

From: MAR, Countess
Sent: 18 June 2015 08:54
To: 'Wooler Elaine (HEALTH AND SOCIAL CARE INFORMATION CENTRE)'
Subject: RE: 947068 - Chronic Fatigue Syndrome

Dear Ms Wooler

Thank you very much indeed. The ME community will be most grateful to you.

With kind regards
Margaret Mar

From: Wooler Elaine (HEALTH AND SOCIAL CARE INFORMATION CENTRE)]
Sent: 18 June 2015 08:47
To: MAR, Countess
Subject: RE: 947068 - Chronic Fatigue Syndrome

Dear Countess Mar

Thank you for your email. I can indeed confirm that the decision has not changed and the relationship with 74732009 Mental disorder has been retired from 52702003 | Chronic fatigue syndrome (disorder).

Each concept has more than one description in SNOMED to take account of different ways of expressing the same thing. 52702003 | Chronic fatigue syndrome (disorder) has a synonym "ME - Myalgic encephalomyelitis" attached to it so this would meet your requirement below.

The change in the International Edition although published on the IHTSDO website from July will be available in the UK when we publish the six monthly update to the UK Edition on the 1st October 2015. The difference in date is due to the fact the UK Edition includes the International Edition plus UK specific content and authoring of UK specific content takes place at a staggered schedule to the International Edition.

Please let me know if you have any queries or I can be of any further help.

Kind regards
Elaine

From: MAR, Countess [<mailto:MARM@parliament.uk>]
Sent: 17 June 2015 16:09
To: Wooler Elaine (HEALTH AND SOCIAL CARE INFORMATION CENTRE)
Subject: RE: 947068 - Chronic Fatigue Syndrome

Dear Ms Wooler

Thank you for your positive response to my request.

I am writing to you now, as July is fast approaching, to ask whether you will confirm that this decision has not changed and, as the condition is universally known as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) or CFS/ME – see the attached paper, whether it would be possible to incorporate ME in 52702003 rather than leaving it just as CFS. I look forward to hearing from you.

With kind regards
Margaret Mar

From: Wooler Elaine (HEALTH AND SOCIAL CARE INFORMATION CENTRE)
Sent: 20 March 2015 12:52

To: MAR, Countess

Subject: RE: 947068 - Chronic Fatigue Syndrome

Dear Countess Mar

Further to the international review of the representation of ME - Myalgic encephalomyelitis in SNOMED concept 52702003 | Chronic fatigue syndrome (disorder). IHTSDO have advised that the relationship with 74732009|Mental disorder (disorder) has been retired from the concept as requested.

52702003|Chronic fatigue syndrome (disorder) now is a subtype of 281867008|Multisystem disorder (disorder). In addition 51771007|Postviral fatigue syndrome (disorder) has been removed as a subtype of 52702003|Chronic fatigue syndrome (disorder).

IHTSDO always add the caveat that this may be subject to change until the time of release in July 2015. I will confirm the change at that point.

I think this will meet with your expectations but if you have any further queries please let me know. Thank you for highlighting this issue to enable a true representation of current clinical knowledge in the terminology.

Kind regards

Elaine Elaine Wooler

Advanced Clinical Terminology Specialist

[UK Terminology Centre](#)

[Health and Social Care Information Centre](#)

From: Liburd Leon (HEALTH AND SOCIAL CARE INFORMATION CENTRE)Sent: 13 November 2014 08:4

To: MAR, Countess

Subject: REF: 947068 - Chronic Fatigue Syndrome

Dear Countess MAR

Thank you for your enquiry to the information standards helpdesk.

We can confirm your observation that Chronic fatigue syndrome

(disorder) (synonym: Myalgic encephalomyelitis) SNOMED CT concept id

52702003 is indeed currently classified in the international data of

SNOMED CT as a kind of 74732009 | Mental disorder (disorder). A

historical review of the data suggests that this has been the case since

the July 2002 release.

Recognising that this may not be the prevailing expert clinical view

(and noting that SNOMED CT's design allows changes to be made when

errors are detected) the UK Terminology Centre would be happy to

forward this request for change to the owners of the International

content of SNOMED CT (organisation named IHTSDO) on behalf of the

enquirer. The IHTSDO content team would consider the classification of

Chronic fatigue syndrome and a review of the acceptability of all the

currently assigned synonyms.

It is also noted that the corresponding representation in the UK's Clinical Terms Version 3 terminology product Xa01F | Chronic fatigue syndrome is classified as both a Neurological disorder and a Mental health disorder. As such, any conclusions emerging from the SNOMED CT discussions would also be reflected in the CTV3 UK product.

Regards

Leon

Leon Liburd

Senior Support Analyst

Systems and Service Delivery

Health and Social Care Information Centre