

## TITLE PAGE

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**Title:** Participatory Interactive Objectivity in Psychiatry

### **Abstract:**

This paper challenges the exclusion of patients from epistemic practices in psychiatry by examining the creation and revision processes of the Diagnostic and Statistical Manual of Mental Disorders (DSM), a document produced by the American Psychiatric Association that identifies the properties of mental disorders and thereby guides research, diagnosis, treatment, and various administrative tasks. It argues there are epistemic – rather than exclusively social/political – reasons for including patients in the DSM revision process. Individuals with mental disorders are indispensable resources to enhance psychiatric epistemology, especially in the context of the crisis, controversy, and uncertainty surrounding mental health research and treatment.

## **Participatory Interactive Objectivity in Psychiatry**

### **1. Introduction**

As a branch of both science and medicine, psychiatry draws on a variety of scientific and medical practices to glean information about the properties of mental disorders and thereby enable their diagnosis and treatment. These include scientific research on mental disorders, such as stem cell research for unpacking mechanisms underlying schizophrenia, clinical drug trials, or case studies for depression treatment. Simply stated, the goal is to develop effective interventions into mental disorders. While the first-person reports of individuals with mental disorders provide irreplaceable resources for investigating the properties of mental disorders and designing interventions, dominant psychiatric frameworks have not systematically included patients in scientific inquiry. I challenge this problematic epistemic exclusion in the context of the creation and revision processes of the Diagnostic and Statistical Manual of Mental Disorders (DSM) – a primary classificatory schema developed by the American Psychiatric Association (APA) to identify the properties of mental disorders and used as a guide for research, diagnosis, and various administrative tasks. Part 2 outlines the development process of the series of DSMs; part 3 examines APA’s position that the inclusion of patients in the DSM’s epistemic practices would impede psychiatry’s goal to be objective. Part 4 demonstrates that the notion of objectivity operant therein is insufficiently developed. Part 5 develops an alternative view, Participatory Interactive Objectivity (PIO), according to which patients’ inclusion is necessary for objectivity in psychiatry. Taking cues from feminist epistemology, feminist philosophy, and science and technology studies, I argue knowledge about mental disorders must be generated by a community of experts, including those with training-based expertise and those with experience-

based expertise (Collins and Evans 2002). Engagement between different kinds of experts would allow a diversity of standpoints to go through a process of transformative criticism (Longino 1990), enhancing objectivity while also increasing public trust in the DSM (Bueter 2021).

## **2. DSM Creation and Revision Process**

Created by the APA, the DSM is the primary classificatory framework for mental disorders. With a mandate to serve “clinical, research, and educational purposes,” it expands knowledge on mental disorders (APA 1994; 2013). In addition to clinical contexts where decisions about mental disorder treatments are made, DSM criteria are used to select subjects for research and clinical trials, to apply for and receive research funding, to educate health professionals, and to provide a uniform language across different settings. Since its inception in 1952, the DSM has been regarded as a *work-in-progress*; the idea was to continue to improve/revise the diagnostic criteria in light of the most recent scientific research with guidance from experts.

The DSMs have historically been developed and revised in the following manner. The APA selects a task force to guide the process from the members of the APA. The membership of the task force has evolved over time; however, members have mostly been psychiatrists. For example, in DSM-I, psychiatrists and neurologists, in collaboration with the military, were in charge, as the manual was created for statistical purposes to determine who was fit to serve in the Korean War (APA 1952; Grinker 2010). In DSM-II, the military was excluded, but the rest of the group remained the same (APA 1968). Starting with the DSM-III<sup>1</sup>, the task force committee

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<sup>1</sup> One reason for this was the effort to make the DSM more evidence based and scientifically valid, as the DSM-I and the DSM-II frameworks were heavily criticized for their psychoanalytic orientation. For more on this, see Grinker (2010); Tekin (2019).

membership remained the same, but the APA collected input for the diagnostic criteria, not only from APA-affiliated psychiatrists but also from scientists and practitioners in other stakeholder organizations, including the American Psychological Association, Association of Women Psychiatrists, and American Psychoanalytic Association (APA 1980; 1994).

The designated task force works closely with various working groups who are also mostly psychiatrists. Working groups specialize in various disorders and engage in research and clinical trials to determine how to best classify mental disorders. This collective epistemic practice, which can be thought of as an epistemic ritual (Solomon 2015), ultimately results in the DSM task force's final decisions on the categories of mental disorders. Throughout the history of the DSM development, patients<sup>2</sup> have never been included in this process as "subjects" who generate research on mental disorders. A review of the members of the DSM task forces and working groups listed in the introductions of the DSMs – from the DSM-I to the DSM-5 – shows patients have *never* been part of the decision-making process; i.e., they have never been members of the DSM task force or members of a working group (APA 1952; 1968; 1980; 1994; 2013). To the extent that they were part of the DSM's research into mental disorders, they have almost always been simply the "objects" of investigation, e.g., when recruited for clinical trials. It is also important to note that in DSM-III and DSM-IV, the APA highlights that it sought the "advice of *experts* in each specific area under consideration" (APA 1994, xv; my italics). "Experts" in the DSM language refer to scientifically trained researchers or clinicians with recognized degrees who treat individuals with mental disorders. During the DSM-5 revision

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<sup>2</sup> I use the word "patient" to refer to the individual who is in a position of need due to the distress she is experiencing and who seeks help from a professional to address her condition. I recognize that "patients" are not homogenous, and some prefer being referred to as client/survivor/ex-patient. For my purposes in this article, I use these terms interchangeably.

process, there were calls to the APA to include patients, by involving them in the decision-making process about the diagnostic criteria. However, this was not accepted by the DSM-5 Task Force, on the grounds that patient inclusion would reduce objectivity in the scientific process.

### **3. DSM-5, Patient Inclusion and Objectivity**

Prior to the publication of DSM-5, various groups, including patients, caregivers, mental health activists, advocacy groups, philosophers, and clinicians, invited the APA to involve patients in the revision process by making them members of the task force or working groups. Most calls cited social and political reasons for inclusion. Some invoked the need for the process to be democratic and thus include all stakeholders, i.e., members of the public with a direct interest in the diagnostic criteria, such as patients and their families (Sadler and Fulford 2004). Others approached it from the perspective of patient advocacy and emphasized the need “for scientific experts to review their nosological recommendations in light of rigorous consideration of consumer experience and feedback” (Stein and Phillips 2013). Still others argued the DSM was facing a crisis of public trust and needed to increase the integration of patients into the revision process to address the issue (Bueter 2021).

Epistemic and ethical reasons were also cited. Some clinicians argued patients bring a different perspective to the conversation on psychiatric classifications because they can report on their subjective experiences, and this would enable mental health professionals to be more empathetic (Flanagan, Davidson, and Strauss 2010). The DSM-5 Task Force appeared sympathetic to the social and political reasons, as it acknowledged the potential benefits of patients’ inclusion in the DSM creation process; however, the Task Force thought the time prior to the publication of DSM-5 was too limited for an elaborate engagement with patients. It

suggested the APA's call for feedback from the public through an online forum on DSM-5 was a positive step towards including patient input, insofar as patients are also members of the general public.

Note that in the DSM-5 Task Force's response, patients' potential contributions to DSM-5 were framed as having the same value as that of the general public – the ability of their unique standpoint, as those directly encountering mental disorder, to improve the diagnostic criteria for mental disorders was dismissed. In fact, the DSM-5 Task Force members had epistemic concerns about patient inclusion. They thought the “subjectivity of the data” coming through patients' reports conflicted with psychiatry's desire to establish itself as an objective form of inquiry (Regier et al. 2010). To explain why patients were not invited to be a part of the DSM-5 revision process, the Task Force stated the following:

We recognize that subjecting criteria to patient review may allow DSM-V<sup>3</sup> to draw a more complete and clinically meaningful picture of disorders based on individual experiences... of patients.... Integrating objective diagnostic criteria and patient-subjective data may serve to enhance the therapeutic alliance, since it could assist the clinician in better understanding the source of an individual patient's distress, not simply the clinician's preconceived assertions about what a given diagnosis is and is not. By definition, subjectivity is variable from person to person, therefore making it impossible to develop definitive criteria that would apply to every disorder (Regier et al. 2010, 309).

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<sup>3</sup> Before DSM-5 was published, it was referred to as “DSM-V,” following the numbering norms of previous DSMs. Yet it was published as DSM-5. The quotation comes from a statement prior to the publication of DSM-5.

Regier et al. do not define precisely what they mean by “objective” or “subjective” in the context of the DSM creation, but I formulate possible interpretations in the following section. For now, let me emphasize that following the statement above, DSM-5 was published without patient input; patients were not included in the task force or the working groups. Nor were they invited to provide systematic feedback *by virtue of their status as patients*.

### **3.1. Assumptions of Objectivity in the DSM**

Focusing on Regier et al.’s (2010) article on patient inclusion, I unpack two assumptions about objectivity, using Heather Douglas’s taxonomy of objectivity in science (Douglas 2000). These assumptions are (i) *objectivity as the opposite of subjectivity* and (ii) *objectivity as concordance*. Both are reminiscent of the logical positivistic notion of objectivity, and neither fits the purposes of inquiry in psychiatry.

According to logical positivism, knowledge is based either on logical reasoning or empirical experience. When the objectivity of scientific knowledge is evaluated, the focus is on the outcome of scientific inquiry. Justifiable evidence constitutes observational data, enabled when scientists adopt a “view from nowhere” perspective to the phenomenon under investigation. The detachment reflects the value neutrality of scientific knowledge. Thus, in this view, science is objective to the extent that it is detached from researchers’ perspectives and values, and evidence is grounded on impartial (third-person) observational data verified by the world. Otherwise stated, objective science is considered impartial, value-neutral, and uncontestable.

One of the methods of scientific inquiry adopted by logical positivists to attain this goal is operationalism. Operational definitions characterize an otherwise complex scientific phenomenon by defining its features in a way that easily lends itself to scientific measurement and analysis. Operationalism was adopted in the DSM formulation, starting with DSM-III, with observable signs and symptoms becoming the defining features of mental disorders.<sup>4</sup>

In the DSM-5 Task Force's statement above, the first assumption about objectivity is the consideration of (i) *objectivity as the opposite of subjectivity* (Regier et al 2010). In the citation, "objective diagnostic criteria" and "patient-subjective data" are juxtaposed. Their relationship is framed as complementary; working together, they "serve to enhance the therapeutic alliance" and "assist the clinician in better understanding the source of an individual patient's distress" (Regier et al 2010). Although not explained, "objective diagnostic criteria" seem to refer to the symptoms (observed by the patient) and signs (observed by others) of mental disorders, as, starting with DSM-III, symptoms and signs were considered observable features of mental disorders, with the same phenomenon consistently appearing across different settings. What seems to be the main difference between "objective diagnostic criteria," and "patient-subjective data," then, is whether the encounter with mental distress is directly reported from the third person perspective, such as the clinician, through observation (objective diagnostic criteria), or from the first-person perspective (patient-subjective data). "Patient-subjective data" seem to be patients' first-person reports about their experiences, and "objective diagnostic criteria" seem to be third-person reports.

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<sup>4</sup> For more on logical positivist influence on the DSM, see Tekin (2019); Tabb and Schaffner (2014).



The conception of objectivity as the opposite of subjectivity is reminiscent of the positivistic view that science is only objective if its observations and theories reflect a view from nowhere, independent of scientists' subjective perspectives. Thinking of objectivity as the opposite of subjectivity is a limited interpretation of complex concepts used in myriad ways in scientific practices and philosophy of science (Douglas 2000). Douglas argues that conceiving objectivity as the opposite of subjectivity represents a kind of "detached objectivity," with an attempt to maintain a metaphorical "distance" or "detachment" between "the knower and the subject" (Douglas 2004). Such detachment or distance is thought to keep the individual observer from being overly invested in a particular outcome or fearing another, thus biasing/spoiling her understanding of the phenomenon in question. In the positivistic view, science should be based on impartial or third-person observations, not "subjective" or first-person perspectives.

In the above statement, when the DSM-5 Task Force raises questions about using "patient-subjective data" by citing variability from person to person, it seems to want diagnostic criteria to be "detached" and "impartial," with a distance between the knower and the subject. Such impartiality or detached perspective on mental disorder is assumed to be only possible through the third-person observations of clinicians, hence the preference for "objective diagnostic criteria." However, the subject matter of the science in question – psychiatry – is mental disorder, a phenomenon that directly affects the subject in question. Patients' perspectives on their own experiences are not only constitutive of mental disorders but are also epistemically indispensable in identifying the properties of mental disorders to develop treatments – the main goal of psychiatry as a scientific and medical discipline.

We have to understand what each subject is experiencing to determine if her experience is a typical feature of the mental disorder in question. So, the "subjective" reports in the

knowledge production process cannot be construed as ancillary to the knowledge possessed by medical professionals; rather, these subjective standpoints are necessary for a fine-grained objective understanding of mental disorders. Subjectivity and objectivity are not opposites; the former is necessary for the latter. We must strive for a pluralism that combines patients' perspectives with those of medical professionals and researchers to acquire knowledge in psychiatry.

The second assumption is *(ii) objectivity as concordance*. As seen in the DSM creation and revision processes, the goal is to reach agreement between trained experts. When the DSM-5 Task Force expresses worry about patient involvement, it questions “whose subjective point of view is to be considered.” If more than one patient is reporting on experiences of illness or the social context, whose experience must be taken as representative? Various reports on the same disorder, e.g., PTSD, may very well be contradictory.<sup>5</sup> The Task Force's worry is that no single perspective will have the uncontested agreement of all participants. It seems concerned about how to square expert judgments with patient judgments. The DSM-5 Task Force is interested in attaining what Douglas calls “concordant objectivity,” which requires the agreement of all involved experts with the perspective offered. Concordant objectivity leaves no room for interaction, debate, or conversation among participants.

The assumptions apparent in the Task Force's concerns about patient inclusion, i.e., *objectivity as the opposite of subjectivity* and *objectivity as concordance*, do not align with psychiatry's goal as a branch of medicine and science. Psychiatry's target of inquiry is mental disorder, and this is necessarily encountered by a subject. Therefore, engaging with patients'

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<sup>5</sup> See Anne Marie Gagné-Julien on the value-free ideal of science and psychiatry (Gagné-Julien 2021).

perspectives on their experiences is integral to arriving at knowledge. Patients' accounts of their encounter with mental disorder (subjective) are directly relevant for making sense of the phenomenon, thus obtaining a more accurate picture of both the nature of mental disorder and its treatment. In addition, expecting to arrive at a concordant account, wherein the judgments of all experts in the process concur on a particular observation, is not a plausible expectation. The phenomenon under investigation is mostly unknown, rich, and complex. This requires and invites conversation, interaction, and even conflicts between those who encounter and those who treat mental disorders. In fact, the very inclusion of differently trained experts in the current DSM creation process shows that the process of inquiry is interactional, collaborative, and critical, not uncontested concordance with a certain viewpoint.

In what follows, I propose and develop Participatory Interactive Objectivity (PIO) to address the kinds of concerns raised by the DSM-5 Task Force, especially those that involve adjudicating multiple perspectives of patients and psychiatrists. PIO, guided by feminist epistemologists' conception of objectivity, better fits the goals of psychiatric inquiry and can establish venues within which to settle disagreements between patients and psychiatrists in the DSM deliberation process.

#### **4. Participatory Interactive Objectivity in Psychiatry**

Participatory Interactive Objectivity (PIO) takes psychiatry to be a form of social epistemology, i.e., a collective enterprise shaped by a variety of scientific, medical, and testimonial practices that aims to develop knowledge on effective treatments for mental disorders. Building on feminist philosophy of science, it conceptualizes science as a community activity and takes this social feature of science to be necessary for the objectivity of scientific

inquiry. PIO highlights the value of procedural objectivity and includes individuals with a first-person encounter with mental disorder in the community of knowers and knowledge generators in psychiatry, thus expanding the notion of expertise to include both the professionals trained in psychopathology and those with experiential knowledge. PIO leaves behind “objectivity as the opposite of subjectivity” and “objectivity as concordance” because they do not reflect the nature of inquiry in psychiatry. Instead, PIO sees objectivity as a participatory and interactive negotiation process.

Scientific knowledge must not be understood as the “simple sum of finished products” of individual scientists, but as the product of collaboration and critical engagement among a plurality of scientists (Longino 1990). The social nature of scientific activity leads to the mechanism of transformative criticism, i.e., a process that facilitates the adjudication of values if they jeopardize the objectivity of science. For example, peer review of scientists’ work in the publication process allows a body of knowledge to be scrutinized by a group of experts. Thus, including a diversity of scientists in the knowledge production process, along with the mechanism of transformative criticism, makes procedural objectivity possible (Longino 1990). The DSM creation/revision process, aimed at generating knowledge about mental disorders, is guided by a community of scientists, i.e., members of the DSM task force who are psychiatrists trained in psychopathology, as well as those in working groups who coordinate research on mental disorders and make recommendations on diagnostic criteria to the task force. Thus, the process is designed to be collaborative and critically engaging. The argument for the inclusion of patients in the community of knowers and critical engagers is a natural extension of this process; to ensure objectivity in psychiatry, we must recognize and encourage the social process of

attaining knowledge and include not only the professionals with training in psychopathology but also those with first-hand experience.

When it comes to the scientific investigation of mental disorders through the creation/revision of diagnostic criteria, should patients' input carry the same weight as that of psychiatrists and other scientific and clinical experts? After all, in her discussion of transformative criticism, Longino says scientists are the ultimate decision makers, even though she highlights the importance of having a diverse community of scientists, representing different viewpoints. Perhaps Longino herself may be reluctant to advocate including patients in the scientific decision-making process, as they are not scientists.

While PIO departs from Longino's discussions of transformative criticism and objectivity in its promotion of the inclusion of patients (i.e., non-scientists), it is consistent with Longino's contextualism in so far as it promotes viewing science as practice by highlighting the importance of paying attention to the nature of the scientific practice at hand. Because the unknowns of mental disorders are still greater than the knowns, we have to commit to the practice (rather than the products) of psychiatric research as it unfolds. If we pay attention to the nature of research in psychiatry, the inclusion of patients in the group of researchers working on mental disorders is necessary for epistemic reasons. Psychiatry is an intervention-oriented science; its main goal is the discovery of the scientifically relevant properties of mental disorders that yield successful explanations, reliable predictions, and effective interventions. To discover and then investigate these features, it is necessary to adopt a trilateral strategy (Tekin 2016), where we examine not only the clinical and scientific work on mental disorders but also the first-person reports of those experiencing them. Taken together, these epistemic resources may help develop interventions, as

they may disclose the underlying causes, suggest their effective treatment, and clarify what it is like to have a mental disorder.

The inclusion of patient perspectives allows us to engage with different types of evidence that might be overlooked in conventional case-reporting scenarios. For example, it is important to know the nature of schizophrenia and the kind of interventions that are helpful through the perspectives of clinicians, but it is also important to gather data from first-person reports. Thus, what I am proposing here is to expand the community of knowers in research in psychiatry to include patients. Patients offer a special kind of expertise on mental disorders; they are “experts by experience” (Collins and Evans 2002).

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 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 of labelling or framing these experiences will be more conducive to treatment.

Consider what patients bring to the table. First, those who have been living with mental disorder can expose the orientational challenges (Tekin 2014) of mental disorders, including their symptoms and the context in which they emerge, possibly revealing patterns previously missed by clinically trained experts. Second, patients possess information about potential responses to different treatments, such as psychotropic medications or psychotherapy. Third, they understand how mental disorders affect their interpersonal relationships and the reactions of

others to their illness. Fourth, they know how the scientific frameworks that label their mental disorder (e.g., their DSM diagnosis) affect their self-concepts (Hacking 1995; Tekin 2011). Fifth, the ways their illness are narrated in the larger culture influence their conceptual resources in understanding and responding to their conditions. Finally, those who have developed a good quality of life despite their illness have a good grasp of the resources required to cope with disruptions in their daily lives (Tekin and Outram 2018). Given the wealth of patients' perspectives, their inclusion can only benefit the process of knowledge production in psychiatric epistemology.

In the context of the DSM in particular, this means refining the categories of mental disorders in light of patient input. For example, one of the symptoms of schizophrenia listed in the DSM is “affective flattening, alogia, or avolition,” defined as lacking interest in social relationships (APA 2013). However, patients with schizophrenia report that it is not so much about lacking interest in social relationships; rather, they point to an intense desire but perceived inability to initiate and build such relationships (Parnas and Henriksen 2014). As this example suggests, including patients in the DSM revision process would help make the disorder descriptions more representative of the patients' lived experiences.

Now that we have established who must participate in the knowledge generation process in psychiatry, a second question concerns what kind of “objectivity” psychiatry should strive for, at least in the context of the DSM, if we were to say it is not “the opposite of subjectivity” or a product of “concordance”. According to PIO, a diverse group of experts which includes both patients and psychiatrists should be members of the DSM task force and its working groups. This means they must establish a shared decision-making process through which they can deliberate each other's standpoints, perspectives, and proposals and then make decisions.

Instead of thinking of objectivity as the opposite of subjectivity and striving for a concordance of viewpoints, we must embrace group discussion and disagreement. Participants in the DSM revision process must be invited to argue with each other and to ferret out the sources of their disagreements. The clinically trained experts and the patients, i.e., experience-based experts, can scrutinize each other's hypotheses and evidential reasoning, thereby limiting the intrusion of subjective preferences into the DSM revisions. This means that neither intersubjective agreement nor consensus will be necessary; rather, shared norms of agreement must be established (in advance) to determine how conflicts and disagreements will be resolved. It is beyond the scope of this paper to establish what those norms may look like, but existing models of shared decision-making processes in other fields of citizen-engaged scientific practices can serve as models (e.g., Whyte 2018). For example, we must consider the values that must be a part of this process, including, but not limited to, the need for both trained experts and experience-based experts to trust the other party has a meaningful epistemic contribution to make and remain open to criticism. In the end, including patients in the DSM development process will enhance psychiatric epistemology, by encouraging transformative criticism and ensuring different points of view are part of the scientific decision-making process.

## **5. Conclusion**

This paper argued for the inclusion of patients in the DSM revision process for epistemic reasons – seeing it as an important step in the production of knowledge on mental disorders in contemporary psychiatry more broadly. Arguing that patients are experience-based experts, I challenged the dominant notion of objectivity used by the DSM-5 Task Force, pointing out that this understanding undermines the epistemic value of the inclusion of patients' perspectives.



Drawing on insights from feminist philosophy of science, I suggested Participatory Interactive Objectivity is a good fit for DSM revisions in particular and psychiatric epistemology in general.

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