

# US panel redefines chronic fatigue syndrome

Recommendation to change name to systemic exertion intolerance disease ignites controversy.

Sara Reardon

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The mysterious disease known as chronic fatigue syndrome (CFS) has long defied classification, because the symptoms vary greatly in the millions of people who are affected by it. Now, a panel commissioned by the US Department of Health and Human Services (HHS) has produced what is sure to be an influential report on how the disease should be diagnosed. The guidelines come with a new moniker: systemic exertion intolerance disease (SEID).

The report, released by the US Institute of Medicine (IOM) on 10 February, says that the new name better reflects the key symptom of the disease — the body's inability to tolerate any exertion. It argues that other symptoms, such as cognitive impairment, are secondary. But some experts are already challenging the changes.

Leonard Jason, a psychologist at DePaul University in Chicago, Illinois, expects that patient advocacy groups will find fault with the name, and feel that they were not adequately consulted. “As a community psychologist who values citizen participation in critical decisions, I think this was a strategic mistake,” he says.

By contrast, members of the IOM panel say that the name should help people who are affected by the disease, the existence of which has long been doubted and even mocked. “If I never hear another person say ‘I’m chronically fatigued too’, it won’t be too soon,” says committee chair Ellen Wright Clayton, an expert on law and genetics at Vanderbilt University in Nashville, Tennessee.

## Widespread scepticism

Research has shown that even many physicians are sceptical about the existence of CFS, and most do not know how to diagnose it<sup>1</sup>. More specific criteria should address that problem. “That will in the end get more people cared for and treated,” says Peter Rowe, a paediatrician and chronic-fatigue expert at Johns Hopkins Children’s Center in Baltimore, Maryland, and a member of the IOM panel.

The report also attempts to simplify the diagnostic criteria, addressing concerns that previous definitions were too complex. For instance, people who have a mental illness can be diagnosed with SEID; they had been excluded from a CFS diagnosis because fatigue is also a symptom of depression.

Patients and researchers are universally thrilled about one aspect of the report: its definitive statement that the disease is real. It even recommends that SEID be entered into the *International Classification of Diseases* — the book that physicians around the world use to make diagnoses. A patient at the IOM press conference described that as “the best thing that’s happened to me” since her CFS diagnosis years ago.

Still, Derek Enlander, a physician in New York City who specializes in chronic fatigue syndrome, worries that the revised criteria are too broad, and will result in too many patients being diagnosed. And the new name, he says, is bound to confuse patients, physicians and researchers, especially those who are not familiar with the condition.

Enlander says that the HHS, which spent US\$1 million on the report, is likely to adopt the new definition. But the debate over the diagnostic criteria is sure to continue. “This is round one,” Jason says.

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## Clarifications

**Clarified:** An earlier version of this story implied that psychological diseases are not real. This implication has now been removed.

## References

1. Bayliss, K. *et al. BMC Fam. Pract.* **15**, 44 (2014).