffrey Gordon and coauthors examine recordings of patient visits to 43 physicians and classified statements as expressing uncertainty or not.[179] They found that physicians expressed uncertainty in 71% of visits and that patients generally expressed more satisfaction in those encounters.[180] They note that this satisfaction, however, did not occur independently of other verbal behaviors known to be associated with satisfaction.[181] Other studies find decidedly mixed evidence, suggesting that patients feel more vulnerable in the presence of explicit uncertainty.[182]

The issue with relying on informed consent in the context of emerging

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176. *See, e.g.*, Canterbury v. Spence, 464 F.2d 772, 782 (D.C. Cir. 1972) ("More recently, we ourselves have found 'in the fiducial qualities of [the physician-patient] relationship the physician's duty to reveal to the patient that which in his best interests it is important that he should know.' We now find, as a part of the physician's overall obligation to the patient, a similar duty of reasonable disclosure of the choices with respect to proposed therapy and the dangers inherently and potentially involved.").

177. *Id.*

178. *Id.* at 786-87.

179. Geoffrey H. Gordon et al., *Physician Expressions of Uncertainty During Patient Encounters*, 40 PATIENT EDUC. & COUNSELING 59, 62 (2000).

180. *Id.*

181. *Id.*

182. *See* Arabella L. Simpkin & Katrina A. Armstrong, *Communicating Uncertainty: A Narrative Review and Framework for Future Research*, 34 J. GEN. INTERNAL MED. 2586, 2588 (2019) (citing prior studies expressing mixed patient responses to expressions of uncertainty). Other work explores the determinants of physicians' comfort expressing uncertainty. Mary C. Polti & France Legare, *Physicians' Reactions To Uncertainty In The Context Of Shared Decision Making*, 80 PATIENT EDUC. & COUNSELING 155 (2010); *see also* R. McGovern & D. Harmon, *Patient Response To Physician Expressions Of Uncertainty: A Systematic Review*, 186 IRISH J. MED. SCI. 1061 (2017).

illnesses, however, is more fundamental. Because this solution is litigation-based, its success relies on patients actually choosing to bring suit. When patients do not feel heard by their physicians, they often find alternative care—including no care—rather than retaliate against a physician who did not listen.[183]

The other issue with using informed consent is that the lack of informed consent must result in demonstrable harm.[184] The physician's inability to correctly describe the uncertainty surrounding the condition—if corrected—must have resulted (1) in a different course of treatment chosen which (2) would have prevented the current harm.[185] Given the above discussion regarding causation difficulties, this is an ambitious task for plaintiffs.

Finally, while such claims would be arbitrated on an individual physician-patient basis, the injury that society really suffers is the harm to the trust the patient has in mainstream medicine. Relying on physical harm as the basis for informed consent violations does not fully capture this harm.

b. Medical malpractice.—Given that decisions on how to treat uncertain ailments come down to scrutinizing treatment decisions, malpractice claims for the failure to provide due care may seem like an intuitive option. Uncertain illnesses, however, comprise a subset of cases that likely will not be successful at trial.[186]

First, in most jurisdictions, the standard of care is largely based on custom.[187] The "minimally competent" physician standard incorporates conventional notions of medicine.[188] However, in the context of emerging risks, there may be no established standard of care. These ailments are by definition novel, and—relative to other illnesses—custom is likely less established. Physician treatment in this context may be difficult to hold liable.

Second, causation is likely difficult to establish for malpractice based on poor treatment of an emerging illness. While a patient might experience poor health, it will be difficult to prove that the emerging illness—and the negligent or lack of treatment of the emerging illness—caused their current distress. Given that causation is essentially contested on a global scale for contested illnesses, proving causation within a malpractice case would be challenging.

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183. *See* Joanna Shepherd, *Uncovering the Silent Victims of the American Medical Liability System*, 67 VAND. L. REV. 151 (2014) (describing the damage thresholds necessary to make a malpractice suit profitable for an attorney to bring); TOM BAKER, THE MEDICAL MALPRACTICE MYTH 22-44 (2004) (describing the low prevalence of malpractice claims relative to malpractice); *Physicians Underestimate Consumer Likelihood to Switch Doctors*, ALTARUM INST. CTR. FOR CONSUMER CHOICE IN HEALTH CARE, https://altarum.org/sites/default/files/uploaded-related-files/CCCHCResults03_LikelihoodSwitch_0.pdf [https://perma.cc/C4FU-ZSNC] (last visited Feb. 2, 2023) (describing a survey noting that 69% of patients said that they were likely to switch doctors if the doctor did not listen to concerns).

184. Canterbury v. Spence, 464 F.2d 772, 790 (D.C. Cir. 1972).

185. *Id.*

186. And, accordingly, will be unlikely to be brought, *see* George L. Priest & Benjamin Klein, *The Selection of Disputes for Litigation*, 13 J. LEGAL STUD. 1, 4 (1984).

187. *Cf.* Helling v. Carey, 83 Wash. 2d 514, 517-19 (Wash. 1974), *disapproved of by* Barton v. Owen, 71 Cal. App. 3d 484 (Cal. Ct. App. 1977).

188. Outside of courts adopting a more *Helling v. Carey* approach.

c. Disciplinary action.—Another option for incentivizing the proper communication of uncertainty is through disciplinary action by medical boards. Because one of the purposes of medical boards is to provide some minimal standard for expertise through licensure,[189] disciplinary action by a medical board can also be used to protect against fringe and exploitative treatments. On the other hand, aggressive interference in treatment choice can stifle innovative practice. In the context of contested illnesses, there have been notable disciplinary sanctions for a variety of reasons.

Some of these sanctions seem to be spurred by significant patient harm or scientific fraud. For example, one of the leading researchers of chronic Lyme and Morgellons, Raphael Stricker, faced discipline for falsifying data in a grant application to the NIH.[190] He agreed to not apply for federal grants and not serve on various boards, committees, or peer review groups for three years after his sanction.[191]

Other actions toe the line between patient protection and policing treatment styles. Virginia Savely, a nurse practitioner who treated many Morgellons patients in Texas before moving to California, was disciplined by the Texas Medical Board and publicly reproved by the State of California for failing "to use appropriate physician-delegated protocols while managing medical aspects of care for a patient," which resulted in "subtherapeutic levels" of antibiotic therapies.[192] She eventually moved from Texas to California when she could no longer find a physician to supervise her.[193]

Other targets of medical board discipline in the chronic Lyme field include Joseph Burrascano, one of the leaders of ILADS.[194] After allegations that he was negligent in his treatment of eight patients (among other things), he was only found negligent in two cases (one for reasons seemingly unrelated to Lyme).[195] His license was suspended for six months, during which time he had to practice under supervision.[196]

For chronic Lyme, the professional conflict goes both ways. In 2006, Connecticut AG called for the investigation of IDSA for antitrust violations in

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189. In practice, this does not seem to be the type of sanctions boards generally impose. Prior empirical work has noted that board discipline is largely concentrated on physicians engaging in drug use and sexual exploitation of their patients. *See* David A. Hyman, Mohammad Rahmati, & Bernard Black, *Medical Malpractice And Physician Discipline: The Good, The Bad And The Ugly*, 18 J. EMPIRICAL LEGAL STUD., 131-66 (2021).

190. Nat'l Inst. of Health, *Final Findings of Scientific Misconduct*, 22 NIH GUIDE (June 25, 1993).

191. *Id.*

192. Virginia Riley Savely, No. 2011-461 (2011), https://lymescience.org/rogues/Virginia-Ginger-Savely/Virginia-Ginger-Savely-Discipline-2011.pdf [https://perma.cc/CCX5-CYJ4].

193. Mary Ann Roser, *Nurse Practitioner Said No Austin Doctor Willing to Practice With Her*, STATESMAN.COM (Mar. 30, 2006), https://web.archive.org/web/20060409194530/https://www.statesman.com/news/content/news/stories/local/03/30LYME.html [https://perma.cc/ZMK4-8JKA].

194. Joseph Burrascano, M.D., No. 01-265 (2001), https://centerforinquiry.org/wp-content/uploads/sites/33/quackwatch/findings.pdf [https://perma.cc/496K-7A8V].

195. *Id.*

196. *Id.*

promulgating Lyme disease guidelines.[197] In 2008, IDSA reached an agreement with the AG's office in which an independent Review Panel would assess the medical soundness of the guidelines.[198] The Review Panel found that "each was medically and scientifically justified in light of all the evidence and information and required no revision."[199] IDSA scientists point to this incident as an "antiscientific, baseless and unethical attack[]."[200]

This legal tit-for-tat demonstrates the fractured nature of communications surrounding these illnesses. While some of these actions involve scientific fraud or such egregious treatment as to lead to patient harm,[201] other actions seem reminiscent of power struggles over what should ultimately be professional differences.

Sanctioning certain characterizations of an illness may be beneficial once a contested illness has reached the status of discredited rather than merely uncertain. For a sufficient degree of confidence in the assessment of this transition, board action to sanction certain treatments seems necessary for patient safety and in keeping with the board's purpose of ensuring a floor for care.

The ability of a board to ascertain when this transition occurs, however, is questionable. Based on the contentious relationship across camps, a medical board may be tempted to claim certainty prematurely. Moreover, as a tool for regulating beliefs about an emerging illness, disciplinary action can be a bit pernicious: it can easily devolve into a way to retaliate against physicians with whom the board merely disagrees. If mainstream medicine disagrees with alternative practitioners, bringing discipline cases can effectively silence them and remove the competition. This chilling of experimentation is not socially beneficial.[202]

While board decisions often provide a floor of quality, they are not the usual institution for policing innovation. While this Article does not suggest that board discipline should be unavailable for egregious conduct out of step with current data, it is skeptical that it will be an efficacious way to incentivize physicians to communicate uncertainty instead of merely retaliating against practitioners who disagree.

2. Incentives for Public Communications.—The second mechanism for communicating uncertainty is through what the Article will refer to as public communications. The purpose of this type of communication is to communicate

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197. Paul M. Lantos et al., *Final Report of the Lyme Disease Review Panel of the Infectious Diseases Society of America*, 51 CLINICAL INFECTIOUS DISEASES 1 (2010).

198. *Id.*

199. *Id.* at 2-3.

200. Auwaerter, *supra* note 21, at 68.

201. Fran Zell & Tom Boswell, *Wisconsin Lyme Doctor Gets Reprieve*, WIS.COMMUNITY (Jan. 29, 2012), https://www.wis.community/blogarticle/wisconsin-lyme-doctor-gets-reprieve [https://perma.cc/4SST-SUDS].

202. The chilling of experimentation can be seen as the excessive caution described in Part II.B., with the added layer of targeting specific rivals rather than merely prioritizing known treatments.

general statements of science to the public writ large. These communications do not take place in the context of the provider-patient relationship; instead, these players intend to present information to a broad, unidentified audience.

Insofar as communications outside the provider-patient relationship are coupled with expertise, these communications are better suited to educating the population about emerging illnesses. Rather than considering the welfare of one patient—potentially to the exclusion of other patients—these communications are meant to update the body of extant publicly available data. On the other hand, fewer duties bind these communicators. Insofar as "public health" communicators are not tasked with this communication through their jobs, they may not be bound by any professional duty in their communications.

This Part categorizes these communications based on perspective being articulated: that of medical providers, researchers, or patient advocates. Because the same person can theoretically belong to more than one type of category, it is useful to think of these more as the context in which the communication takes place.

a. Medical providers.—The prior Part focused on the incentives of physicians and medical providers to communicate uncertainty effectively within the provider-patient relationship. Providers do, however, make medical statements outside of this relationship, often based off of observations from practice. These statements can express opinions on medical issues but fall short of constituting medical advice. Duties accompanying such communications are fewer.[203] Moreover, the value to the general public of statements based on medical practice is limited in two ways.

First, medical providers may not have a very accurate perspective about the overall average effect of certain treatments. Practitioners only treat a small subset of patients, who—depending on the practice—may differ significantly from the average patient. Heuristics such as availability bias[204] may distort a practitioner's view of average outcomes—a concept that often needs a large sample to unearth.

More foundationally, however, the goals of the practice of medicine and of well-designed scientific studies are different: good practice often makes for bad causal inference. This distinction is well-illustrated by randomized controlled trials: if a physician suspects that a treatment may be beneficial for her patient, it is in the patient's best interest to have access to it. However, the efficacy of the treatment will not be discernible without comparison to a control group (i.e.,

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203. The Third Restatement of Torts Tentative Draft No. 1 notes that "[a] medical provider's professional duty of care does not generally extend to third parties outside the patient-care relationship." Restatement (Third) of Torts: Concluding Provisions § 3 (ch 11) (Am. L. Inst., Tentative Draft No. 1, 2022).

204. DANIEL KAHNEMAN, THINKING FAST AND SLOW 129-31 (2011).

patients with the same illness who receive a placebo).[205] In our context, medical practice may seek to actively treat the symptoms of the contested illness, rather than to ascertain whether the illness is purely psychological. Statements making generalizations from medical practice, accordingly, might not reflect relevant information for the general public as to the level of extant uncertainty for a given illness.

b. Researchers.—The second category communicates the perspective of scientific researchers, defined as those who engage primarily in the promulgation of knowledge—not the treatment of patients. Researchers tend to communicate through more formal venues, such as working papers and published studies. The benefit of such formal communications is that they tend to provide more rigorous assessments of an emerging disease.[206] On the other hand, studies take a very long time to formulate and publish.[207]

While medical providers are not bound by the same duties in their public communications as they are in practice, the same may not be true for researchers. Insofar as the type of publication is formal—or if the communication fulfills a professional obligation—some duties may attach; otherwise, precision is sought only with an eye toward general credibility. Researcher's communications in their official capacities (e.g., at a formal conference) may not differ as much from their non-official capacities (e.g., posting their research on Twitter). For researchers, their research rarely reflects the views of their institutional body; despite this, every research presentation has a connection to their professional credibility.

While researchers may be adept at communicating their work in nuanced, careful ways, they are not tasked with summarizing the weight of the evidence in the literature.[208] Neither is this a task which the peer-review process is meant to perform. While peer-review is meant to ensure that published studies meet some standard of credibility, it functions as a very poor aid to lay readers in the context of scientific uncertainty. First, given the number of medical and scientific journals available, the ability to publish is not always a very precise signal of quality.[209] Second, while a lay reader can attempt to find the impact

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205. As the Belmont Report—the foundational text for ethical research—states, "Research and practice may be carried on together when research is designed to evaluate the safety and efficacy of a therapy . . . [T]he general rule is that if there is any element of research in an activity, that activity should undergo review for the protection of human subjects."

206. *See* Scales, *supra* note 162 (noting that value of studies vary by study design).

207. Lauren A. Maggio et al., *When Will I Get My Paper Back? A Replication Study of Publication Timelines for Health Professions Education Resear*ch, 9 PERSPS. ON MED. EDUC. 139 (2020) (describing the time to publication).

208. A notable exception occurs when researchers publish meta-analyses.

209. Richard A. Rison, Jennifer Kelly Shepphird, & Michael R. Kidd, *How to Choose the Best Journal for Your Case Report*, 11 J. MED. CASE REP. 198 (2017) ("As scientific publishing shifts from a business model of subscription revenue to open access, the number of open access journals has exploded. However, the proliferation of journals that will publish seemingly anything for a fee has caused alarm among many in the global research community. Alongside many respected open access publishers, others have entered the space acting in bad faith.").

factor of a journal to assess quality, a higher tier journal does not necessarily correspond to a more accepted scientific viewpoint.[210] Some of the most intriguing ideas occur at the very beginning of information creation. These articles may be hypothesis generating, using small samples to propose connections that have not been previously examined. These articles may publish well because of their novelty;[211] however, if their hypotheses are not tested by subsequent work, the probative value remains unestablished. Moreover, given that some journals publish a variety of study designs,[212] focusing on journal tier alone invites problems. Case studies are an important component of medical literature.[213] A case study published at a top-tier journal, however, is not more probative of the average case than a randomized controlled trial published in a lower-ranked journal.

Relatedly, the purpose of peer review is to ensure that research meets disciplinary standards, not to help lay readers navigate issues of great uncertainty.[214] Indeed, peer-reviewed journals may prioritize novelty and studies that cast doubt on previously published material.[215] The conclusion a lay reader should draw about a topic from a single study is not entirely clarified by the process of peer review.

c. Patient advocates.—Finally, patient advocates or lay advocates are predominantly focused on elevating patient voices. Some may suffer from the disease themselves; others may just have a close connection to the discussion of the disease. A great example of a patient advocate for long COVID-19 is Diana Berrant. A lawyer by training, with no purported scientific credentials, her posts about long COVID-19 have gained a lot of traction based on her role as a patient advocate.[216] The strength of patient advocates is that they present a human face to the disease; in the face of uncertainty, they remind the scientific community that real people actually suffer from the disease.

Patient advocates have also criticized traditional research for not communicating with patients; without this contribution, they believe, research cannot be fully responsive to a patient's experience.[217] Indeed, open communication between patients and researchers may help target research questions, remove confounders, and increase compliance with research

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210. Per O Seglen, *Why the Impact Factor of Journals Should Not be Used for Evaluating Research*, 314 BMJ 498 (Feb. 15, 1997).

211. Misha Teplitskiy et al., *Is Novel Research Worth Doing? Evidence from Peer Review at 49 Journals*, PNAS (Nov. 17, 2022).

212. *See, e.g.*, Rison, Shepphird, & Kidd, *supra* note 209 (noting that general medical journals publish case reports, though sparingly).

213. *Id.*

214. Jacalyn Kelly, Tara Sadeghieh, & Khosrow Adeli, *Peer Review in Scientific Publications: Benefits, Critiques, & A Survival Guide*, 25 EJIFCC 227, 227 (2014).

215. *See* Teplitskiy et al., *supra* note 211.

216. Dhruv Khullar, *The Struggle to Define Long Covid*, NEW YORKER (Sept. 20, 2021), https://www.newyorker.com/magazine/2021/09/27/the-struggle-to-define-long-covid [https://perma.cc/C7VJ-H2QK].

217. *Id.*

protocols. Some distance between patients and researchers, however, is necessary. To the extent that patients have a particular outcome in mind, such as finding a physiological rather than psychological cause for their ailments, research must remain agnostic.[218] The outcome-based criticism demonstrated in the PACE study, as opposed to the process-based criticism, is not good research methodology.[219] Moreover, a single individual cannot make strong inferences about an uncertain illness: there are too many confounders in a single observation and over-inference from salient but unrelated sources is a real danger.[220] While patients may compare their experiences to research, there will necessarily be differences.[221] Though important, patient experience is an incomplete—and in the extreme, a biasing—guidepost, upon which society cannot rely for careful communication of uncertainty.

In light of this gap in the ability and incentive to carefully communicate uncertainty, a new entity must synthesize existing data and explicitly state when scientific uncertainty persists. Given the inability of existing institutions to perform this task, a government-coordinated digest is necessary to both elucidate the state of evidence on contested illnesses and to educate the public on the harmony between uncertainty and the scientific process.

B. Benefits of a Government Digest

In light of the failure of traditional policy levers in encouraging careful communication of uncertainty, the government digest not only fills this gap but provides a number of benefits. First, and most obviously, making this information easily available to the public reduces the need for private science intermediaries to translate scientific data into uncertainty ratings. Given the difficulty in incentivizing physicians to accurately communicate uncertainty to their patients, as well as the toothless obligation of researchers to extensively summarize the data, this is a significant benefit.

Moreover, these ratings can be used to improve some of the largely ineffective levers described in the prior section. For example, while medical boards may be unreliable arbiters of when an illness has transitioned from an uncertain illness to a discredited illness, they can reasonably rely on the digest rating to ensure that licensed practitioners do not perpetuate discredited views.

In addition to these obvious benefits, however, this intervention would explicitly acknowledge—rather than embarrassedly suppress—uncertainty, coordinate research efforts to fill existing gaps in the literature, incorporate patient feedback appropriately, and model the scientific process.

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218. *See, e.g.*, Anthony, *supra* note 112.

219. *See supra* Section II.A.

220. Rison, Shepphird, & Kidd, *supra* note 209.

221. In the simplest example, research generally isolates average treatment effects; the statistical measure of variance captures the deviation of individual observations from this average effect. CASELLA & BERGER, *supra* note 72, at 59.

1. Explicit Acknowledgement of Uncertainty.—As noted above, in order to address the concern of patient marginalization, premature resolution of uncertainty must be avoided. Because the government cannot control how providers speak to their patients—particularly given the incompatibility of liability through medical malpractice and informed consent for poor treatment of contested illnesses—a broader public education agenda is necessary. The digest fills this gap in two ways. First, patients have an independent (government-associated) objective metric with which to assure themselves that their illness is not yet discredited. This visible signal from public health authorities that uncertainty is not yet resolved undermines the alienating forces associated with patient marginalization. Second, this metric can help to change physician behavior. Insofar as medical providers have learned to instinctively dismiss their patients' experience in the presence of uncertainty, these uncertainty ratings provide a more accurate understanding of contested illnesses.

While explicit acknowledgement of uncertainty may feel inconsistent with improving public confidence in science, this inconsistency is illusionary. This assumption is based on the current dynamic in which uncertainty is not well understood and rarely acknowledged. Currently, the public's interaction with uncertainty often occurs when a previously made confident statement is later amended to acknowledge a new truth. The chief benefit of the government digest is to break this problematic dynamic.

2. Coordination of Research.—Identification of gaps in the literature, and provision of incentives for entities willing to fill these gaps, can work to help resolve uncertainty. Rather than remain mired in contradictory studies that do not respond to concerns raised by other work, incentives for research studies that would fill a need can help address the contradictory evidence and ensure a neutral basis for design. As educational institutions value their researchers working on government-funded projects, and as the government is already heavily involved in funding research,[222] this would be fairly easy to implement.

Indeed, one dimension in which this would be particularly helpful is the incorporation of feedback by patient advocates. One of the primary weaknesses of the current siloed research lines associated with contested illnesses is that completed studies are criticized by patient advocates for poor design after the results are known.[223] The timing makes the criticism appear based on the outcome of the study, rather than the design; such feedback runs the danger of creating further bias. Despite this, some of these critiques may be reasonable requests to improve the study design. Feedback from patient advocate groups may indeed better target research questions and incorporate patient realities with which researchers may not otherwise be familiar. By allowing patient advocate groups and researchers to voice concerns over design prior to the

222. BEETHIKA KHAN ET AL., NAT'L. CTR. FOR SCI. & ENG'G. STAT., THE STATE OF U.S. SCIENCE AND ENGINEERING 2020 (2020).

223. *See supra* Section II.A.

implementation of the study, valid issues can be incorporated under the veil of ignorance. The government can offer funding for studies that fulfill such a need. By doing this, the agency would be moving us toward resolution of uncertainty as well, rather than remaining mired in polarized camps.

3. Publicly Model the Scientific Process.—This explicit acknowledgment of uncertainty—and transparent updating of this measure—has the additional benefit of enhancing the broader public's understanding of scientific uncertainty. Rather than wait for definitive evidence of a causal mechanism to acknowledge the patient experience, the digest simultaneously validates the patient experience while articulating the existing efforts to understand the mechanism and remaining work. Explicitly acknowledging the contradictory—or nonexistent—information about the illness helps prevent patient marginalization.

Moreover, by publicizing and circulating these uncertainty ratings, the agency has the ability to present the scientific process as an evolution. Guiding the public through the process of assessing scientific uncertainty will demonstrate that updating beliefs is not a failure of the scientific process, but rather, the scientific process *itself*. This broader public education will have spillover effects for patient sophistication.

The perceived tradeoff between professed certainty and public confidence is precisely a product of an erroneous interpretation of the scientific process. Rather than perpetuating the fiction that scientific truth is known with certainty immediately, we should invest in bolstering confidence in the *process* of uncovering scientific truths using the most unbiased methods and acknowledging where they fall short. By educating the public on how to incorporate new information into beliefs and how doing so actually exemplifies the scientific process, the government digest makes society less vulnerable to bad science. Indeed, not addressing this issue of social understanding only leaves us more vulnerable to future areas of uncertainty.

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CONCLUSION

For patients seeking answers for their very real suffering, the only thing more frustrating than uncertainty is the premature assertion of certainty in dismissing their experiences. Such artificially certain statements are not only inaccurate but create a danger of eroding trust in the scientific community. This rush to certainty is created in part based on unrealistic expectations of omniscience for the scientific community, and its legacy is deep ideological rifts that endanger patients.

Because recovered COVID-19 patients are currently at risk for developing long COVID—another still-uncertain illness—now is the time to correct this dynamic. Artificially aping confidence has created a history of entrenched and antagonist viewpoints, siloed research agendas, and the marginalization of

certain patient communities. Whether or not the evidence eventually supports the proposed mechanism, the medical community's dismissal of patients experiencing novel ailments creates an additional harm: the erosion of public trust in the scientific process. If the patients wrestling with long COVID lose faith in the medical community, future public health initiatives may be doomed.

Drawing from the economics literature to assess the challenges associated with contested illnesses, this Article presents premature statements of certainty as irreversible choices that can lead to irreversible harms like patient marginalization. Despite the fact that excessive restraint can itself harm patients, the irreversibility of losing the public's trust can weigh in favor of postponing statements resolving uncertainty for later periods. The framework also provides a way to identify when uncertainty remains significant. This clarification of the difference in probative value of null results in the presence of well-designed studies and those in case studies/small sample studies help to ensure that we do not remain mired in uncertainty indefinitely. A rush to certainty, however, is counterproductive to this purpose.

Because current legal incentives are not sufficient to make providers and officials provide such careful, nuanced communication of uncertainty, this Article proposes a new entity to collect and synthesize existing information on contested illnesses. This government digest would provide raw data (existing studies) on the illness, along with an inclusion and weighting methodology that gives rise to a certainty rating. While the certainty rating is itself helpful in identifying where uncertainty remains high (and reassuring patients that they are not forgotten or disbelieved), it also helps to move scientific knowledge forward. This Article provides concrete suggestions for how such an analysis may be conducted, crucially suggesting that missing results be imputed as null results and that patient advocate feedback be incorporated before a study is conducted. The government digest will also identify gaps in the literature and use funding incentives to help fill this gap.

The benefit of this informational intervention is to provide a neutral basis on which the scientific community can engage. The explicit acknowledgement of uncertainty will guard against patient marginalization, which contributes to the development of divided scientific camps. Moreover, the unflinching acknowledgement of uncertainty and transparent approach to updating beliefs about risk will educate the public on the iterative nature of the scientific process. Rather than hold science to an artificially static standard, society will be better able to navigate whatever health risks the future holds.