

## Til Folketingets Sundhedsudvalg

**Vedrørende:** Anerkendelse af lidelsen Multiple Chemical Sensitivity (MCS)

**Bilag:** 4 stk.

**Kopi:** Sundhedstyrelsen

4. januar 2010

I forlængelse af MCS-Danmarks foretræde for Folketingets Sundhedsudvalg den 9. december 2009 henvender vi os hermed med en skrivelse med henblik på en Ministerudtalelse vedrørende anerkendelse af lidelsen Multiple Chemical Sensitivity (MCS).

MCS er anerkendt som en fysisk lidelse i en række lande.

Tyskland, Østrig, Schweiz og Luxemborg har anerkendt lidelsen efter WHO's ICD-10 liste, kode nr T 78. 4, Allergy non specified (se bilag).

Tysklands DIMDI (German Institute of Medical Documentation and Information), der er anerkendt af WHO (se bilag), har lavet en tillægsliste/udvidet liste til ICD-10 listen. Denne hedder ICD-10 GM. De øvrige Europæiske lande, der har anerkendt MCS, benytter sig, helt i overensstemmelse med WHO, af denne tyske liste ICD-10 GM.

Japan har ligeledes lavet en revideret ICD-10 liste, og Medis-DC (Medical Information System Development Center) har offentliggjort, at man pr. 1. okt. 2009 har anerkendt lidelsen efter ICD-10, kode T 65.9, Toxic effects of unspecified substances and hypersensitivity (se bilag).

Baggrunden for anvendelsen af forskellige koder er, at man endnu ikke kender lidelsens præcise årsagssammenhænge. Men MCS er en yderst velbeskrevet lidelse og heraf dens optagelse på de reviderede ICD-10 lister. Den første gennemførte beskrivelse af lidelsen fremkom i 1987. Denne beskrivelse er fortsat i overensstemmelse med nuværende studier.

Der er lavet adskillige befolkningsundersøgelser, Canada, USA, Sverige, Japan, Danmark, Italien, Tyskland, Australien, der alle påviser det samme symptombillede og sygdomsudløsende faktorer, og stort set de samme definitioner af lidelsen fremkommer.

Ligeledes viser de alle, at et sted mellem ca. 0,5 % - 3 % af befolkningen lider af MCS.

Fra den danske befolkningsundersøgelse, foretaget af Videncenter for Duft- og Kemikalieoverfølsomhed, ved vi, at mindst 17.000 danskere lider af MCS i så svær grad, at det påvirker deres sociale liv og deres arbejdsliv.

I Danmark er MCS ikke klassificeret og anerkendt, hvilket har den konsekvens, at MCS-ramte har meget svært ved at blive korrekt diagnosticeret, og ved at få den hjælp, de har behov for fra såvel offentlige instanser som eget sociale netværk. Også for sundhedssystemet er den manglende anerkendelse en belastning, idet MCS-ramte i årevis sendes til forskellige speciallæger med henblik på en udredning, som ofte er forgæves.

Mange MCS-ramte i Danmark lever i dag under helt uacceptable vilkår. Vi er dagligt i kontakt med MCS-syge mennesker, der må leve af kontanthjælp i op til 5-6 år. Andre må bo i campingvogn i årevis fordi indeklimaet i deres boliger gør dem syge; og mange MCS-ramte er på sammenbruddets rand, da de pga. sygdommen har mistet deres helbred, arbejde, økonomi og bolig, uden at have udsigt til at kunne få nogen form for hjælp.

Vi finder det helt utilladeligt og uforståeligt at dette forekommer, når vi har at gøre med en lidelse, der er så velbeskrevet og med dokumentation for dens invalideringsgrad.

Vi opfordrer derfor til at Danmark anerkender/klassificerer MCS ved, som de andre mindre Europæiske lande, at anvende Tysklands, eller som en anden mulighed Japans, reviderede ICD-10 liste.

Venlig hilsen  
MCS - Danmark

Formand  
Esther Egeriis  
og  
Bestyrelsesmedlem  
Ellen Vibede Destremau

## **DIMDI confirmed as WHO Collaborating Centre for International Classifications**

Jun 18, 2008

The World Health Organisation has confirmed the German Institute of Medical Documentation and Information as a WHO Collaborating Centre for the Family of International Classifications. The appointment valid for the next four years is the result of the successful work undertaken by the Institute and underlines the years of expertise it has acquired in this area.

“We are very proud of the clear expression of appreciation by the WHO for our work, confirming as it does that we are experts in the area of medical classifications and terminologies for medical and information technology interfaces”, said Dr. Dietrich Kaiser, Director of DIMDI, of the renewal of the Institute's appointment as a WHO Collaborating Centre.

DIMDI was appointed WHO Collaborating Centre for the Family of International Classifications for the first time in 2003. This constituted institutional recognition of the many years of work performed by DIMDI in the field of national and international classifications.

“Standardised terminologies and classifications are essential tools for the unambiguous exchange of data in modern medicine”, says Dr. Michael Schopen, Director of the WHO Collaborating Centre and Head of DIMDI's Medical Information department, whose many years of classification work are the reason for the appointment by the WHO.

The Family of International Classifications encompasses the International Classification of Diseases (ICD), the International Classification of Functioning, Disability and Health (ICF) and the associated International Classification of Diseases for Oncology for the codification of tumour diseases.

Apart from translation and carrying out year-round reviews, DIMDI works on the ongoing development and use of classifications, on the development of methods for the application of these as well as examining relations to other terminologies and nomenclatures. DIMDI plays an active role in international methods for quality assurance and the development of teaching materials and courses.

DIMDI is therefore actively involved in numerous working groups of the WHO Collaborating Centres for classifications: in the WHO FIC Council, the Update Reference Committee, the Mortality Reference Group, the Morbidity Reference Group, the Family Development Committee, the Education Committee and the Implementation Committee. DIMDI chairs the Electronic Tools Committee (ETC), which plays a supporting role to the WHO in the development and provision of electronic tools for classifications. The Institute is currently working on the development of a Classification Tool Kit for the administration and continued development of classifications.

DIMDI provides high quality information for all health care areas. It develops and operates database-supported information systems for drugs and medical devices and is responsible for a programme that evaluates medical procedures and technology (Health Technology Assessment, HTA).

DIMDI is the publisher of official medical classifications such as ICD-10-GM and OPS (German procedure classification) and maintains medical terminologies, thesauri, nomenclatures and catalogues (e.g. MeSH, UMDNS, Alpha-ID, LOINC, OID) that are important for health care telematics and other applications.

DIMDI facilitates online access to its information systems and 70 databases covering the entire field of medicine. It also develops and maintains software applications and operates its own data processing centre

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Ihr Zeichen:  
Ihre Nachricht vom: 13. August 2008

Aktenzeichen DIMDI: K10.105  
(Bei allen Antworten bitte angeben!)  
Nachricht vom:

Ansprechpartner/in:  
Dr. Ursula Küppers  
Durchwahl: - [redacted]  
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#### Klassifizierung von MCS in der ICD-10-GM

Sehr geehrter Herr [redacted],

die o.g. Erkrankung wird in der ICD-10-GM wie folgt klassifiziert:

MCS (Multiple Chemical Sensitivity) wird klassifiziert unter:  
T78.4 ... Allergie, nicht näher bezeichnet;  
Kapitel 19 (Verletzungen, Vergiftungen und bestimmte andere Folgen äußerer Ursachen), Abschnitt T66-T78 (Sonstige und nicht näher bezeichnete Schäden durch äußere Ursachen)

Eine Zuordnung der MCS zum Kapitel 5 (Psychische und Verhaltensstörungen) ist seitens der ICD-10 nicht vorgesehen.

Mit freundlichen Grüßen  
Im Auftrag

Dr. Ursula Küppers  
Arbeitsgruppe Medizinische Klassifikationen

4. September 2008

Japansk anerkendelse af MCS.

"Der er gode nyheder.

Den 1. oktober 2009, offentliggjorde Medical Information System Development Center (Medis-DC), et datterselskab organisering af sundhedsministerium Labor and Welfare (MHLW) den reviderede liste over [ICD-10](#) Japansk Standard Sygdomme Code Master i hvilken MCS er kategoriseret i T65.9: Giftig effekt af andre og uspecificerede stoffer / Giftig effekt af uspecificerede stof.

Det er nu klart anerkendt i Japan, at MCS er IKKE en psykisk sygdom, men en fysisk sygdom." .....

[www.csn-deutschland.de/mcs\\_class.pdf](http://www.csn-deutschland.de/mcs_class.pdf) (google oversættelse)

## The Department of Health of the Austrian Government recognizes MCS – Multiple Chemical Sensitivity as a physical disease

Just like Germany, Austria is now classifying Chemical Sensitivity / MCS – Multiple Chemical Sensitivity as a physical disease under the code T78.4 of the ICD-10 (the register of diseases). The news comes from a recent letter by the Department of Health of the Austrian Government.

### **MCS in the ICD-10 in Germany**

In a letter dated September 4, 2008 the DIMDI, the Cooperation Partner for Germany of the WHO, wrote that [MCS – Multiple Chemical Sensitivity was classified](#) in the register ICD-10 GM which is valid in Germany:

*MCS – Multiple Chemical Sensitivity*

*T78.4...Allergy, not otherwise specified;*

*Chapter 19 (Injuries, Intoxication and certain other outcomes), Article T66-T78 (Other and unspecified injuries caused by external causes).*

### **MCS in Austria recognized as physical disease**

With a letter dated June 24, 2009 regarding “Chemical Sensitivity / MCS – Multiple Chemical Sensitivity (T78.4)”, the Department of Health of the Austrian Government declares that:

In response to your letter dated 4/14/2009 to the Minister of Health Mr. Stoerger, we inform you that the WHO ICD-10 Code modified for Germany from DIMDI is used in Austria as well.

### **Also in Austria MCS is not a psychological disease**

It should be emphasized that the German Institute for Medical Documentation and Information (DIMDI) declared explicitly that there is not any allocation of MCS in Chapter 5 (Mental and behavioural disorders) of the ICD-10-GM. Thus, the debate about MCS as mental illness is at an end.

In Germany doctors who document the diagnosis and the hospital administrations work under the Social Security Code V, which states that the diagnoses have to be made according to the systematic list of ICD-10-GM. Thus, the ICD-10 classification is legally binding.

The Department of Health of the Austrian Government refers in the letter that MCS – Multiple Chemical Sensitivity is recognized in Austria as a physical disease, because also there it will have the code T78.4 in the ICD-10.

**Author:** Silvia K. Müller, CSN – Chemical Sensitivity Network, 26. June 2009

### **References:**

[Bundesministerium für Gesundheit, Chemikalien-Sensitivität / MCS – Multiple Chemical Sensitivity \(ICD-10 T78.4\), 24.06.2009, Wien, Österreich.](#)

[DIMDI Letter to CSN, MCS ICD-10, 04.09.2008](#)

[DIMDI Letter, 04.09.2008](#)