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Research Article

Patient Perceptions Regarding Possible Changes to the Name and Criteria for Chronic Fatigue Syndrome and Myalgic Encephalomyelitis

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Abstract

For decades, researchers and patients have been debating the terms and criteria for chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME). This has led to considerable difficulties in clearly communicating to the public the nature of these illnesses, and has produced considerable methodological challenges for researchers who study these illnesses. If different laboratories do not employ comparable criteria to select patients, this will have negative consequences for understanding epidemiology, etiology, diagnostic and treatment approaches. In part due to this ongoing controversy, the Institute of Medicine in 2015 recommended new criteria and a new name. The present study surveyed a relatively large sample of patients both in and outside the US to determine attitudes toward the primary names and criteria that have been used to characterize these patients. Assessing patient opinions is an activity that might help provide gatekeepers (i.e., federal officials, scientific and patient organizations) with valuable input for ultimately clarifying this debate regarding names and criteria.

ABBREVIATIONS

CFS: Chronic Fatigue Syndrome; ME: Myalgic Encephalomyelitis; ME/CFS: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; SEID: Systemic Exertion Intolerance Disease; NDS: Neuroendocrineimmune Dysfunction Syndrome; MDD: Major Depressive Disorder; ME-ICC: International Consensus Criteria for Myalgic Encephalomyelitis; IOM: Institute of Medicine

INTRODUCTION

The term Myalgic Encephalomyelitis (ME) [1,2] was used in Europe and by the World Health Organization since the 1970s. Melvin Ramsay [1,2] described Myalgic Encephalomyelitis as having: (1) muscle fatigability after minimal exertion and a delay in the restoration of muscle power, (2) cerebral dysfunction, and (3) impaired circulation. In addition, he described patients as often having daily variations in symptoms and physical findings, and that there was a propensity for the illness to become chronic. Unfortunately, this case definition was rarely used in research studies, and this might have been due to difficulties in operationalizing these criteria [3].

In the U.K., the Oxford definition was later established by Sharpe et al., [4]. Patients that meet the Oxford criteria are required to experience 6 months of either mental or physical chronic fatigue; no other symptoms are required. In the US, first Holmes et al. (1998) [5], and later Fukuda et al. (1994) [6], described the illness chronic fatigue syndrome (CFS). Over the past 20 years, the Fukuda et al. criteria have been used by the majority of scientists studying CFS. Patients that meet these Fukuda et al. criteria are required to experience chronic fatigue and the concurrent occurrence of at least four of the following eight symptoms: sore throat, tender cervical or axillary lymph nodes, muscle pain, multiple joint pain without joint swelling or redness, headaches of a new type, pattern, or severity, unrefreshing sleep, post exertional malaise lasting more than twenty-four hours and persistent or recurring impairment in short term memory or concentration. One problem with this case definition is that the last three symptoms (i.e., unrefreshing sleep, post exertional malaise lasting more than twenty-four hours and persistent or recurring impairment in short term memory or concentration) have been considered fundamental aspects of CFS [7], but because the polythetic Fukuda et al. criteria require only four out of eight symptoms, it is possible for a patient to be classified as having CFS without having any of these core

symptoms.

A number of other problems were encountered with the Fukuda et al., (1994) criteria [6]. For example, in the 1990s, Jason et al., (1999) found that people who had Major Depressive Disorders (MDD) have many of the Fukuda et al. (1994) symptoms [8]. Symptoms of depression often include chronic fatigue and multiple somatic symptoms, including unrefreshing sleep, joint pain, muscle pain and impairment in concentration. MDD is one of the more prevalent psychiatric disorders, occurring in about 2.3% of the population. However, many of the symptoms experienced by patients with CFS, such as prolonged fatigue after physical exertion, night sweats, sore throats, and swollen lymph nodes, are not commonly found among individuals suffering from MDD. Moreover, illness onset with CFS is often sudden, occurring over a few hours or days, whereas primary depression generally shows a more gradual onset [9]. When using sensitive assessment instruments, it is possible to differentiate with 100% accuracy MDD, when it is a solely psychiatric illness, from CFS [10].

A clinical case definition was developed called the Canadian Consensus Criteria, and referred to as ME/CFS [11]. This case definition specified core symptoms, including post exertional malaise, impairment of memory and concentration, unrefreshing sleep, arthralgia and/or myalgia, and several autonomic, neuroendocrine, and immune manifestations. Unfortunately, in the Johnston, Brenu, Staines, and Marshall-Gradisnik [12] review of 31 CFS prevalence studies, only one study reported prevalence according to the ME/CFS Canadian Consensus Criteria. A case definition for ME was developed in 2011 known as the International Consensus Criteria for Myalgic Encephalomyelitis (ME-ICC) [13]. To meet the ME-ICC criteria, a person must have symptoms from the following four domains: Post-Exertional Neuroimmune Exhaustion; Neurological Impairments; Immune, Gastro-intestinal, and Genitourinary Impairments; and Energy Production/Transportation Impairments. Brown, Jason, Evans, and Flores [14] contrasted the ME-ICC [11] with the Fukuda [6] criteria. Findings indicated that the ME-ICC criteria patients with more functional impairments and physical, mental, and cognitive problems than the larger group of patients who met the Fukuda et al. criteria. However, the patients who met the ME-ICC criteria also had significantly greater rates of psychiatric comorbidity.

Case definitions in medicine and psychology are a set of rules that allow investigators and clinicians to determine who has and who does not have an illness and they had important implications for the etiology, epidemiology, diagnosis, and treatment illnesses. Jason and Choi [15] maintain that individuals with CFS suffer from what is called diagnostic unreliability, due to criterion variance, which involve the formal inclusion and exclusion criteria to classify patients into diagnostic categories. Due to the ambiguities that occur in case definitions, investigators might select samples of patients who are different on fundamental aspects of their illnesses, and this has been an impediment to replicating findings, and if consistent findings are not found, it is more likely to assume that there are no biological markers.

In the spring of 2015, the Institute of Medicine (IOM) recommended a new clinical case criterion involving the following four symptoms: substantial reduction or impairment in the ability to engage in pre-illness levels of occupational, education, social or personal activities; post-exertional malaise; unrefreshing sleep; and at least one of the two following symptoms: cognitive impairment or orthostatic intolerance [16]. These four symptoms for the most part are having been found in a number of factor analytic studies [17]. Although studies have found cognitive impairment in patients, orthostatic intolerance tends to occur less frequently [18]. According to the IOM, if a patient has these four domains, the new clinical criteria would be met. However, the core IOM symptoms are not unique to SEID, as other illnesses have some of these symptoms (e.g., cancer, Hashimoto, lupus, chronic heart failure, multiple sclerosis).

Jason, Sunnquist, Brown, Newton, Strand, and Vernon [18] found that the IOM criteria appear to identify a group of patients comparable in size to the Fukuda et al., criteria. Jason, Sunnquist, Brown, McManimen, and Furst [7] found that the IOM and Fukuda criteria identify a larger group of patients than would meet the Canadian ME/CFS and ME-ICC criteria, but these results came from a clinically based samples. Jason, Sunnquist, Kot, and Brown [19] examined the IOM criteria with a number of data sets including one from a community based epidemiology study, which went beyond more clinic and tertiary care type settings. Because of less restrictive exclusionary criteria, they found that the IOM's new clinical criteria would increase prior CFS prevalence rates by 2.8 times. For example, 47% of those with Melancholic Depression would have been exclusionary under the Fukuda et al. criteria but met the IOM criteria.

The IOM also recommended changing the name CFS to Systemic Exertion Intolerance Disease (SEID) [16]. In the spring of 2015, Lisa Petrison from Paradigm Change conducted a patient survey [20] and found that the majority of respondents expressed negative opinions about the proposed name (SEID) and the proposed naming process. However, this poll was not published in a scientific journal, and the survey did not attempt to determine preferences for the criteria for the names. In addition, Nicholson, Brown, Jason, Ohanian, and O'Connor examined data collected by another patient-research organization (Solve ME/CFS Initiative), which asked its members an open-ended question regarding preferences for specific illness labels [21]. They found that 96% of participants disliked/ strongly disliked CFS. Myalgic encephalomyelitis (ME) was the majority's first preference (55%) and was chosen four times more than any other name given. However, this was a limited sample in that only one question was asked regarding the name, and this poll occurred before the IOM (2015) released their name change recommendations [21].

Understanding patient perspectives on illness labels and criteria may facilitate improved communication and efforts to arrive at a consensus among scientists, government officials and patients. The present study assessed patient attitudes toward different names and criteria, with the intention of better understanding opinions on these contentious topics. We believe that this was an important step towards building consensus among the major gatekeepers in this effort to resolve the controversy regarding names and criteria that have been debated over the past decades.

MATERIALS AND METHODS

Participants were recruited from social media outlets (e.g.

Facebook), ME or CFS organizations, and various online patient forums. Responses were collected over a two month period. This study obtained approval from DePaul University's Institutional Review Board prior to participant recruitment.

To be eligible to participate, patients needed to indicate a self-reported diagnosis of ME or CFS. Alternatively, they could be a family member/advocate of someone who is diagnosed, a healthcare worker that treats patients with ME or CFS, or a researcher who studies this illness. In addition, participants were required to be 18 years of age or older and capable of reading and comprehending English. The results presented in this report focused on patient opinions; data on family members, healthcare workers, and researchers' opinions will be reported elsewhere. Respondents indicated what country they were from, as well as their age, sex, ethnicity, educational level, marital status, and disability/working status. The survey was developed to assess participants' attitudes on terminology of the current criteria used to classify this illness. The survey was kept brief to encourage participation, particularly among severely ill patients with limited stamina. There were 27 questions, and most used either yes/no responses or rating scales that ranged from Definitely do not like it, Do not like it, Not sure, Like it, and Definitely like it. We also had an open ended question at the end that asked: "Please provide comments in the box below to further explain your responses to the survey questions." In addition to sociodemographic questions, the topics assessed involved the different names and the different criteria that have been published over the past decades. Questions about case definitions included hyperlinks to PDFs and web pages to provide more in-depth information. The survey requested from respondents demographic characteristics, and assessed attitudes regarding current illness labels and widely used case definitions. The survey was hosted on Research Electronic Data Capture (REDCap), an online data collection tool [22]. Three highly visible patient activists, Jill McLaughlin, Patricia Fero and Mary Dimmock, all who have or had a child ill with either ME or CFS, contributed to the construction of the questionnaire. These individuals were selected to help in this questionnaire development process and interpretation of the data as they represented a variety of different points of view on both the name and criteria.

RESULTS AND DISCUSSION

Table 1 represents the countries of origin of the 1,045 participants who lived in either the US (N = 408) or outside of the US (International) (N=637). Only (N = 624) of the International participants gave a response for country of origin and the remaining 13 did not. Of the 1,045 participants, 39.5% said they lived in the US and 32.9% resided in the UK. Respondents also reported that their country of origin was Australia (6.6%), The Netherlands (6.2%), Canada (6%) and the remaining 8.8% were split among other countries listed in (Table 1).

Table 2 presents sociodemographic characteristics of the 1,045 patients who lived in either the US (N = 408) or outside the US (International) (N = 637). Chi-squared and t-tests were used to evaluate differences in the two samples. The International sample was significantly younger (M = 46.4 years versus M = 51.9 years), and more likely to be male (17% versus 11%). Most participants were white, although a significantly higher

Table 1: Patients and Country of Origin.

Country	%	(*n*)
US	39.50%	408
UK	32.90%	340
Australia	6.60%	68
Netherlands	6.20%	64
Canada	6.00%	62
Norway	1.80%	19
New Zealand	1.60%	17
Belgium	1.60%	16
Ireland	1.50%	15
Sweden	0.60%	6
France	0.40%	4
Germany	0.40%	4
Finland	0.20%	2
Holland	0.20%	2
Spain	0.20%	2
South Africa	0.10%	1
Italy	0.10%	1
Bahamas	0.10%	1
Total	100%	1032

percentage of those of Latino or of Hispanic origin were from the US (4% versus 1%). There was also a significant difference in educational level with the International sample having more individuals with a graduate/professional degree (35% versus 25%) and more individuals with a high school education or less (16% versus 11%). Regarding work status, there was another significant difference; with a higher percentage from the International group being on disability (57% versus 50%) and fewer of these patients were unemployed (8% versus 16%). There were also significant differences in marital status, with a higher percentage of the International sample being never married than the US sample (31% versus 23%). Given the differences between the two samples, results on names and criteria were analyzed separately for the US and International samples.

Opinions on names

Table 3 presents that overall results for the two samples on the names, and there were significant differences for the terms ME, CFS, and ME/CFS. The most favorable attitudes were found for ME, where 65% of the US sample and 68% of the International sample liked or definitely liked this term. For ME/CFS, only 31% of the US sample and 21% of the International sample liked or definitely liked this term. Still lower percentages were found for CFS, where only 22% of the US sample and 6% of the International sample liked or definitely liked this term.

There were no significant differences for NDS (Neuroendocrineimmune Dysfunction Syndrome, a name that had been proposed by the Name Change Work group that was appointed by the CFS Coordinating Committee; see http://iacfsme.org/ME-CFS-Primer-Education/Pages/ME-CFS-Name-Change.aspx) with 38% liking or definitely liking this term, but 30-31% were not sure. However for the SEID term, only from 16% to 17% liked or definitely liked this term.

Opinions on case definitions

Table 4 presents results on the case definitions, where

Table 2: Diagnosed Patient Demographics (n = 1045).

	U.S		International		
	(n= 408)		(n= 637)		
	M	(SD)	M	(SD)	Sig.
Age	51.9	(11.5)	46.4	(12.3)	***
	%	(n)	%	(n)	
Gender					**
Female	89%	(359)	83%	(528)	
Male	11%	(45)	17%	(105)	
Race (*could select more than one*)					
White	95%	(386)	96%	(612)	
American Indian/Alaskan Native	3%	(12)	1%	(4)	
African American	2%	(10)	0%	(0)	
Asian/Pacific Islander	1%	(5)	1%	(5)	
Other	2%	(7)	3%	(20)	
Latino or Hispanic Origin					**
No	96%	(388)	99%	(618)	
Yes	4%	(16)	1%	(7)	
Education Level					***
Graduate / Professional degree	25%	(102)	35%	(219)	
College degree	34%	(138)	27%	(171)	
Partial college / Specialized training	30%	(121)	21%	(133)	
High school or less	11%	(46)	16%	(103)	
Work Status *(could select multiple)*					**
On disability	50%	(204)	57%	(361)	
Unemployed	16%	(64)	8%	(54)	
Retired	14%	(58)	12%	(75)	
Working part-time	9%	(36)	13%	(85)	
Working full-time	9%	(37)	6%	(39)	
Homemaker	7%	(27)	5%	(33)	
Student	2%	(10)	3%	(22)	
Marital Status					***
Married / Living with partner	52%	(213)	49%	(309)	
Never married	23%	(92)	31%	(197)	
Divorced	20%	(82)	14%	(90)	
Widowed	3%	(13)	1%	(9)	
Separated	1%	(6)	4%	(25)	

*** = p > .001 and ** = p > .01

there was only one significant difference between the US and International samples for the Ramsay-based criteria, with 30% of the US sample liking or definitely liking these criteria, whereas 49% of the International group felt similarly. In general, there were three criteria that patients provided overall positive ratings of like or definitely like and those were the ME/CFS Canadian Consensus Criteria (from 58% to 64%), a data driven approach (from 57% to 59%), and the ME-ICC criteria (from 55% to 58%). However, only 32% to 35% liked or definitely liked the IOM criteria whereas only 16% liked or definitely liked the Fukuda et al. criteria.

CONCLUSION

The findings from this study are rather clear concerning the terms CFS and SEID. Only 22% of the US sample and 6% of the International sample liked or definitely liked the illness label CFS, whereas only 16% to 17% liked or definitely liked SEID. In other words, the majority of individuals were not in favor of either term, and this matches what has been previously found regarding the terms CFS [21,23] and SEID [20]. These findings indicate that it is of importance to find names that can gain greater approval from the patient community. Two other terms with slightly better approval ratings were ME/CFS (21% to 31%) and NDS (38%), but the latter term might have been less familiar to many respondents. Clearly, in this comparison of names, the most favorable attitudes were found for ME (65% to 68%), thus indicating that there appears to be the highest consensus for ME among the patient community, which is supported by scientific data suggesting that there are less negative attributions associated with this name [24,25].

As with the names, two of the lowest rated criteria were the Fukuda et al. [6], (approval ratings of 16%) and the IOM [16] (approval ratings of 32% to 35%) criteria. The Ramsay-based definition fared slightly better in terms of approval ratings (30% to 49%), but it is likely that many patients were less familiar with this set of criteria. The highest approval ratings were for the ME/

Table 3: Opinion of current names.

CFS (*n*=1042)	U.S. (n = 406)	International (n= 636)	
	% (n)	% (n)	Sig.
Definitely do not like	56%(229)	58%(366)	***
Do not like	18%(72)	23%(146)	
Like	17%(69)	5%(30)	
Definitely like	5%(19)	1%(6)	
Not sure	35%(141)	14%(88)	

ME(*n* = 1042)	U.S. (n = 408)	International (n = 634)	
	% (n)	% (n)	Sig.
Definitely do not like	5%(22)	3%(17)	**
Do not like	13%(55)	11%(69)	
Like	42%(171)	36%(230)	
Definitely like	23%(93)	32%(201)	
Not sure	16%(67)	18%(117)	

ME/CFS(*n* = 1040)	U.S. (n = 407)	International (n = 633)	
	%(n)	%(n)	Sig.
Definitely do not like	13%(52)	22%(138)	***
Do not like	33%(133)	34%(214)	
Like	29%(117)	19%(120)	
Definitely like	2%(10)	2%(12)	
Not sure	23%(95)	24%(149)	

SEID(*n* = 1043)	U.S. (n = 407)	International (n = 636)	
	% (n)	% (n)	Sig.
Definitely do not like	37%(151)	32%(203)	
Do not like	27%(108)	30%(189)	
Like	13%(51)	13%(184)	
Definitely like	4%(17)	3%(18)	
Not sure	20%(80)	22%(142)	

NDS(*n*= 1037)	U.S. (n = 405)	International (n = 632)	
	%(n)	%(n)	Sig.
Definitely do not like	12%(49)	11%(71)	
Do not like	20%(82)	19%(121)	
Like	28%(112)	29%(184)	
Definitely like	10%(41)	9%(58)	
Not sure	30%(121)	31%(198)	

Abbreviations: CFS: Chronic Fatigue Syndrome; ME: Myalgic Encephalomyelitis; ME/CFS: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; SEID: Systemic Exertion Intolerance Disease; NDS: Neuro endocrine immune Dysfunction Syndrome

CFS Canadian Consensus Criteria (58% to 64%), a data driven approach (57% to 59%), and the ME-ICC criteria (55% to 58%).

These findings above are of importance as they occurred following the release of the IOM (2015) report, and had the committee members polled patients prior to announcing the new SEID name, they would have been unlikely to endorse this name. In a similar way, polling patients regarding criteria might have also been a way of helping the IOM committee members gain a sense of what the patient community was most likely to endorse.

There are currently multiple case definitions, some focusing on clinical and others on research criteria. It is critical to develop a consensus on one clinical and one research case definition. The broader IOM criteria was developed for clinical purposes, and a more restrictive criteria could be used for research purposes, either involving the ME/CFS Canadian Consensus Criteria [11], the ME-ICCC criteria [13] the operationalized Ramsay criteria [26,3], or a more empirically based set of criteria [27].

The name for the different groups of patients identified as meeting clinical or research criteria remains a challenge. Below is one possible classification systems that could be considered. The term Myalgic Encephalomyelitis (endorsed by the majority of patients) could be reserved for those patients who meet the research criteria, and it would identify a smaller more homogenous group of patients with more functional impairment. Another group of patients would be those who meet the IOM clinical criteria, with a subtype within this category identifying those with psychiatric or medical reasons for their fatigue [28]. The terms CFS and SEID would not gather much patient support for such a clinical entity, and ME/CFS might also be problematic given the small percentage of patients that support this label. A new term for the IOM (2015) criteria might need to be considered, and a decade ago, there was an effort to bring about a new name by the CFS Coordinating Committee's Name Change Work group, and this process could serve as a template for how to bring about a consensus on such a term [23,29]. Those that do not meet the criteria for the above groups could be classified as having chronic fatigue, which is the most general category, and represents those with six or more months of fatigue.

There are several limitations of the present study. The findings relate to patients, and clearly the attitudes of clinicians, scientists and government officials also need to be systematically assessed. In addition, the patients self-reported having either ME or CFS, and without a thorough medical work up, it is possible that some respondents had other illnesses accounting for their symptoms. Another limitation is that some patients did not have access to technology to complete the surveys. In addition, even though there were links to definitions for the different definitions, some

Table 4: Opinions of current case definitions.

Fakuda Criteria (*n* = 1033)			
	U.S.	International	
	(*n* = 403)	(n = 630)	
	%(n)	%(n)	Sig.
Definitely do not like	22%(89)	22%(137)	
Do not like	21%(83)	23%(143)	
Like	13%(52)	13%(85)	
Definitely like	3%(13)	3%(20)	
Not sure	29%(115)	28%9175)	
Unfamiliar with criteria	13%(51)	11%(70)	

ME-ICC Criteria(*n* = 1033)			
	U.S.	International	
	(n = 403)	(n = 630)	
	%(n)	%(n)	Sig.
Definitely do not like	2%(5)	1%(7)	***
Do not like	5%(15)	4%(18)	
Like	29%(95)	26%(127)	
Definitely like	26%(83)	32%(156)	
Not sure	22%(70)	22%(105)	
Unfamiliar with criteria	17%(56)	15%(75)	

Canadian Criteria(*n* = 813)			
	U.S.	International	
	(n = 327)	(n = 486)	
	%(n)	%(n)	Sig.
Definitely do not like	1%(3)	1%(5)	
Do not like	4%(13)	3%(15)	
Like	31%(102)	31%(150)	
Definitely like	27%(89)	33%(158)	
Not sure	21%(68)	19%(92)	
Unfamiliar with criteria	16%(52)	14%(66)	

Ramasay Based London ME Criteria(*n* = 802)			
	U.S.	International	
	(n = 319)	(n = 483)	
	%(n)	%(n)	Sig.
Definitely do not like	6%(18)	3.%(14)	***
Do not like	13%(41)	8%(39)	
Like	20%(64)	32%(153)	
Definitely like	10%(33)	17%(80)	
Not sure	31%(99)	24%(118)	
Unfamiliar with criteria	20%(64)	16%(79)	

IOM Criteria(*n* = 1016)			
	U.S.	International	
	(n = 399)	(n = 617)	
	%(n)	%(n)	Sig.
Definitely do not like	10%(41)	8%(50)	
Do not like	14%(55)	15%(91)	
Like	24%(95)	24%(148)	
Definitely like	11%(44)	8%(49)	
Not sure	29%(114)	34%(212)	
Unfamiliar with criteria	13%(50)	11%(67)	

Data Driven Apporach(*n* = 818)			
	U.S.	International	
	(n = 328)	(n = 490)	
	%(n)	%(n)	Sig.
Definitely do not like	2%(6)	2%(11)	
Do not like	3%(10)	4%(21)	
Like	32%(105)	31%(150)	
Definitely like	27%(89)	26%(126)	
Not sure	25%(81)	28%(138)	
Unfamiliar with criteria	11%(37)	9%(44)	

Abbreviations: ME-ICC: International Consensus Criteria for Myalgic Encephalomyelitis; IOM: Institute of Medicine

are better known by respondents and have been in existence for a longer period of time, and this certainly could have biased some of the findings. Finally, there are many other names and criteria that have been used over the past few decades, and most were not assessed in this survey, and the reason was to reduce the burden on the respondents, but clearly more items regarding names and criteria could be included in future surveys.

The term CFS and the problems with identifying a research and clinical case definition have probably contributed to the stigma experienced by many patients [30]. A survey of healthcare providers found that 20% agreed with the statement, "I believe that CFS is all in a patient's head" [31]. Adding to this problem, thousands of patients cannot find a single knowledgeable and sympathetic physician to care for them [32]. It is very possible that looser criteria are inappropriately used as the basis of statements about the nature of the disease and recommendations about treatments for patients, as witnessed regarding the controversy over the PACE trial and its use of the Oxford criteria.

In an effort to rectify these problems, progress needs to be made on contributing factors such as the confusion concerning names and criteria. There is a need for decision making to involve all interested parties, including international representatives. In contrast to prior efforts, a collaborative, open, and inclusive vetting process could involve committees being charged with making recommendations, and key gatekeepers, including patients, scientists, clinicians, and government officials, working collaboratively to build a consensus for change. In addition, it is of importance to develop a consensus for operationalizing such criteria with reliable questionnaires, and using structured clinical interviews so that questions are asked in a similar way, with decisions also being made about what threshold of frequency and severity a symptom need to meet.

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