



RESEARCHER & CLINICIAN SURVEY RESULTS

Last week, we presented information about the diagnostic criteria, exploring their similarities and differences. [Click here to read that article.](#)

This week, we're reporting on a survey we sent to ME-literate researchers and clinicians. We contacted clinicians who treat or have treated pwME as their main patient population, and researchers who study ME as one of their main areas of focus. We contacted 65 researchers and clinicians, receiving **22** completed survey questionnaires and four sets of stand-alone comments via email. No biopsychosocial (BPS) theorists or clinicians, who view the disease as treatable via changes in behavior, were contacted.

Bottom line response:

The **Canadian Consensus Criteria was judged best definition for research and clinical use, including by mainstream medical practitioners.** Though some questions required a definitive answer, while in others, responders were able to choose multiple sets of criteria, the most popular responses were **always, in order:**

1. **Canadian Consensus Criteria (CCC)**
2. **National Academies of Medicine / Institute of Medicine criteria (NAM/IOM)**
3. **International Consensus Criteria (ICC)**

There were significant gaps between the popularity of these responses. For example, 82% of responders agreed that CCC is appropriate for clinical use, including 100% of clinicians. 64% considered NAM/IOM appropriate for clinical use, and 41% agreed ICC is appropriate for clinical use.

Our survey also showed that there is low confidence in the adequacy of current criteria overall. When asked whether current definitions are adequate for research and clinical use, the most common response was that **none of the definitions are adequate but there is not enough evidence to produce a new set of criteria.**



About our survey:

In our solicitation, we urged responders to provide their honest opinion in aid of our Values and Policy process, and provided no other specific guidance on addressing the questions.

The survey has some limitations. Contacting researchers and clinicians via email, text message, and in person provides us with a [convenience sample](#). Given #MEAction's outreach, we have contact information for a significant percentage of active researchers and clinicians, but responses will still be determined by who we've communicated with before, along with how important they considered the central question(s), and how comfortable they felt sharing the honest opinion we solicited. Researchers often change email addresses as they change institutions, and it is possible that some of the email addresses were no longer in use.

#MEAction's goal was to solicit the opinions of researchers and clinicians regarding the diagnostic criteria used both clinically and in research. You can access a [pdf of the survey questions here](#).

Six individuals who described their professional role as 'clinical' completed the survey. Some of these individuals listed researcher as well.

16 individuals listed their role as solely research-oriented. However, of these, **25%** also had a **medical degree** (MD), meaning just under half of responders were trained as clinicians.

Note that inclusion of an answer choice on the survey is not equivalent to agreement with that answer choice. Rather, we included a spectrum of opinions we have heard expressed in conversations with researchers and clinicians in the past.

Finally, note that for ease of understanding, we've arranged our data such that popular answers appear first when the chart is read left to right. **These were not necessarily the first questions asked**. Specifically, when inquiring about diagnostic criteria, we listed them in chronological order.



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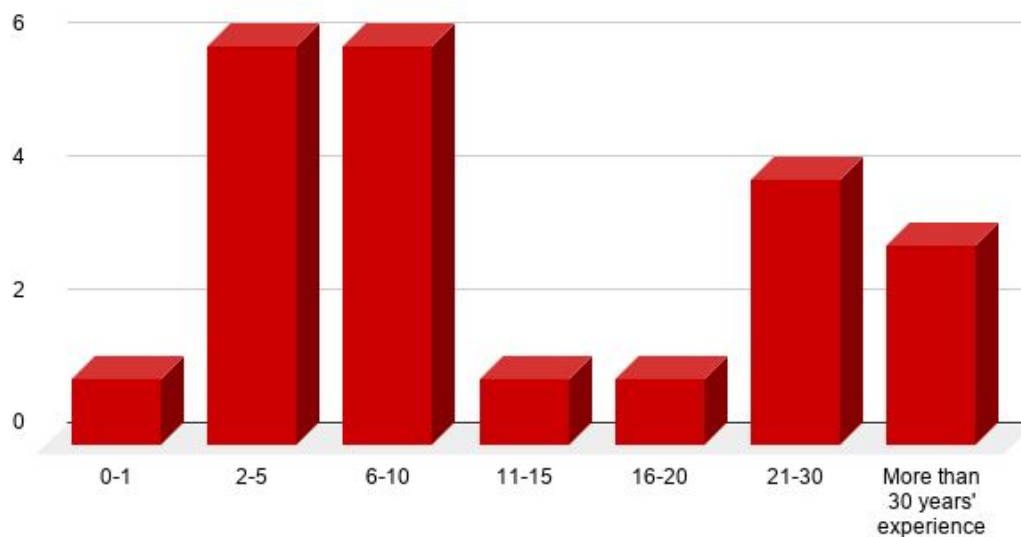
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INTRODUCTION

Responders were from the following countries: Australia; Netherlands; Sweden; the United Kingdom; and the United States. Responders were asked about their years of experience in the field. The most common answer was 2-5 and 6-10 years, but there was a second peak at 21-30 years.

How many years of experience do you have in the ME/CFS field?



This may represent positive growth: new researchers and clinicians have entered the field in the past two to ten years while our most experienced researchers and clinicians are still active. Half of the clinicians fell into the “more than 30 years’ experience” category, while the other half were either in the 2-5 or 6-10 category, generally reflecting the spread of the data as a whole.

We asked about people’s connections to ME and found that:

- 23% of responders were **people with ME**
- 14% were **caregivers**
- 23% had a **family member with ME**



- 18% had a **connection to another chronic, debilitating illness** that led to their interest in ME.

There were some unique answers, including one responder who shared that a few colleagues had ME, and another who stated “patients were prevalent in my PhD cohort”. Several researchers’ and clinicians’ only connection to ME was with their patients or research subjects. Every option was chosen a comparable number of times, showing responders had a variety of reasons to research ME or engage in clinical care or clinical research for people with ME.

CLINICAL DEFINITION

#MEAction solicited questions about the definitions and criteria in clinical use separately from those used for research. Questions relating to the clinical definition are laid out below.

There are many clinical definitions currently in use for ME/CFS. How important is the clinical definition to ensuring the best possible clinical care?

Responders were asked to answer the question on a scale of 0 to 5, where **0 is unimportant** and **5 is extremely important**.

- **Clinicians** responded with a **mean** of 3.8, a **median** of 4, and a **mode** of 3 and 5, which had an equal number of responses.
- **Researchers** rated the clinical criteria’s importance to clinical care more highly, with a **mean** of 4.2, a **median** of 5, and a **mode** of 5.
- **Overall**, ME professionals rated the importance of the clinical criteria to clinical care at a **mean** of 4.1, a **median** of 5, and a **mode** of 5. It’s interesting to note that **clinicians rated the criteria’s importance** in providing the best possible clinical care **significantly lower than researchers**.



Which statement or statements best describe(s) the importance of clinical criteria?

	Overall	Clinicians	Researchers
It is an important tool to educate non-expert clinicians.	73%	83%	69%
It is an important tool to educate patients.	68%	100%	56%
It aids in differential diagnosis.	64%	100%	50%
It is important for insurance and disability.	50%	67%	44%
It is a tool I use to diagnose patients.	41%	83%	25%
The clinician's best judgement is more useful for accurate diagnosis than any single clinical criteria.	32%	50%	31%

Additional comments

Clinicians and clinician-researchers:

"It is important for public health in terms of figuring out what the mortality, morbidity, economic costs, etc. are of a condition and to help funding agencies plan for care."

Researchers:

"It validates patients' symptoms."

"Current clinical definitions are poor, so they are not particularly useful. Clinical judgement is the best, but only for experienced clinicians. Steps towards improving clinical definitions (esp. with objective markers) are important."

"Important for selection of research subjects"



How do you use clinical definitions in your practice?

	Clinicians	Researchers
I use it as an instrument to diagnose ME	83%	9%
I use it to support insurance and disability claims	83%	n/a
I incorporate it into an intake form for new patients.	50%	n/a
I diagnose based on my experience and do not rely on any single criteria	50%	n/a
I use it as evidence for the necessity of school and/or work accommodations	50%	n/a
While I may consult clinical definitions, I rely primarily on my own best judgement. A clinician's personal experience is more useful in a clinical context than any single diagnostic criteria.	50%	n/a
I am not in clinical practice.	17%	68%

Primarily clinicians responded to the above question, given it specifically inquires about clinical work.

Additional comments

Only researchers had comments in this section.

“Our research team have them incorporated into research questionnaires and clinical assessments.”



RESEARCH DEFINITION

There are many research definitions currently in use for ME/CFS. How important to scientific progress is the research definition used?

Responders were asked to answer the question on a scale of 0 to 5, where 0 is unimportant and 5 is extremely important.

- **Clinicians** responded with a **mean** of 4.2, a **median** of 4, and a **mode** of 4.
- **Researchers** rated the research definition's importance to scientific progress similarly, with a **mean** of 4.3, a **median** of 5, and a **mode** of 5. There were a few very low scores for the importance of the research definition, including a zero and a one.
- **Overall**, ME professionals rated the importance of the research criteria to scientific progress at a **mean** of 4.2, a **median** of 5, and a **mode** of 5.

Which statement or statements best describe the importance of research criteria? (Check all that apply).

	Overall	Clinicians	Researchers
A consistent definition is important for comparability of research results across studies.	95%	83%	100%
A consistent definition is important to ensure that results derived from a given ME/CFS population apply to the entire ME/CFS population (is externally valid).	64%	50%	69%
It is only important that the research definition is one of the three that require post-exertional malaise (PEM) or post-exertional neuroimmune exhaustion (PENE).	41%	67%	25%



There is an overemphasis on the importance of the criteria, given that there are no biomarkers with which to validate criteria.	27%	33%	25%
Researchers can use whatever definition they like so long as they clearly identify it in published work.	14%	17%	13%
There is an overemphasis on which criteria is used, given that current research definitions likely capture individuals with a variety of similar conditions rather than ME alone.	14%	0%	19%
Only one definition accurately describes ME. Using any of the other criteria will capture the wrong group of patients.	9%	17%	6%
There is an overemphasis on which criteria is used, given that they all capture the same basic cohort.	5%	0%	6%

Note that of those who agreed that only one definition accurately describes ME, one was a researcher and another was a clinician. The clinician listed multiple acceptable diagnostic criteria in subsequent questions as being adequate.

Additional comments

Clinicians and clinician-researchers:

“The most important factor to me is researchers identify which criteria they use and how they classified people according to that criteria. That is very basic but some papers still do not do that. In terms of consistency, what I mean is not one specific criteria but that when we compare studies they should be between the same criteria. Too many reviews lump criteria together or don’t try to analyze definitions together and then apart. Ultimately more research needs to be done to figure out which criteria is useful. Figuring it out is more than about a biomarker: for instance, criteria can be distinguished / validated if they are associated with different etiologies, prognoses, responses to treatment.”



Researchers:

“A combination of more restrictive diagnostic criteria, is crucial for improving ME/CFS research validity, by avoiding selection bias and disease misclassification”

“Research criteria need to be stricter than clinical criteria”

“The criteria matter for comparability [*sic*] across studies, but they are still not very good. We use a combination of ICC and an experienced clinician who does a very detailed workup looking for exclusions. Ultimately, this is a heterogenous [*sic*] population and people can study what they think is important, as long as it is reported clearly.”

How do you use the definition in a research context?

	Overall	Clinicians	Researchers
I use a diagnostic tool (such as CCC) in a research context in order to determine who has the disease.	41%	33%	44%
I use a clinician's diagnosis in order to determine who has the disease, then report which criteria/instrument the clinician used	27%	50%	19%
I use a clinician's diagnosis in order to determine who has the disease, then validate using the criteria/instrument I need for my study	27%	33%	25%
I use a clinician's diagnosis; their expertise with the disease is more important than which criteria/instrument they have used.	14%	17%	13%

Additional comments

Clinicians and clinician-researchers:

“Another important factor is that criteria being used in the clinics should also be used in research studies. Otherwise, results using criteria different from that used in clinic may end up yielding results which may not apply to patients diagnosed with the clinical criteria. Currently, studies suggest that only about 70% of Fukuda-diagnosed patients fit CCC and only 50% fit ME-ICC. So my concern is if studies use only those criteria, their results may not apply to many Fukuda-diagnosed patients.”



Researchers:

“It is important to compare or combine studies which only use the same case definition.”

“I use a diagnostic tool in a research context to define a population” [We folded this into “I use a diagnostic tool” responses, but understand the distinction between “determining who has a particular disease” and “defining a population” and are reporting this person’s short answer here.]

“We do the above option, but the ICC includes gastroimmune/genitourinary symptoms, we do not consider [lack of these] exclusionary”

“We use CCC and then use a clinicians’ experience as confirmation. We ask them if they are convinced that they have the disease.”

WHICH CRITERIA?

Keep in mind that these results are obtained from a non-random sample and that we’re making no certain claim that this is the point of view of ME researchers and clinicians as a whole. On the other hand, we also performed a very general outreach without preference for individuals with particular views beyond not inviting researchers or clinicians with psychosomatic views to respond.

Let’s dive in!

Are current definitions of ME adequate in a clinical context? Check all that apply.

	Overall	Clinicians	Researchers
None of the definitions are adequate, but there is not enough evidence to produce a new criteria	36%	33%	38%
Yes, one or more of the current definition(s) for ME are adequate	32%	50%	25%



While I believe in the importance of a clinical criteria, I do not believe there is sufficient evidence to support one single criteria strongly	27%	17%	31%
Other (four researchers replied that they did not have sufficient expertise to discuss the adequacy of criteria in clinical practice).	18%	0%	25%
None of the definitions are adequate: new clinical criteria are required	9%	0%	13%

Additional comments

Clinicians and clinician-researchers:

“In terms of ME, do you mean only the ME-ICC because the other criteria are labelled CFS, ME/CFS.”

Researchers:

[Note: this person replied that Yes, one or more of the current definition(s) for ME are adequate.] “However, while some better definitions may be challenging to be implemented in the clinical setting, we must consider the potential misleading numbers from broad definitions that impact epidemiological studies, i.e. discrepancy on prevalence and incidence of this disease.”

“Many of the questions in this survey are double-barrelled (ask 2 questions in 1). For example, we think None of the definitions are adequate but there IS enough evidence to do better”

Which definition(s) do you feel are appropriate in a clinical context? (Check all that apply)

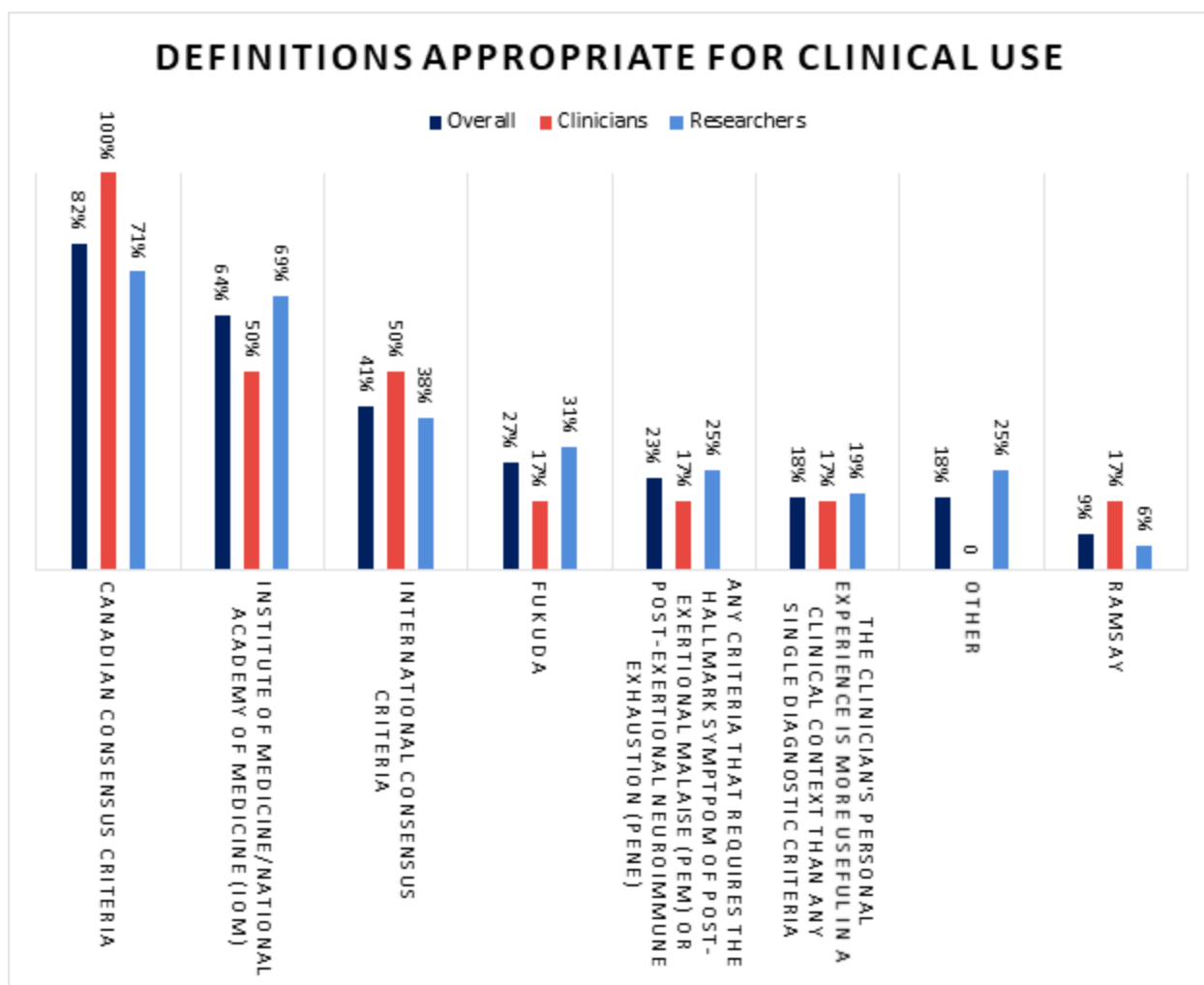
Researchers and clinicians were asked to list all the definitions that they felt were appropriate in a clinical context. We’ve summarized the answer choices for ease of reading the graph below, so let’s lay them out in more detail, here:

- Ramsay
- Fukuda



- Canadian Consensus Criteria
- International Consensus Criteria
- Institute of Medicine/National Academy of Medicine Criteria
- Any criteria that requires the hallmark symptom of post-exertional malaise (PEM) or post-exertional neuroimmune exhaustion (PENE)
- The clinician's personal experience is more useful in a clinical context than any single diagnostic criteria.
- None of the above are appropriate
- Other

We received the following, ordered from the fewest to greatest number of votes:



Overall, the Canadian Consensus Criteria (CCC) received the greatest number of votes, and all clinicians surveyed considered CCC adequate in a clinical context.

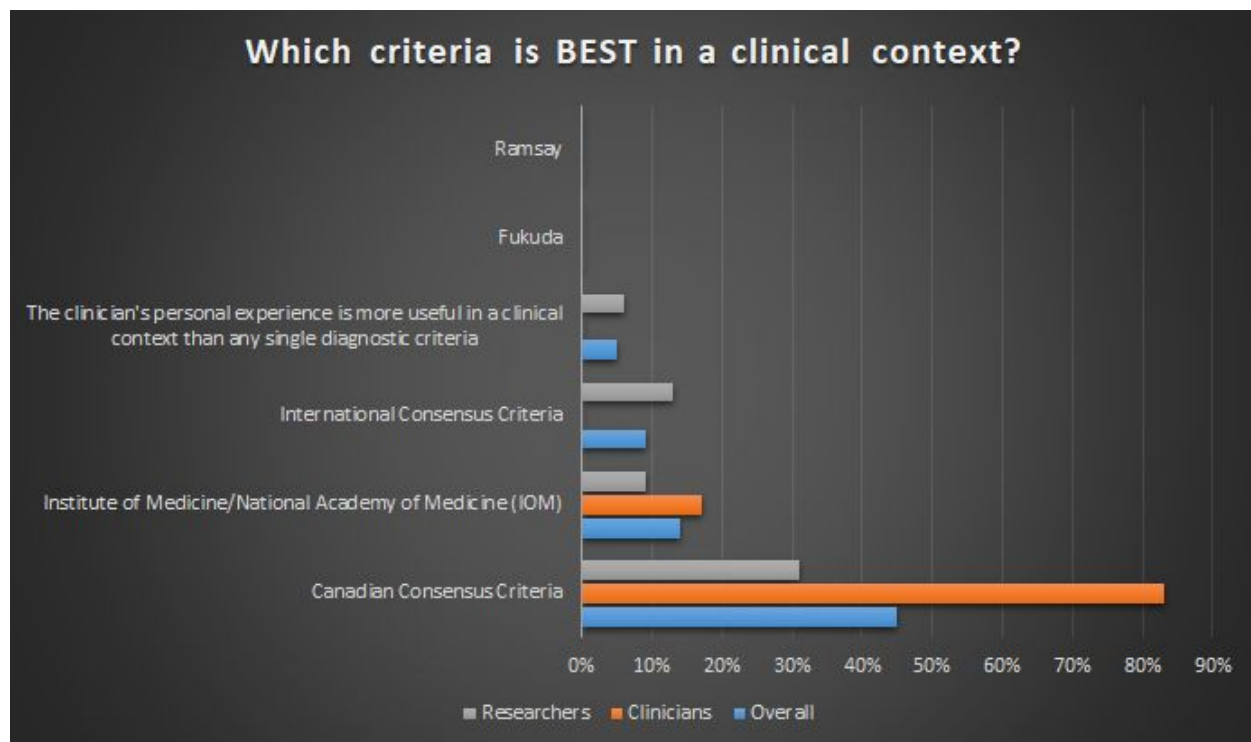


There were **five researchers** who did not list CCC among their answers. Of these, **two** replied that they did not have the background or expertise to comment, adding “do not know”, and “not sure about clinical” as their answers. A **third** answer further elaborated, stating, “I am part of a research group that is considering recommendations for ME/CFS diagnosis in the clinical context, which is still on-going.” This responder did not list which criteria were considered acceptable.

Finally, there were two individuals who picked criteria apart from CCC. The **first solely listed the National Academy of Medicine/Institute of Medicine criteria**. The second suggested **ICC or the clinician’s personal judgement**, adding, “but only for an experienced clinician”.

Which definition do you feel is BEST in a clinical context? (Check one)

Next, researchers and clinicians were asked which criteria or definition was best out of all available criteria in a clinical context.



Once again, more researchers and clinicians replied with the **Canadian Consensus Criteria (CCC)** than any other definition, with all clinicians choosing either CCC or the IOM/NAM criteria as their preferred clinical criteria. Once again, NAM/IOM was the second preferred criteria overall, and ICC was the third, with two researchers choosing this criteria. It’s worth noting, however, that one of these two listed IOM/NAM as their sole answer to the previous question, “which criteria are appropriate for clinical use?” It may be that this researcher misunderstood



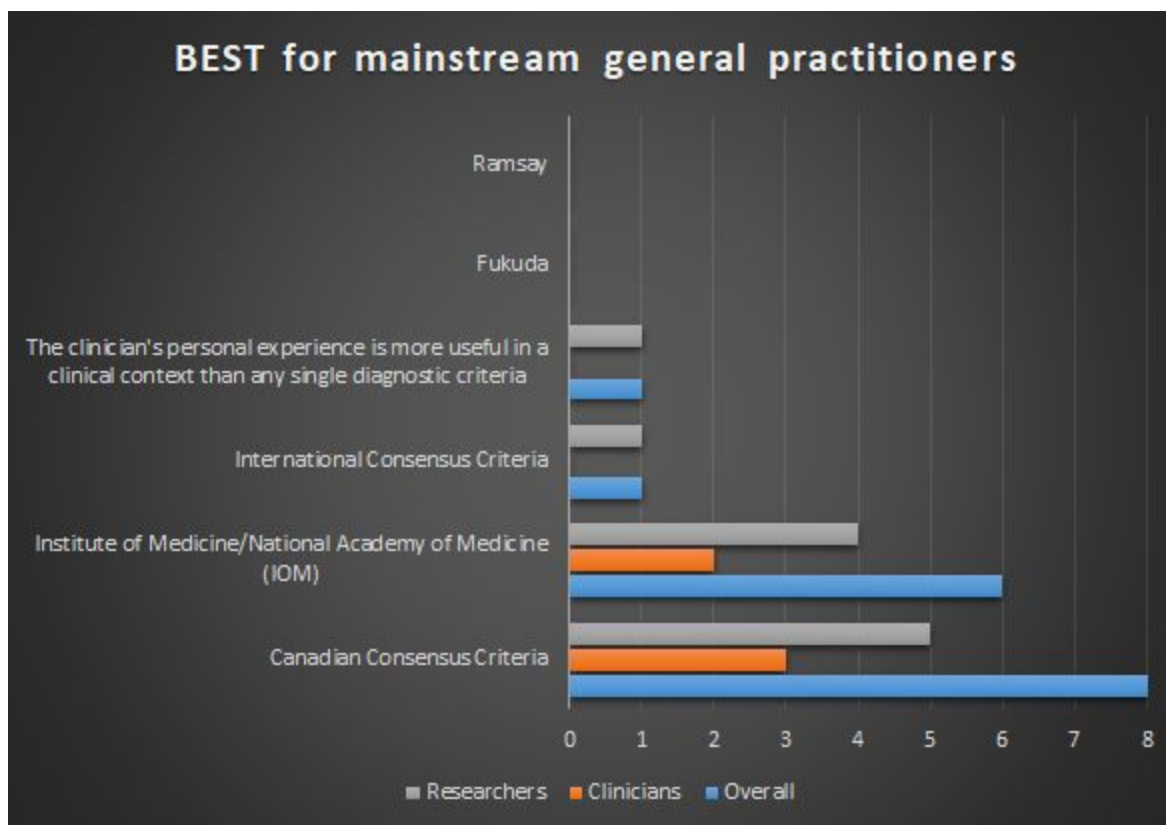
these two questions. When pressed to choose, no researcher or clinician chose Ramsay or Fukuda, and no one stated that none of the criteria available were appropriate. One researcher stated that the clinician's personal experience was more useful in a clinical context than any single set of criteria.

Additional comments

Only researchers had additional comments in regards to this question.

Four researchers responded by acknowledging a lack of expertise in the matter, stating, "Not my expertise", "I am not a clinician", "Do not know", and "Not sure about clinical". Finally, one researcher added, "Until ME/CFS can be demonstrated to be one illness or disease, it is pointless to discuss which are the best criteria."

Which definition do you feel is BEST for use by mainstream medical practitioners? (Mark only one)



The order remains unchanged: the Canadian Consensus Criteria is still the most popular set of criteria for the use of general practitioners who do not specialize in treating people with ME.



However, the gap between CCC and NAM/IOM criteria narrows significantly between this question and the last, dropping from a 107% difference to a 29% difference.

We switched from percentages to values above because of the number of researchers (five) who stated that they did not know a reasonable answer. Once again, no one chose Ramsay or Fukuda, even though Fukuda has in the past been recommended for general practitioner use. Likewise, no one chose the answer that none of the above were appropriate.

Additional comments

Once again, all additional comments were made by people in the researcher group.

“Again, we are considering a staged approach for primary and secondary (specialist services), maybe by combining definitions that are feasible for being implemented by each level of care.”

Several that were identical to previous “I don’t know” answers but one adding, “I trust our doctors”.

Please further explain your answer to the previous two questions

[re: which definition is best in a clinical context and which is best for mainstream med practitioners].

Comments

Clinicians and clinician-researchers:

“These definitions are the most comprehensive.”

[Responder chose Fukuda and CCC, CCC, CCC. for which are acceptable for clinical use]

“Often some patients either cognition, pain or sleep is not affected - so the canadian criteria has more flexibility to include these patients”

[Responder chose CCC for all three questions.]



“1. Clinical definitions which are too long or complicated are not likely to be used. At least historically, the Fukuda, ME-ICC, and CCC have not seemed to increase the numbers of patients being diagnosed, esp. by mainstream providers.

“2. Part of the problem is in an effort to capture all or most of the symptoms patients have (and not the most common symptoms), the ME-ICC and CCC can just as well capture patients with other medical conditions. Too many symptoms may also convey to healthcare professionals that this is just a conglomeration of symptoms and not a distinctive diagnostic entity.

“3. Many of the ME-ICC and CCC symptoms are not well-researched and thus there is a lack of evidence how common they are, how well they distinguish ME/CFS vs. other conditions, etc. Lack of research of a symptom does not mean it is not important but we cannot make assumptions without good data.”

[Responder chose CCC and IOM for acceptable clinical criteria, IOM for best clinical criteria, and IOM for best criteria for mainstream practitioners]

“CCC best defines all the presenting aspects of illness. The IOM criteria are more straightforward, good for screening using the core symptoms, are evidence based and widely available to all practicing clinicians.”

[Responder chose CCC, ICC, and IOM for acceptable criteria; CCC for best clinical criteria, and IOM for the best criteria for mainstream practitioners].

Researchers:

“The CCC is the better of the options given, but is open to criticism”

“The criteria only need to be sufficiently accurate for use. Once sufficient accuracy has been established, then the criteria which are easiest to be used, should be used.”

[The responder chose CCC, ICC, NAM/IOM, and clinicians' best judgement for which clinical criteria were acceptable, did not choose the best set of criteria for clinical practice overall, and chose IOM for which was best for mainstream practitioners.]



“The clinician wants a simple method of defining or separating cases into groups so that treatment approaches can be used. This is difficult if there are no treatments though”

[The responder chose CCC, ICC, and NAM/IOM as acceptable clinical criteria, ICC for best for clinical practice overall, and CCC for which was best for mainstream medical practitioners.]

“IOM is a simplified version of CCC: a way to get a GP to recognize the disease when they see it and refer out to a specialist. CCC captures a specific cohort and has the four required symptoms of fatigue, PEM, sleep dysfunction, and pain with symptoms from specific categories. Since ICC requires PEM/PENE and a sampling of other symptoms, it may capture people with other complex chronic illnesses more easily than CCC.”

[Responder stated that Fukuda, CCC, ICC, NAM/IOM, any criteria that includes PEM/PENE, and clinician’s best judgement were all appropriate for clinical use, that CCC is best in a clinical context, and that NAM/IOM is best for mainstream medical practitioners.]

“You can't cop out of this -- the clinician actually has to work to reach diagnosis.”

[Note: this responder stated that they confirm their suspected diagnosis with a clinician.]

Are current definitions of ME adequate for research?

(Check all that apply)

	Overall	Clinicians	Researchers
Yes, there is a current definition or definitions that are adequate	36%	33%	38%
While I don't believe that there is sufficient evidence to support any single definition over another, I think it's essential that all patients have hallmark symptoms such as PEM.	36%	17%	44%



While I believe in the importance of a research criteria, there is not sufficient evidence to support the use of one single criteria strongly.	32%	50%	25%
None of the definitions are adequate, but there is not enough evidence to produce a new criteria	32%	33%	31%
None of the definitions are adequate; new criteria are required for research.	18%	33%	13%

Note that **approximately 1/3 of ME-literate researchers and clinicians agreed with the first four statements**. Half of clinician responders agreed that the criteria in use were not adequate for research, but that there was not enough evidence to produce a new set of criteria.

Additional comments

Clinicians and clinician-researchers:

“I do think that these are a mixed group of patients - so for research it’s important to divide them in subgroups - or else we may not see the research outcome for these reasons.”

Researchers:

“It is time to subtype ME/CFS, and perform research on the subtypes.”

“Detailed descriptions of patient characteristics in the methods are more important than any specific criteria.”

Which definition(s) do you think are appropriate in a research context? (Check all that apply)

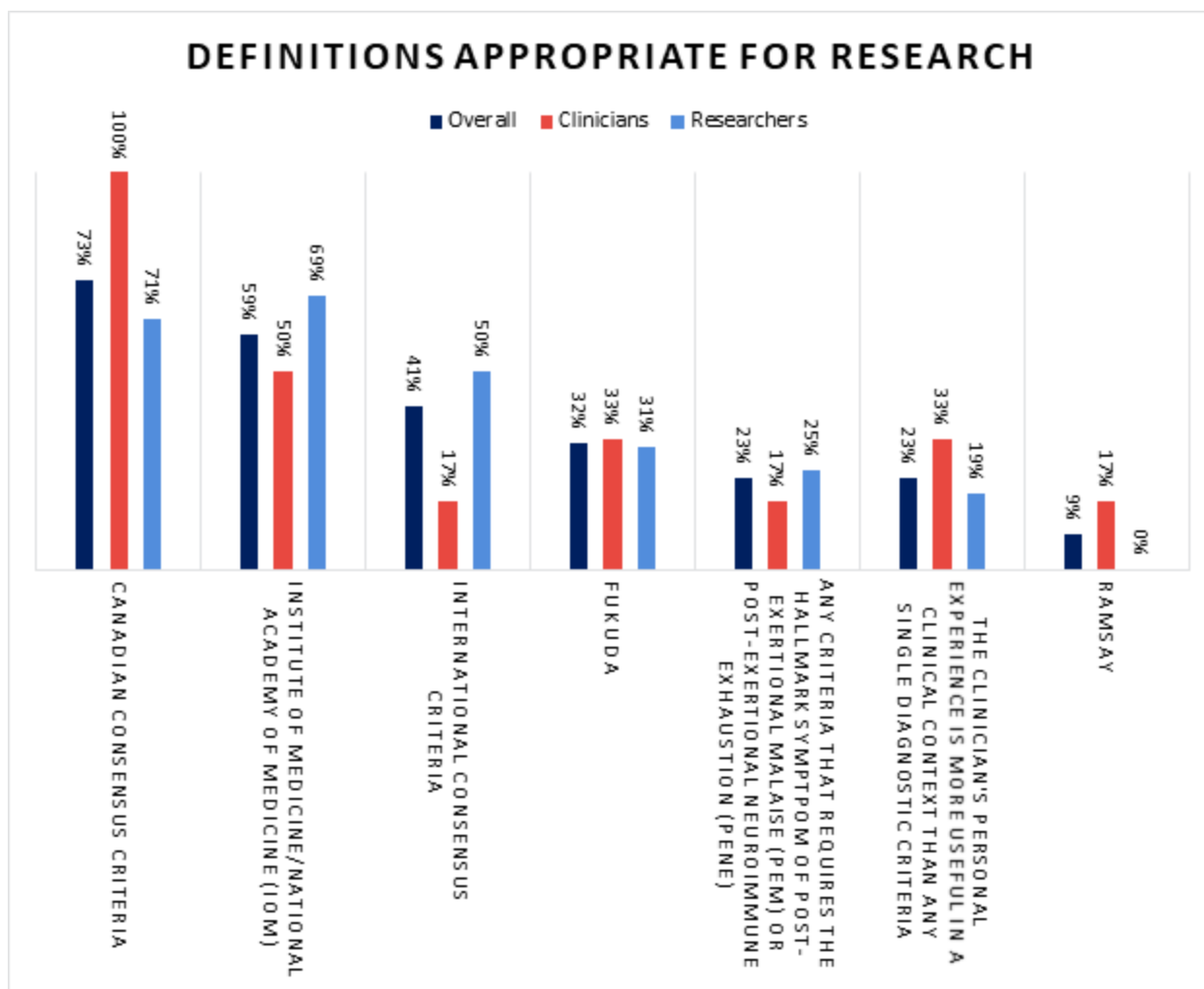
We’ve summarized the answer choices for ease of reading the graph below, so let’s lay them out in more detail, here:

- Ramsay
- Fukuda
- Canadian Consensus Criteria (CCC)



- International Consensus Criteria (ICC)
- Institute of Medicine/National Academy of Medicine Criteria (IOM)
- Any criteria that requires the hallmark symptom of post-exertional malaise (PEM) or post-exertional neuroimmune exhaustion (PENE)
- The clinician's personal experience is more useful in a clinical context than any single diagnostic criteria
- None of the above are appropriate for research
- Other

We received the following, ordered from the fewest to greatest number of votes:



Once again, the **Canadian Consensus Criteria** is most popular as a choice overall, with **100% of clinicians** surveyed agreeing that CCC is appropriate within a research context.

This is followed by the **Institute of Medicine (NAM/IOM)** criteria, with the **International Consensus Criteria** still a popular choice, with nearly half of responders agreeing it is



appropriate for research. **Fukuda** still made a strong showing, with approximately one out of three responders agreeing it is appropriate in a research context. And one of four ME-literate researchers and clinicians highlighted the importance of a clinician's confirmation of diagnosis in a research context.

Additional comments

Clinicians and clinician-researchers:

“Ideally, patients would be identified in clinic or screened with the NAM criteria and then further subclassified, perhaps with the CCC. Then contrast those who fit CCC + NAM vs. CCC but not NAM. Another factor is what the purpose of the study is as there are pros and cons to using different definitions.”

Researchers

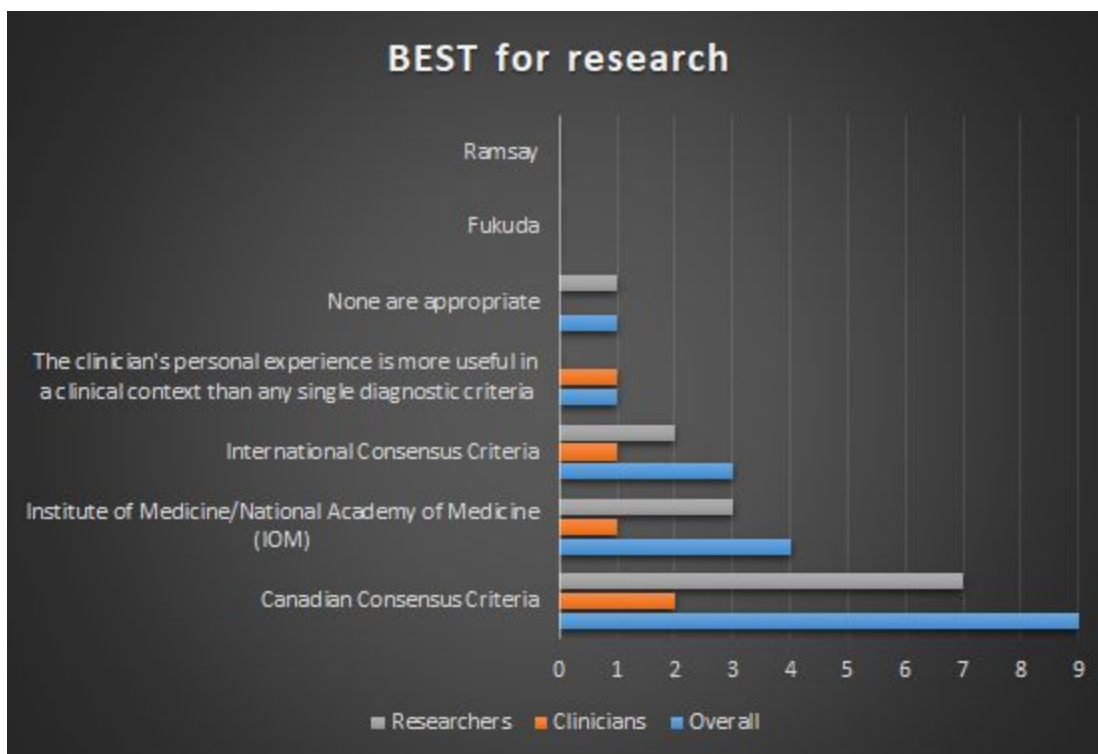
“A combination of some of the above definition would minimise selection bias and misclassification”

“Don't know”

“Still think the question is unanswered.”

Which definition do you feel is BEST in a research context? (Check one)

We've once again laid this out in number of responses rather than percentages, due to the number who did not choose a set of criteria for research. The answers, from least to most often chosen are as follows:



The **Canadian Consensus Criteria** was still the most popular choice, with **NAM/IOM** second, and **ICC** third. One responder stated that none are appropriate/best for research, adding “We have no gold standard to prove the reliability of criteria” in their comments.

Additional comments

Clinicians and clinician-researchers:

“Ideally, patients would be identified in clinic or screened with the NAM criteria and then further subclassified, perhaps with the CCC. Then contrast those who fit CCC + NAM vs. CCC but not NAM. Another factor is what the purpose of the study is as there are pros and cons to using different definitions.”

Researchers:

“A combination of some of the above definition would minimise selection bias and misclassification”

“Don't know”

“Still think the question is unanswered.”



Please further explain your answer to the previous question. Why do you think the definition(s) you chose above should be used in research? (Optional).

Answers

Clinicians and clinician-researchers:

"I think that CCC delimits the most homogen group."

Researchers:

"The CCC is the best of the options but open to criticism"

[Of the CCC:] "Fairly comprehensive, and clinician approved."

[None of the above are 'best']: "We have no gold standard to prove the reliability of criteria"

[Of the CCC]: It has the most required symptoms.

"See previous comments about Canadian -- they're more complex but well within the ability of a researcher to create a one-pager to capture yes-no questions and/or seek advice from an expert clinician. With their greater number of required symptoms, they are more likely to capture a specific cohort."

"CCC best fits many of the symptoms that the patients have, and it requires PEM. Any definition that doesn't require PEM shouldn't be used."

[None of the above are 'best']: "current criteria may still pick up diseases that are not ME/CFS"



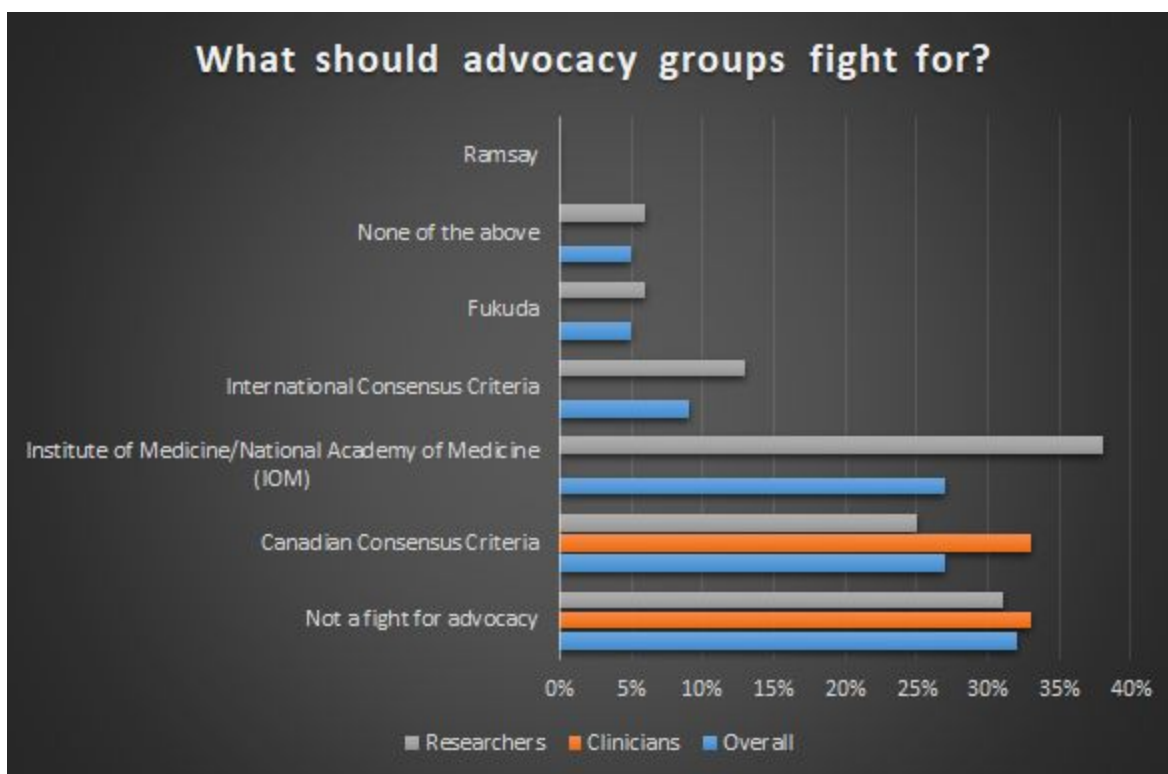
Which clinical definition(s) do you think patient advocacy organizations should advocate for? Check all that apply.

And now, for our final question, we asked: what role should advocacy groups play in fighting for one set of criteria over another? We focused on clinical practice.

We've summarized the answer choices for ease of reading the graph below, so let's lay them out in more detail, here:

- Ramsay
- Fukuda
- Canadian Consensus Criteria (CCC)
- International Consensus Criteria (ICC)
- Institute of Medicine/National Academy of Medicine Criteria (IOM)
- None of the above
- I do not think patient advocacy organizations should advocate for any particular clinical definition.
- Other

We received the following, ordered from the fewest to greatest number of votes:





Perhaps unsurprisingly, given the contention and misrepresentation around the topic, the most common answer was that advocacy organizations should **not** advocate for any particular set of clinical criteria.

25% of ME-literate clinicians and researchers agreed advocating for the **Canadian Consensus Criteria** was sensible, and the same number agreed on **NAM/IOM-related** advocacy. Two responders agreed that **ICC advocacy** was a good choice. Fukuda and 'none of the above' received one vote, each.

Additional answers:

Clinicians and clinician-researchers:

“Don't know.”

“The definition that describes the people they represent.”

“If patients' organizations advocate for anything regarding definitions, I feel advocating for more research comparing/ contrasting definitions is important. This doesn't mean just comparing symptom presentations but how different definitions may lead to different prognoses, be associated with different biomarkers/ etiologies, respond differently to treatment. Without good data, everything is speculation. Definitions in and of themselves aren't the end all: rather it's about how they can help clinicians care better for patients or help researchers learn more about a disease. My feeling is that the lay public believes there is more evidence to inform which definition is the "best" than there currently is. Also, what the public believes to be good evidence is very different than what clinicians and researchers believe to be good evidence. Finally, patients can sometimes let emotion, popular opinion, etc, shape or sway their ideas too easily. Clinicians and scientists aren't immune to popularity or emotion either but the point is to be aware of and guard against such influences. Early opposition in some circles against the NAM criteria may have set this whole field back, creating confusion, when current research continues to suggest that exertional intolerance is the heart of this illness. Some of that might be simply a knee-jerk reaction to change rather than a careful assessment.”

Researchers:

“The support of the patient advocacy organizations has been fundamental for the advancements on ME/CFS research and health care. I would suggest the most restrict definitions for the reasons stated above. However, I would not single out any of them, as each of them have strong and weak points.”



"I don't think patient advocacy organizations are qualified to advocate for a particular set of diagnostic criteria." [Added to "I do not think patient advocacy organizations should advocate..." in tallying but included here to note the difference.]

"Tempted to say advocacy orgs should abandon advocating for any one criteria, but how we define the disease is important. It's more the snafu it creates with patients. My sense is that the criteria has become more of a sense of identity for patients than anything related to research or clinical work, and that a lot of people are being misled re: what constitutes evidence"