SNOMED CT Report Two | September 2020

In the ME Global Chronicle's March 2020 issue, I reported on a request submitted in November 2019 for addition of the term "Systemic exertion intolerance disease" to the SNOMED CT terminology system.

The SNOMED CT terminology is a systematically organised computer processable collection of medical terms used in electronic medical records, clinical documentation and data reporting.

SNOMED International has 39 member countries and SNOMED CT is the recommended terminology system in the UK, US, Canada, New Zealand and Australia.

For NHS England, SNOMED CT UK Edition is the mandatory terminology system for use at the point of care across all primary and secondary healthcare settings.

Request #30104 (submitted November 30, 2019) requested addition of the term, "Systemic exertion intolerance disease" as a Synonym under the existing SNOMED CT Concept: 52702003 Chronic fatigue syndrome.

The brief rationale text in support of this request can be read on the NHS Digital Request Submission Portal, here: http://bit.ly/39Pz4vy

NHS Digital, who manage the SNOMED CT UK Edition, had referred the request on to SNOMED International's terminology leads for their consideration.

After drawing attention to this request on Twitter, a senior member of SNOMED International's team contacted me and confirmed that NHS Digital had submitted the request for consideration for addition to the SNOMED CT International Edition.

I was advised that this request had already been processed and pending any further changes, was scheduled for implementation in the International Edition's July 2020 release.

(Note: If the term "Systemic exertion intolerance disease (SEID)" was added to the International Edition, the term would then be absorbed by the various national editions when they released their next updates.)

I outlined my concerns about the potential addition of the (unadopted) SEID term to the SNOMED CT system and these were passed back to SNOMED's terminology specialists for their consideration. I also provided a copy of the report prepared for the ME Global Chronicle's March 2020 issue.

You can read a copy of that report here: **NHS Digital requests addition of SEID to SNOMED CT**: http://bit.ly/2wdYVij

In early June, I was advised that the information I provided had been reviewed by the terminology team; that the team now considered it would be premature to add "Systemic exertion intolerance disease" to SNOMED CT; that approval of this request had been retracted and SEID would not be included in the July release.

This decision is documented on a SNOMED CT internal production page (see last entry under heading: **Concepts to be removed completely from the Alpha release content**): https://bit.ly/2Xed60V

The July 2020 release was published on July 31: https://bit.ly/39HA1a2

I can confirm that the two Synonyms terms that had been added under 52702003 Chronic fatigue syndrome for the Alpha production release:

- 3902795018 SEID systemic exertion intolerance disease
- 3902796017 Systemic exertion intolerance disease

were removed for the finalised July 2020 release.

In the event of a request for a change or addition to SNOMED CT not being accepted there is an appeals process and the submitter may request a further review of the decision.

SNOMED International confirmed that NHS Digital did not submit an appeal against their decision not to add SEID to the finalised July release.

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Update to SNOv2 Last updated: 18.11.20