

Filozofski savjetnik

ČASOPIS ZA FILOZOFSKU PRAKSU · HRVATSKO UDRUŽENJE ZA FILOZOFSKU PRAKSU

SVEZAK Vol. I BROJ Br. 1 GODINA 2026 NAKLADNIK HUFPP, Zagreb

PHILOSOPHY · META-PSYCHIATRY · ORIGINAL SCIENTIFIC ARTICLE

Permeating Boundaries of Expertise in Psychiatry:

Integration of Patients as Contributors in the DSM Revision Periods

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Received: 4. 5. 2026 · Accepted: 20. 5. 2026

ABSTRACT

Objectivity and patient-centered care represent twin commitments of psychiatry that existing diagnostic practices struggle to reconcile. This paper argues that integrating patients as experience-based experts (EBEs) into the American Psychiatric Association's DSM revision process advances both commitments simultaneously. Drawing on Thomas Gieryn's boundary-work framework, I examine how psychiatry's historically permeable disciplinary boundaries have enabled selective gatekeeping over knowledge production, generating epistemic injustices, particularly preemptive testimonial injustice and hermeneutical injustice, that undermine diagnostic validity and clinical outcomes. I first situate psychiatry's unique sociocultural position relative to somatic medicine, demonstrating why its phenomena are epistemically inaccessible without patient testimony. Further, I address well-established reservations surrounding patient integration, including concerns about intersubjective validity, taxonomic disruption, and tokenism, before proposing a structured integration model responsive to these hesitations. Leveraging Şerife Tekin's Multitudinous Self (MuSe) model and recent recommendations from the DSM's Structure and Dimensions Subcommittee, I outline how patient-EBEs can contribute structured phenomenological testimony and participatory review within formal revision committees. As Gieryn anticipated, I conclude that strategic patient integration does not erode psychiatric expertise but rather reveals that its boundaries were always more permeable than their gatekeepers have claimed.

KEYWORDS: Epistemic injustice, Hermeneutical injustice, Social epistemology, Philosophy of psychiatry, DSM, Experience-based expertise (EBE), Patient subjective experience (PSE), Intellectual gatekeeping

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I. *Introduction*

Objectivity is a long-standing conflict within the philosophy of medicine. Across all its specialties, medicine attempts to offer concrete parameters in order to appropriately categorize the plethora of conditions, syndromes, and illnesses with an equal commitment to improve patient quality of life. Therefore, ideally, patients trust their healthcare teams, particularly their physicians, to uphold and apply a rigidity of objectivity in their assessments. This boundary work between roles operates as a function of public trust, honest integrity, and expertise. To the public, the role of the physician reflects an individual who ought to be knowledgeable and value-neutral while optimizing patient outcomes. To philosophers of medicine, this sentiment begins to unravel as we acknowledge the inherent value-ladenness of medicine and the competing interests in patient-centered care, objectivity, consensus on diagnostic criteria, public policy, and insurance corporations at the helm. In this paper, I argue that patients as experience-based-experts in psychiatry, particularly in the American Psychiatric Association's Future *Diagnostic and Statistical Manual for Mental Disorders* (DSM) Strategic Committee, can improve both of the specialty's competing objectives: a scientific commitment to be grounded in valid, reliable scientific constructs and a pragmatic clinical obligation to alleviate mental burdens on patients. These are argued as competing interests of psychiatry by virtue of psychiatry's tumultuous history in establishing credibility and further inquiry as an applied science. This tension resides in the shadows of logical positivism, where greater metaphysical commitments and private cognitive phenomena were black-boxed, making way for empiricism positivism to thrive. This is exemplified by Heather Douglas's "detached objectivity," where the knowledge by the individual is not awarded because of the particular individual accessing such knowledge.¹

The tension arrives in psychiatry because of the necessity of patient testimonials and their diverse cognitive faculties to develop clinical interventions. Sensitive to this tension, I subscribe to Helen Longino's social objectivity, which leverages objectivity as an ideal through collaboration across vetted platforms which support constructive feedback by a breadth of community members.² This

¹ Heather E. Douglas, *Science, Policy, and the Value-Free Ideal* (University of Pittsburgh Press, 2009), 122, <http://ebookcentral.proquest.com/lib/iub-ebooks/detail.action?docID=2038867>.

² Helen E. Longino, *Science as Social Knowledge: Values and Objectivity in Scientific Inquiry*, no. 2 (Princeton University Press, 1990), 25:340–41.

stance acknowledges objectivity as a valuable goal, though without a strong confirmation to an end achievement of complete objectivity.³

I begin introducing how psychiatry has historically and socio-culturally differed from its somatic counterparts. This offers an insight into how Thomas Gieryn's notion of boundary work comes into effect as an activity used to gatekeep power by which scientists selectively decide who can and cannot participate in knowledge production.⁴ This is vital as philosophers of psychiatry highlight how current practices in the field are reaching an impasse. Secondly, I share both retrospective and anticipatory reservations on patient integration in the DSM. Articulating past skepticism on patient integration functions as a mechanism to defend strict boundaries so as not to degrade the integrity of scientific knowledge production. However, strict boundary work reveals a spectrum of epistemic injustices, including preemptive testimonial injustice and hermeneutical ignorance. Uniquely, psychiatric phenomena directly affect subjects, and their interpretations of the phenomena are indispensable for identifying characteristics and developing treatments. To combat these injustices, the DSM's revision committee ought to integrate patients as epistemic contributors to achieve a greater sense of objectivity and improve clinical interventions for patients. Patients as experts reflects the same permeable boundaries Gieryn initially introduces, echoing how boundary work concerns the rhetorical and institutional strategies by which actors demarcate science from non-science, expertise from pedestrian knowledge. This segues into my third goal, to offer an early-stage integration of patients-as-experts to communicate how patients may be able to offer knowledge in psychiatry, which satisfies both of psychiatry's commitments: to increase objectivity and enhance pragmatic clinical outcomes.

II. *The Unique Position of Psychiatry*

Psychiatry has historically and socio-culturally differed from somatic specialties. In particular, to its sociocultural impact, psychiatry's openness to solicit public opinion, including but not limited to

³ Francis E. Reilly, "The Moderate Fallibilism of Science," in *Charles Peirce's Theory of Scientific Method* (Fordham University Press, 2020), <https://www.degruyterbrill.com/document/doi/10.1515/9780823285242-006/html?lang=en>. In recognizing the indeterminant confirmation of absolute assuredness within scientific inquiry, I approach this paper with a sensitivity to Charles Peirce's concept of fallibilism.

⁴ Thomas F. Gieryn, "Boundary-Work and the Demarcation of Science from Non-Science: Strains and Interests in Professional Ideologies of Scientists," *American Sociological Review* 48, no. 6 (1983): 781–95, <https://doi.org/10.2307/2095325>.

social protesting removal of homosexuality in the DSM-II, integration of post-traumatic stress disorder in the DSM-III⁵, and the DSM-5's public online forum, sets it apart from its somatic medical counterparts. Politics of the global North and philosophical conceptions of the self and behavior have also been profound influences. In one instance, the delegitimization of Sigmund Freud's psychodynamic theory, which was championed by the American Psychiatric Association in 1946, was driven by neo-Krapelian frameworks, championing observable, somatic etiology. Neo-Krapelian ideology rose to dominance partly in response to converging pressures: ongoing debates about the ontological status of mental disorders threatening psychiatry's medical legitimacy, escalating psychological casualties from Vietnam and other interwar periods demanding clinical response, and conflicts between physicians and non-physician health professionals contesting the very meaning of psychiatric expertise.

In another instance, contemporary medicine has strayed from paternalistic medicine and increased in pluralistic medicine (i.e., indigenous medicine, global health, complementary medicine), which has made the conception of a medical expert up for negotiation.⁶ Thus, gaps in psychiatric knowledge through the 20th and 21st centuries have opened an opportunity for psychiatry to flourish and the boundaries in expertise to be blurred.

Thomas Gieryn (1983) introduced the idea of boundary-work between science and non-science, where the delineation of expertise, interest, methods, and values constituted what ought to be scientific knowledge. Boundary-work remains both an analytical philosophy issue as well as a pragmatic issue in asserting authority, autonomy, and resources to justify knowledge production. In *Boundary-Work and the Demarcation of Science from Non-Science*, Gieryn revealed the fluidity of boundaries in science, including medicine, as an ever-present force that rejects absolutely necessary conditions and carries asymmetrical epistemic powers in asserting knowledge from ignorance and/or false knowledge. Gieryn's analysis of boundary work illuminates why objectivity rhetoric⁷ functions as a

⁵ Dominic Sisti and Rebecca Johnson, "Revision and Representation: The Controversial Case of Dsm-5," *Public Affairs Quarterly* 29, no. 1 (2015): 92–94. Here, they also highlight that there was still a particular dissatisfaction of this. Under the purview that the manual represented PTSD as "post-Vietnam Syndrome," insinuating that combat veterans who developed the condition all had an underlying predisposition rather than something inflicted by the war in and of itself.

⁶ Madison K. Kilbride and Steven Joffe, "The New Age of Patient Autonomy," *JAMA* 320, no. 19 (2018): 1973–74, <https://doi.org/10.1001/jama.2018.14382>.

⁷ P. Rooney, "Rationality and Objectivity in Feminist Philosophy," in *Routledge Companion to Feminist Philosophy*, ed. Ann Garry et al. (Routledge, 2017), 244. Significant debates in feminist epistemology also lean into this sentiment. Phyllis

demarcation strategy as much as an epistemic ideal, particularly in fields such as psychiatry. The very criteria for what count as observable and done by whom, what warrants diagnostic recognition, and what constitutes valid evidence necessarily incorporate normative commitments about human interactions, social functioning, the pathology of behavior, and disability.

III. *Ethical and Epistemic Conflicts of the American Psychiatric Association's (APA) Monopolization of the DSM*

The DSM, alongside other psychiatry manuals (i.e., ICD, RDoC), is an internationally recognized tool overseen by the American Psychiatric Association (APA) that has the power to inform research, education, media, medical policy, insurance coverage, patients and their communities, and law, among other social endeavors. Historically, boundary work in knowledge production protects current scientific inquiry from undesirable redirection by non-science influences. No more urgently than in psychiatry are these tensions about credibility. On the other hand, this intellectual gatekeeping reinforces habits of determining who is permitted to be an expert⁸, which is not without the influence of social and political norms in the relevant zeitgeist. Numerous philosophers of science raise issues with the strict demarcation of expertise on the premise of committing two flavors of epistemic injustices – preemptive testimonial injustice and hermeneutical injustices.⁹ Miranda Fricker originally introduced both concepts, where she defines testimonial injustice as “when a speaker is wrong specifically in her capacity as a knower” due to identity-based credibility deficits.¹⁰ This kind of injustice is commonly experienced across medicine, where the *a priori* authority is defaulted to the provider, which instantiates a normative framework in which patient reports are presumptively challenged.

Rooney is just one example: “The sterile linguistic conventions of somatic medicine historically dismissed ‘flowery’ language about emotion and subjective experience as feminine and therefore epistemically suspect.”

⁸ Gieryn, “Boundary-Work and the Demarcation of Science from Non-Science.”

⁹ Anke Bueter, “Epistemic Injustice and Psychiatric Classification,” *Philosophy of Science* 86, no. 5 (2019): 1064–74, <https://doi.org/10.1086/705443>; Miranda Fricker, *Epistemic Injustice: Power and the Ethics of Knowing* (Oxford University Press, 2007), <https://doi.org/10.1093/acprof:oso/9780198237907.001.0001>; Bennett Knox, “Exclusion of the Psychopathologized and Hermeneutical Ignorance Threaten Objectivity,” *Philosophy, Psychiatry, & Psychology* 29, no. 4 (2022): 253–66; Rosa Ritunnano, “Overcoming Hermeneutical Injustice in Mental Health: A Role for Critical Phenomenology,” *Journal of the British Society for Phenomenology* 53, no. 3 (2022): 243–60, <https://doi.org/10.1080/00071773.2022.2031234>.

¹⁰ Fricker, *Epistemic Injustice*, 18–20.

Likewise, Fricker's hermeneutical injustice is defined as "the injustice of having some significant area of one's social experience obscured from collective understanding owing to persistent and wide-ranging hermeneutical marginalization" which require three conditions: "(1) a limited battery of interpretive resources; (2) that limitation arising from the subject's hermeneutically marginalized social position; (3) harm from the resulting gap in meaning-making, communication, and self-interpretation."¹¹ In other words, hermeneutical injustices argue that technical communication discounts the cognitive faculties of the individual patient. Highlighting epistemic injustices here repositions our understanding of why and to what extent psychiatry has reached a standstill in its development.¹² In maintaining its utility and prestige as a science, expanding who can contribute to psychiatric knowledge production absolves these two tensions.

For psychiatry, highlighting boundary work and its risks of epistemic injustices is pertinent for two reasons. Firstly, psychiatric phenomenology is generally epistemically restricted to patients. Contrary to somatic specialties, empirical observation of malignancies oftentimes gets reduced to behavioral observation. Rather, Şerife Tekin situates psychiatry as "an intervention-oriented science where prediction and explanation depend on sources of knowledge that extend beyond controlled observation."¹³ This realignment offers an opportunity that Longino advocates for in her social objectivity¹⁴: to diversify intellectual authority.

The second reason is that current strategies have reached limitations in treatment intervention.¹⁵ This can be induced by multiple factors – deltas between preclinical and clinical implementation, sociopolitical factors, funding research, or discrepancies in the understanding of the condition. For instance, a 2017 meta-analytical study on various schizophrenia treatments across

¹¹ Fricker, *Epistemic Injustice*, 151–54.

¹² Owen Whooley, "On the Heels of Ignorance: Psychiatry and the Politics of Not Knowing," April 23, 2019.

¹³ Şerife Tekin, "Participatory Interactive Objectivity in Psychiatry," *Philosophy of Science* 89, no. 5 (2022): 1172–73, <https://doi.org/10.1017/psa.2022.47>.

¹⁴ Longino provides a critical footnote in *The Fate of Knowledge* on demarcating cognitive authority (i.e., professional degrees) versus intellectual authority. She states "In this distinction, cognitive authority has to do with the amount of knowledge one has and is thus fairly domain specific. One can be cognitively authoritative with respect to matters in astrophysics but ignorant of cell biology. Intellectual authority is less a matter of having knowledge than of having cognitive or intellectual skills of observation, synthesis, or analysis, which enable one to make cogent comments about matters concerning which one knows less than another.

¹⁵ T. M. Luhrmann, *Of Two Minds: The Growing Disorder in American Psychiatry* / (Knopf, 2000); Kilbride and Joffe, "The New Age of Patient Autonomy"; Whooley, "On the Heels of Ignorance."

29,823 patients; yet they revealed that 71.7% of the group experienced treatment failure.¹⁶ This study revealed both a lacuna in therapeutic intervention – affecting pragmatic clinical interventions – and in fluidity of condition manifestation – affecting objectivity in medicine.¹⁷ A deliberate movement to have patients as contributors in DSM revision processes would allow all community members to more effectively comprehend the conditions and develop downstream utilitarian interventions. As arguably one of the most influential manuals in psychiatry¹⁸, the DSM's breadth of community members who serve on revision committees is heavily restricted. In addition to the APA's membership restrictions, task force committees (TFC) are also comprised of recruited psychologists, licensed clinical social workers, advanced practice psychiatric nurses, mental health nurses, licensed counselors, and licensed marriage and family therapists.¹⁹ This breadth still demonstrates limited scope, by virtue of its finite diversity of epistemic contributors (e.g., *a priori* assumption as the dominant knower). Moreover, to their own admission, the DSM revision committees are restricted in their own ability to accurately capture the symptoms and descriptions of conditions listed in the DSM.²⁰ Sisti and Johnson (2015) further advocate for a diversification of contributors, including primary care physicians, philosophers of medicine, and patients. Indeed, by doing so, we see increased participatory representation, enhancing what Helen Longino and Şerife Tekin argue enhances objectivity. She posits,

“Thinking of patients as experts by experience requires recognition that knowledge is situated, and the social location of agents enhances or limits what we know (Wylie 2015). Patients have tacit and experiential knowledge that is not shared by clinicians or psychiatrists. Their mental disorders and their diagnoses shape the material conditions of their lives and the conceptual

¹⁶ Jari Tiihonen et al., “Real-World Effectiveness of Antipsychotic Treatments in a Nationwide Cohort of 29 823 Patients With Schizophrenia,” *JAMA Psychiatry* 74, no. 7 (2017): 686–93, <https://doi.org/10.1001/jamapsychiatry.2017.1322>.

¹⁷ A remedy which was integrated was the DSM-5's continuums of manifestation, rating from none to severe (Öngür et al. 2026, p. 1). The DSM-5's attempt to transcend the binary boundary previously upheld but its predecessor is clear. Nevertheless, community members pragmatic clinical outcomes have not caught up to the means of classification.

¹⁸ Dost Öngür et al., “The Future of DSM: A Report From the Structure and Dimensions Subcommittee,” *American Journal of Psychiatry* 0 (January 2026): appi.ajp.20250876, <https://doi.org/10.1176/appi.ajp.20250876>.

¹⁹ American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders : Fifth Edition Text Revision DSM-5-TR™* (American Psychiatric Publishing, 2013), 2.

²⁰ Elizabeth H. Flanagan et al., “The Need for Patient-Subjective Data in the DSM and the ICD,” *Psychiatry* 73, no. 4 (2010): 298, <https://doi.org/10.1521/psyc.2010.73.4.297>; María A. Oquendo et al., “Initial Strategy for the Future of DSM,” *American Journal of Psychiatry* 0 (January 2026): 2–4, <https://doi.org/10.1176/appi.ajp.20250878>.

resources through which they represent and interpret these experiences. Their perspectives on the properties of mental disorders will give us access to their embodied experiences and allow us to contemplate which ways labeling or framing these experiences will be more conducive to treatment.”²¹

Critically, additional philosophers of science have advocated for the involvement of patients on these committees on ethical, political, and epistemic grounds.²² In ethical and political terms, they argue that patients have a moral obligation to participate in the diagnostic revision process because they are ultimately the most impacted by diagnostic criteria, symptoms, and depiction of the condition. On epistemic grounds, their social and political position – leveraging Sandra Harding’s feminist standpoint epistemology²³ – may offer advances in knowledge production because of their unique cognitive phenomena.

Platforming patients as epistemic contributors can provide new knowledge on these exact concerns. One example is in the case of schizophrenia. The DSM-5 describes a feature of schizophrenia as a lack of interest in social relationships, but Parnas & Henriksen (2014) found that patients with this diagnosis do have a desire for social relationships, but a perceived inability to initiate these relationships.²⁴ If patient-integration is introduced, it can reveal orientational challenges in the status quo, provide first-hand knowledge on how scientific frameworks label their experiences, elucidate how disorders affect their social relationships, and ultimately narrate how greater contexts respond to their conditions.

IV. *Reservations on Patient Integration*

The ethical and epistemic concerns of patient-integration concerned are not novel arguments. In this section, I will briefly highlight three well-established hesitations – limits of intersubjective

²¹ Tekin, “Participatory Interactive Objectivity in Psychiatry,” 1173.

²² Anke Bueter, “Public Epistemic Trustworthiness and the Integration of Patients in Psychiatric Classification,” *Synthese* 198, no. 19 (2021): 4711–29, <https://doi.org/10.1007/s11229-018-01913-z>; Anne-Marie Gagné-Julien and Phoebe Friesen, “Why Should People with Lived Experience Be Included in the DSM Revision Process?,” *Hastings Center Report* 56, no. 2 (2026): 46–56, <https://doi.org/10.1002/hast.70051>; Şerife Tekin, *Reclaiming the Self in Psychiatry: Centering Personal Narratives for a Humanist Science* (Routledge, 2025), <https://doi.org/10.4324/9781003055556>.

²³ Kristen Intemann, *Feminist Standpoint Theory* (SAGE Publications Ltd, 2019), <https://doi.org/10.4135/9781526421036747550>.

²⁴ Josef Parnas and Mads Gram Henriksen, “Disordered Self in the Schizophrenia Spectrum: A Clinical and Research Perspective,” *Harvard Review of Psychiatry* 22, no. 5 (2014): 251–65, <https://doi.org/10.1097/HRP.000000000000040>.

criticism, complete recategorization of the DSM, and patient tokenism - from clinicians, researchers, and fellow philosophers of science who raise apprehensions with patient-integration before offering a palatable introduction for patients as experience-based experts in the final section. I argue that these are necessary to highlight here before revealing a new integration method.

The chief apprehension is the scope of intersubjective validity. While the DSM-5 made greater strides for holistic review, these efforts were minimized at the 11th hour of its publication. Even before the DSM-5 was in production, the discussion of reconceptualizing expertise was tumultuous. Notoriously, Robert Spitzer, a leading voice in DSM-IV and DSM-5 revision, outwardly opposed patient-integration into the DSM, calling it politically correct nonsense.²⁵ In essence, discounting the laborious technical training professionals endure to that of patients is crude and a disservice to clinicians and researchers. However, this does reveal the tendency to take patients as incompetent and therefore preemptively excluded from discussion by their (predominantly) assumed status as laypersons. Feeding into this tendency, the involvement of patients in the DSM-5 as contributors was denied on the grounds of protecting objectivity. This ideal for objectivity reflects what Heather Douglas calls “concordant objectivity,” that expertise in the field comes to a unified agreement between professionals in consensus discussions. Lest it be forgotten that the necessary condition of psychiatry is for patients to recount their experiences, this does not make this ideal attainable. Psychiatry cannot operate in isolation from its patients, thus *a priori* necessitating a broader scope of members involved. If we entertain, however, that psychiatry ought to abide by concordant objectivity, T.M. Luhrmann amplifies how this operates as a flavor of epistemic injustice because it assumes that theoretical training supersedes lived experience as an epistemic credential. It no longer stands as epistemically neutral; it reflects contingent professional hierarchies, not a principled account of knowledge.²⁶

²⁵ Robert L. Spitzer, “Good Idea or Politically Correct Nonsense?,” *Psychiatric Services* 55 (February 2004): 113, <https://doi.org/10.1176/appi.ps.55.2.113>. Spitzer argued on the account that “[i]t is insulting to the mental health professionals involved in the DSM revision process, many of whom have family members with psychiatric illness or have experienced illness themselves, to suggest that they are insensitive to such issues and that they need to be educated by patients and families.”

²⁶ *Of Two Minds* by T.M. Luhrmann “Who gives a young psychiatrist the authority to say, ((You're more depressed than you think"? That "you have an illness that impairs your thinking and so I cannot believe what you say"? A more psychodynamic approach handles this major epistemological issue by emphasizing that all mental states, including the psychiatrist's, are inherently complex, layered, and to some extent unknowable” (Luhrmann 2000, p. 138).

The expectation of the DSM to be verifiable and evidence-based elucidates why necessitating intersubjective validity, a popular rejection of first-hand reports. Tekin rebuts this and reveals a lacuna of current efforts: the self, as in first-hand accounts of patients, is a moving target. First-hand accounts are a dynamic phenomenon that scientists try to understand with more “measurable” variables. Because the reports of patients are phenomenologically inaccessible to others, this makes clinicians and researchers skeptical of recognizing patients as experts. Thus, giving attention to other components (i.e., behaviorism) and ignoring the first-hand reports adopts a subgenre of epistemic injustice: preemptive testimonial injustice. This injustice is characterized as precluding opportunity for individuals, like patients, who are deemed insufficiently able to testify to their own experience.

The second area for concern in patient integration is the threat of complete reorganization of the DSM taxonomy. Some philosophers of science are concerned with what psychiatric taxonomy may look like after patient integration. In particular, Fellowes (2023) raises concerns that could overwhelm the current scaffolding of the DSM. Fellowes raises three valid concerns that new categorization via patient-integration will create redundancies, make differential diagnoses harder to rule out, and reformulation of constitutive values (Longino 1990), such as simplicity, precision, and prediction.²⁷ He argues that patients with comorbid diagnoses should be integrated in order to highlight this particular complexity.

The final sector of reservation is patient tokenism. Patient tokenism follows a sociological construction where individuals with a unique social position (i.e., gender or racial identity) are provided a seat at the table but are not representative of the actual contributions by virtue of dominant voices black boxing them from contribution. Gagné-Julien and Friesen (2026) highlight a key concern that we ought to be cognizant of in the preliminary integration of patients as experts. Since the DSM-5, there has been recognition of patients’ perspectives as relevant to the production of knowledge. However, because they were not deliberately integrated into work groups indicated the DSM revision committee’s epistemic limitation.

Though in general agreement with patients as epistemic contributors, they warn of the detriments of not utilizing patients’ expertise within these committees. Mental health researcher Jayasree Kalathil noted, “participating as a token representative in these situations can aggravate feelings of disempowerment already felt on account of discriminatory experiences based on one’s

²⁷ Sam Fellowes, “The Importance of Involving Experts-by-Experience with Different Psychiatric Diagnoses When Revising Diagnostic Criteria,” *Synthese* 202, no. 6 (2023): 178, <https://doi.org/10.1007/s11229-023-04399-6>.

racial identity, mental health status, and position in society.”²⁸ This illustrates that reports of people concerned with tokenism voice that patients do not gain any benefit from their contributions but rather stand in as a diverse member whose input is not epistemically equal to others.

V. *Early-Stage Integration of Patients as Experience-Based-Experts*

Insofar, I have shared how social and political pressures have molded parts of the psychiatric zeitgeist. In achieving the shared goals of accurately reflecting disease states and improving clinical interventions, my preliminary introduction of patient expertise in the DSM revision processes becomes both an epistemic and ethical imperative. It is an epistemic imperative because preemptive testimonial injustices materialize into a poorer conceptualization of disorder through the exclusive conferral of professional status. It is an ethical imperative for patients who have the most at stake: they are living with the condition, laboring under affiliated stigmas, and navigating the medical maintenance of their status. These two imperatives are not independent: when epistemic gatekeeping produces inaccurate diagnostic categories, it is patients who bear the downstream clinical and social consequences.

In this section, I propose a strategy by which selecting patients and assigning particular positions in the task force can provide critical, new knowledge to the forthcoming edition of the DSM. I aim to integrate past recommendations²⁹ while remaining sensitive to the hesitations raised in the previous section. To this end, I leverage Şerife Tekin's Multitudinous Self (MuSe) Model and the McPin Foundation's SUN RISE Model as strategies for identifying which patients would be most efficacious in reshaping the DSM. My goal is that this proposal be palatable for all stakeholders: healthcare teams, patients & their families, and law & policy officials. Strategic patient integration, properly structured, will neither fall victim to tokenization nor undermine the professional standing of committee members. Rather, it will demonstrate that the boundaries of psychiatric expertise must be resituated as community members come to accept how knowledge is contextually sensitive.

In light of the upcoming revision period of the DSM-5-TR, the DSM's Structure and Dimensions Subcommittee (DSM SDS) echoes my emphasis that, by virtue of the DSM's international influence,

²⁸ Gagné-Julien and Friesen, “Why Should People with Lived Experience Be Included in the DSM Revision Process?,” 51.

²⁹ Flanagan et al., “The Need for Patient-Subjective Data in the DSM and the ICD.”

it also continues to be under scrutiny for its current shortcomings.³⁰ They offer four tenets of reiteration (contextual, biological, diagnostic, and transdiagnostic) that can improve the conceptualization of psychiatric nosology to achieve greater objectivity and enhance patient flourishing. Crucially, some of these factors "receive insufficient attention, yet they influence psychiatric presentations and should be captured," including contextual factors such as socioeconomic, cultural, and environmental determinants, developmental factors, medical comorbidities, quality of life and functioning, and *the subjective experiences of patients*, as well as biological and transdiagnostic factors.³¹ Transdiagnostic features, in particular, would serve to transcend the rigid diagnostic categories of the status quo. Moreover, the DSM SDS voice that current research suggests dimensional measures alone may be insufficient to arrive at empirically defined disease categories.³² This reaffirms Tekin's argument regarding the impasse the DSM currently faces³³, and it points toward experience-based expertise as a necessary supplement to existing methodological frameworks.

This is precisely where patient integration within the DSM becomes imperative. Oquendo et al. (2026) outline the changes for this particular subcommittee: "the need to redesign or reorganize the DSM; to capture the continuum of mental health; to improve diagnostic validity and enhance personalized treatment; to facilitate research and accommodate new discoveries with a neurodevelopmental focus; to maintain DSM clinical utility; to determine the criteria and framework needed for change; and to incorporate other subcommittees' work into the nosological structure."³⁴ Patient experience-based expertise is uniquely positioned to address several of these charges simultaneously, particularly those concerning contextual factors, dimensional symptom variability, and diagnostic validity. It is a resource the field is already reaching toward but has not yet formally mobilized.

The groundwork for this proposal has been laid by prior scholarship that the DSM revision process has yet to fully act upon. Flanagan et al. (2010) offer a reintroduction of subjective testimonials as a methodologically defensible tool for psychiatric knowledge production. As they argue, "while objective-descriptive methods are useful for assessing the observable characteristics of large numbers

³⁰ Gagné-Julien and Friesen, "Why Should People with Lived Experience Be Included in the DSM Revision Process?," 51.

³¹ Öngür et al., "The Future of DSM," 4. My emphasis.

³² Öngür et al., "The Future of DSM," 5.

³³ Tekin, "Participatory Interactive Objectivity in Psychiatry," 1169–70.

³⁴ Oquendo et al., "Initial Strategy for the Future of DSM," 5.

of people and suggesting cause and effect relationships among these characteristics, subjective-descriptive methods are *better suited for exploring the inner lives of fewer people more intensively and for identifying the meaningful relationships that may exist between objectively identified factors.*"³⁵ Far from undermining scientific rigor, this complementary methodology increases objectivity as understood through Longino's "transformative criticism": when patients help articulate the phenomena they experience, the resulting descriptions in the literature become more accurate and more representative.³⁶ Patient-subjective experience (PSE), as Flanagan et al. posit, is therefore unlikely to diminish the gains in reliability and validity achieved by current methods, especially given that qualitative studies already operate under *a priori* hypotheses. PSEs may additionally reveal knowledge gaps and prompt downstream inquiry more efficiently than purely clinician-directed observation. This is further supported by Ballesteros (2025), Tekin (2022), Beuter (2019), and Knox (2022), who argue that PSE inclusion is a matter of social justice. The goal of soliciting patient testimonials, as they envision it, "would be to determine the networks and relationships that define a person's experience, including their job, family life, relationship with relatives and friends, spiritual and sexual experiences, and role/place in society."³⁷ Institutionalizing this approach in the revision periods would transform these recommendations from aspirational to operational.

Taken together, these convergent gaps point toward the same corrective: a structured integration of patients as experience-based experts (EBEs). Tekin offers the most actionable criteria for identifying who would qualify. She advocates for candidates who "ought to have the experience of mental disorders and be able to articulate that experience through self-reports, and to have learned

³⁵ Flanagan et al., "The Need for Patient-Subjective Data in the DSM and the ICD," 298.

³⁶ The DSM-5 did make an adjacent modification to this, though clinicians and critics illuminated its shortcomings. Specifically, the removal of the Global Assessment of Functioning (GAF) Scale from the DSM-5 was, in part, driven by a call from the field to incorporate patient and proxy reports of patient functioning and to disentangle disability and functioning from the clinical significance criterion for mental disorders. Yet its removal left the determination of functional impairment *solely to the judgment of the clinician* (Drexler et al., 2026, p. 2, my emphasis). The field thereby acknowledged its hermeneutical ignorance but corrected it only partially. In its place, the World Health Organization Disability Assessment Schedule (WHODAS-2.0) was introduced, spanning six domains: cognition, mobility, self-care, interpersonal functioning, life activities, and social participation. However, its placement in Section III of the DSM-5 communicated to practitioners that it was not sufficiently vetted for routine use and thus not critical to psychiatric assessment, diagnosis, and intervention (Drexler et al., 2026, p. 2) The instrument's marginalization within the DSM reproduced the very epistemic hierarchy it was designed to correct.

³⁷ Flanagan et al., "The Need for Patient-Subjective Data in the DSM and the ICD," 303.

from that experience over time with skill and effort, by carefully observing their own experiences as well as those of others.”³⁸ This standard is meaningfully distinct from simply including any patient as a representative. It establishes epistemic credentials that are analogous in their rigor to professional credentialing, grounded in sustained, reflective engagement with the phenomena under study rather than in institutional membership alone.

Moreover, I offer the recommendation on selecting appropriate EBE through methodologies proposed by the McPin Foundation’s SUN RISE (Searching, Unpacking, Naming Research Into Subjective Experiences in mental health) report.³⁹ This report argues that PSE is not a supplemental component of mental health research, but vital for future avenues of knowledge production. Their interdisciplinary research team included academic researchers as well as experts from the Survivor Researcher Network (SRN). This network is an English platform which leverages expertise with an accredited avenue for knowledge production, feedback, and collaboration.⁴⁰ While this is unique to the UK, I suggest future expansion to the SRN, reaching both Global North and Global South regions. Accordingly, EBE is voiced through an established network with accredited clinical and academic collaborations.

Continually, Oquendo et al. assigns EBEs as a significant contributor in the upcoming revision strategy. This situates EBE to operate on the same authoritative plane as professional groups, including the National Institute of Mental Health, as non-voting ex officio through this period.⁴¹ This acknowledgement attempts to avoid intellectual hierarchies and tokenism since both professional agencies and patients hold the same status as non-voting members. Likewise, precision psychiatry strategies are extending the importance of EBE⁴², as they voice concern for all collective community members. In tandem with these biological roadmaps, I lean into Miriam Solomon’s methodological pluralism, which advocates for both PSE and biologically based investigations for mental conditions.⁴³

³⁸ Tekin, *Reclaiming the Self in Psychiatry*, 134.

³⁹ “SUN RISE Study Summary Report,” *The McPin Foundation*, May 12, 2026, <https://mcpin.org/resource/sunrise-summary-report/>.

⁴⁰ *Survivor Research Network | Research, Advocacy & Resources*, March 28, 2021, <https://survivorresearcher.net/>.

⁴¹ Oquendo et al., “Initial Strategy for the Future of DSM,” 4.

⁴² Martien J. H. Kas et al., “Precision Psychiatry Roadmap: Towards a Biology-Informed Framework for Mental Disorders,” *Molecular Psychiatry* 30, no. 8 (2025): 3846–55, <https://doi.org/10.1038/s41380-025-03070-5>.

⁴³ Miriam Solomon, *Making Medical Knowledge* (Oxford University Press, 2015), 206–24, <https://doi.org/10.1093/acprof:oso/9780198732617.001.0001>.

In equalizing authority, I believe this adjudicates tensions of intersubjectivity validity across patient testimonials as well as professional consensus.

Tekin's Multitudinous Self (MuSe) model further operationalizes pluralism in psychiatry. By leveraging five facets of the self (physical, social, experiential, conceptual, and narrative), the model provides a structured framework through which patient-EBEs can articulate and identify the dimensions of their conditions that elude clinical observation. This multidimensional structure synergizes directly with the DSM SDS's stated goals of enhancing descriptive language and capturing the continuum of mental health.⁴⁴ Crucially, it also provides a response to the tokenism concern raised in the previous section: because EBE integration is structured around specific epistemic contributions tied to defined facets of experience, patients are positioned as contributors with a determinate role rather than as symbolic representatives whose input is ultimately overridden.

Veldmeijer et al. offer a complementary reframing that helps situate this methodological contribution within the DSM's broader purpose. They propose reconsidering the DSM not as a fixed scientific pronouncement but as a conversation piece in mental health care, a living document whose value lies in facilitating dialogue between patients, clinicians, and researchers rather than foreclosing it. This reframing is significant for the present argument because it dissolves the apparent tension between scientific authority and patient participation. In fact, their explicit mention of the DSM as a boundary object further elucidates the fluidity of social epistemology within psychiatry.⁴⁵ If the DSM maintains its status as a diagnostic instrument, patient-EBEs are not intruding on scientific territory; they are participating in the communicative function the document is already designed to serve. Their inclusion in revision processes is, on this account, an extension of the DSM's own logic rather than a departure from it.

Together, this interdisciplinary approach voices a necessary participation structure. Within this, patient contributions would take two primary forms: structured PSE testimony on existing diagnostic criteria, flagging discrepancies between clinical description and lived experience; and participatory review of proposed revisions, assessing whether new language accurately reflects the phenomenology of the condition as experienced from within. This is a structured input channel that feeds into the

⁴⁴ Oquendo et al., "Initial Strategy for the Future of DSM," 7.

⁴⁵ Lars Veldmeijer et al., "From Diagnosis to Dialogue – Reconsidering the DSM as a Conversation Piece in Mental Health Care: A Hypothesis and Theory," *Frontiers in Psychiatry* 15 (August 2024): 4, <https://doi.org/10.3389/fpsyt.2024.1426475>.

deliberative process alongside clinical and empirical evidence, consistent with Longino's (1990) account of “transformative criticism” as a mechanism for enhancing objectivity.

Ultimately, this early-stage integration proposal does not ask psychiatry to abandon its commitment to scientific rigor but rather asks psychiatry to recognize that rigor is already being compromised by its current exclusions. This paper has argued that philosophers of science, anthropologists, researchers, clinicians, and, above all, patients share the same fundamental concern. Elucidating the unique historical and sociopolitical position of psychiatry differentiates it from other fields of medicine, requiring all members to innovate ways to commit to both objectivity and clinical optimization. Further, this paper demonstrated how the unique position of psychiatry as a discipline came with epistemic and ethical conversations regarding intellectual gatekeeping in the status quo. Downstream effects of this monopolization represent preemptive testimonial injustices and hermeneutical injustices; both harm the twin commitments of medicine. Moreover, highlighting apprehensions for patient integration functioned both as a disclosure on how integration of patient-EBEs failed to materialize in the DSM-5 as well as a conscientious attempt to not further epistemic or ethical injustices. The commitment to pragmatic clinical intervention requires diagnostic categories that accurately reflect what patients experience. Patient-EBEs, integrated strategically through the MuSe and SUN RISE models and in dialogue with the DSM SDS, satisfy both demands and closing methodological gaps. In doing so, they do not erode the boundaries of psychiatric expertise; they reveal that those boundaries were always, as Gieryn anticipated, more permeable than their gatekeepers have claimed.

“These two imperatives are not independent: when epistemic gatekeeping produces inaccurate diagnostic categories, it is patients who bear the downstream clinical and social consequences.”

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