The CISSD Project and CFS/ME

Report on the CISSD Project
(Conceptual Issues in Somatoform and Similar Disorders)

for
Action for ME

Richard Sykes

(Report to be read in conjunction with the Co-ordinator's Final Report)

"An international and expert project supported by AfME"

December 2007

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Summary

The CISSD project (Conceptual Issues in Somatoform and Similar Disorders) started from a personal concern about the problems arising from the fact that CFS or CFS/ME has not yet been officially classified by the World Health Organization (although this is not always appreciated). As a result some psychiatrists and others have claimed that CFS should be considered and classified as a Mental Disorder, specifically as a Somatoform Disorder. This claim has caused great difficulties in doctor-patient communication.

Somatoform Disorders are a category of Mental Disorders, used mainly by psychiatrists, that are characterized by medically unexplained physical symptoms. There are, however, many systematic difficulties with the category. An appreciation of these difficulties led to the idea of a project that would investigate the whole field of Somatoform Disorders, rather than just CFS alone. The project would be international and interdisciplinary, open to all with a professional interest in the field and designed to explore difficulties on a collaborative and open basis, rather than to promote a particular point of view.

The project operated from 2003 to 2007. From modest beginnings as an unofficial project with a very limited budget, the project developed into a high calibre enterprise. It succeeded in recruiting 44 participating consultants internationally, many of whom were leading experts in the field. Its achievements include the publication of several articles in medical journals and a published final report, in which several recommendations are made and some key issues are highlighted for further consideration.

Some of these recommendations and key issues are very relevant and important for CFS. For example, one recommendation is that the category of Undifferentiated Somatoform Disorder be deleted. This is the proposed "pigeonhole" for CFS among Somatoform Disorders. An example of a key issue highlighted is the extent to which the views of patients should be taken into consideration. Up to now it has generally been considered that the classification of diseases and disorders was the exclusive terrain of doctors.

The final impact of the project will not be known until the international revisions are produced from 2012 onwards. In the meantime there are good reasons for thinking that the CISSD project will be influential in shaping final decisions about the category of Somatoform Disorders overall. The project's recommendations were backed by detailed arguments and were supported by leading experts, several of whom are directly involved in revising the international classifications. They have the potential to make a significant contribution to future international communication and research in this field.

For similar reasons it is likely that the project will also be influential in shaping final decisions about CFS. One important product of the CISSD project is to increase the likelihood that CFS will eventually be classified as a "general medical condition" (as a physical disorder), rather than as a mental disorder.

The support of Action for ME is gratefully acknowledged.

1. Introduction

Background

There is a major problem for people with CFS/ME that arises from the claim, made by many psychiatrists and others, that CFS/ME should be regarded and classified as a Mental Disorder, specifically as a Somatoform Disorder. This claim has caused great offence and concern to patients and has often led to major difficulties in doctor-patient communication. Patients generally consider that their illness is a physical disorder and that to regard it a mental disorder leads to medical misunderstanding and mistreatment.

("CFS" will frequently be used in this report interchangeably with "CFS and CFS/ME". "CFS /ME" is the preferred term in the UK, while "CFS" is used internationally.)

These disputes were the starting point for the CISSD project. They led to questions such as "Why should CFS be considered a Somatoform Disorder?", "What precisely are Somatoform disorders?, How are they described and defined? Why should they be considered Mental Disorders? Etc.

In trying to find answers to these questions, it became clear that there were many complex issues involved and that the answers were not simple.

Aim of project

The CISSD Project was set up to investigate and provide a background report on Conceptual Issues in Somatoform and Similar Disorders. Its aim was to help towards providing a clearer, more practical and more generally acceptable classification of those conditions now classified as Somatoform Disorders

Somatoform Disorders and the International Classifications

Somatoform Disorders are a class of Mental Disorders that are listed in the two main internationally used classifications of Mental Disorders – the International Classification of Diseases (ICD) produced by the World Health Organization (WHO) and the Diagnostic and Statistical Manual (DSM) produced by the American Psychiatric Association (APA).(See also Appendix A.)

While ICD is a classification of all diseases and disorders and is intended for use worldwide, DSM is concerned with "Mental Disorders" only, and is primarily designed for use in the USA. Nevertheless DSM has established a very high reputation and is often used, both in Europe and internationally, in preference to the ICD section on "Mental and Behavioural" Disorders.

For practical and operational reasons, the two main international classifications are only rarely reviewed and revised. However, a major review is to be undertaken from 2012

onwards, which presents an opportunity for input from major stakeholders. This project was an attempt to provide such input.

Mental and Physical Disorders

In ICD every disease or disorder is listed either in the section on "Mental and Behavioural" Disorders or it is listed elsewhere in ICD. One general term that is used to refer to disorders listed in other sections of ICD is the term "General Medical Condition". For ICD there is thus a contrast between "Mental and Behavioural Disorders" and "General Medical Conditions".

"Mental and Behavoural Disorders" is often shortened, both popularly and by DSM, to simply "Mental Disorders". For "General Medical Condition" a popular equivalent is "Physical Disorder".

This yields a contrast between "Mental Disorders" and "Physical Disorders". The contrast is both exhaustive and exclusive. It is exhaustive in that there are no other types of disorders besides mental disorders and physical disorders. It is exclusive in that no disorder can be both a mental and a physical disorder (Note 2). Consequently any considerations which weaken the claim for a disorder to be classified as a mental disorder implicitly strengthen the claim for it to be considered a physical disorder.

CFS and the International Classifications

Despite claims to the contrary, the classification of CFS is still an open issue. CFS and CFS/ME are not mentioned either in the latest edition of ICD (ICD-10), or in the latest edition of DSM (DSM-IV).

It is true that in 2004 permission was given by the WHO for the UK to adapt the WHO classification for the purposes of Primary Care in the UK and that on this basis a classification has been produced for use in the UK which lists CFS and CFS/ME as a neurological disorder. While many consider that this is a step in the right direction, this classification is a UK adaptation only and has not been formally adopted by the WHO. It has no validity in other countries. No formal decision has yet been made by the WHO and it is still an open question what the official WHO classification of CFS and CFS/ME will be in the next revision. (See also App B.)

Need for project

The twofold need for the project has already been indicated. In the first place there is the claim, made by many psychiatrists and others, that CFS should be classified as a Somatoform Disorder. This claim has often led to major difficulties in doctor-patient communication.

Secondly, there are many conceptual and other difficulties with the category of Somatoform Disorders, both with the general category and with individual disorders within the category. These include inconsistencies between ICD and DSM and many other points of confusion or disagreement. (These difficulties have led some psychiatrists and others to call for the whole category to be abolished.)

A classification that was clearer, more practical and more generally agreed could help to resolve the classification disputes in relation to CFS and so help to improve the care of people with this condition. It could also be a significant step forward towards improved international communication and research.

In view of the impending revisions of the international classifications, the timing of the project seemed opportune.

2. Scope and Nature of Project

Salient features of the project include the following:

(a) It was an independent and innovative project. It was not specifically commissioned by the WHO or the APA. It originated from a personal concern about the problems for CFS/ME and the evident confusions and difficulties in the field.
(b) It was a low cost project with a strictly limited budget. CISSD consultants contributed their own time without payment in addition to their usual duties.
(c) The scope of the project was the whole field of Somatoform Disorders rather than purely the classification of CFS/ME.
(d) Its wide scope and limited budget meant that it was a background project, designed to provide helpful suggestions and recommendations on some topics rather than final answers on all issues.
(e) The project was interdisciplinary and international and was thus able to cover a wide range of opinion.
(f) The project was open to all those with a professional interest in the field. The intention and practice was open exploration of the relevant issues rather than the promotion of a particular viewpoint.
(g) Although participation was open to all relevant disciplines, it turned out that, since "somatoform disorders" is a category used mainly by psychiatrists, the large majority of the participants were psychiatrists.

3. Project Activities (See also Co-ordinator's Report.)

The project operated from 2003 to 2007. Its main activities were 3 international and interdisciplinary workshops, email discussion between members and the publication of 9 articles in psychiatric journals, including a final report summarizing the project's discussions and recommendations. This report was published in the July /August 2007 issue of the psychiatric journal *Psychosomatics.*

In addition to coordinating the CISSD project and taking part in the CISSD workshops, my own activities have included travel to meet the main international figures involved in these issues and the organization of a separate workshop on CISSD topics as part of an international conference in Croatia. In addition I gave two presentations at that workshop and further presentations at two other international conferences (in Germany and The Netherlands) and at professional conferences in London, Oxford and Leeds (See App C). I have also produced the co-ordinator's report on the project.

4. Achievements

The achievements of the project can be assessed (a) in terms of its overall achievements and (b) in terms of its achievements in relation to CFS.

Overall achievements

From modest beginnings the project developed into a high calibre project. It was chaired by Professor Kurt Kroenke, perhaps the foremost international researcher in the field of symptoms that are not well understood. It succeeded in attracting many of the leading international experts on the topic. Including the 5 members of the organizing group, there were 44 "active" or "advisory" consultants. (For a list of participating consultants, see App D).

The project was marked by rationality and mutual respect. When opinions differed, as they frequently did, arguments were exchanged in a rational manner. This is strikingly different from many previous discussions where the nature of CFS/ME has been debated with psychiatrists, which have frequently yielded more heat than light. This atmosphere of rationality and mutual respect led to discussions that were productive as well as informative for participants (See Appendix E for some comments from participants).

In view of the way in which the project was set up, there was no attempt to thrash out complete or final answers to all the many and diverse problems associated with the category of Somatoform Disorders. Several key issues such as, "What makes a disorder a mental disorder rather than a physical disorder?" were barely touched on. Similarly, on the key issue of "Should the category of Somatoform Disorders be abolished?" no agreement was reached. These important topics await further examination.

Despite the constraints imposed by the scope and nature of the project, the final published report can claim two clear achievements. It made a number of important recommendations and it placed firmly on the international agenda a number of key issues (See App F for a summary of the recommendations). If these recommendations are implemented and if the issues highlighted are given careful consideration, this will result in significant progress towards a clearer, more practical and more generally agreed classification of those conditions now classified as Somatoform Disorders.

Achievements in relation to CFS

As already mentioned, the focus of the project was on the whole field of Somatoform Disorders, rather than on CFS. Nevertheless, three of the recommendations made and two of the issues highlighted are important and relevant to the classification of CFS. They bring out considerations which undermine the case for classifying CFS as a mental disorder and so implicitly support the case for classifying CFS as a physical disorder.

The first of the three recommendations is that the subcategory of Undifferentiated Somatoform Disorder is deleted. This is the main subcategory or "pigeonhole" where some psychiatrists have wished to place CFS. If this pigeonhole is deleted, there is no obvious remaining pigeonhole in DSM-IV in which to place CFS and the way is left clear for re-classifying CFS as a physical disorder. (See also Note 3)

The second recommendation is that, if the category of Somatoform Disorder is retained, some kind of "psychological" criterion should be added to the existing characterization of Somatoform Disorder. This recommendation takes the debate to a deeper level and is somewhat technical. But its immediate effect is to make it more difficult to classify CFS as a Somatoform Disorder. It also has a further, more subtle effect, in that it raises an additional difficulty about the whole category of Somatoform Disorder. Because finding an adequate psychological criterion is likely to prove very difficult, this recommendation in effect adds another argument in favour of dispensing with the whole category of Somatoform Disorder (within which is the subcategory of Undifferentiated Somatoform Disorder) and so removing the suggested pigeonhole for CFS.

The third recommendation is that, if possible, language that gives offence to patients should be avoided. This recognition that the perspective of the patient should be taken into consideration could lead to discarding terms such as "pseudoneurological", "doctor-shopping" and similar derogative terms which have been applied to the symptoms and behaviour of people with CFS.

The first issue that that was placed clearly on the agenda for discussion was whether the whole category of Somatoform Disorders should be abolished. Since the abolition of the whole category would remove the pigeonhole for CFS, this is clearly very relevant..

The second issue that was highlighted was the extent to which the views of patients should be taken into consideration in drawing up formal classifications of disorders. Until very recently the classification of disorders has generally been considered a purely professional issue. Since patients with CFS tend to have strong views that CFS should not be considered or classified as a mental illness, this is also very relevant.

5. Impact

Overall impact

The ultimate test of the overall impact of the project will lie in how many of the project's recommendations are incorporated in the next revisions of ICD and DSM and in what answers are given to the issues that have been highlighted. This will not be known until 2012 or later when the revised classifications are produced. .

In the meantime, in attempting to assess the likely impact of the project, the constraints within which the project operated need to be kept in mind. This was an unofficial project with a restricted budget which aimed to make a limited background contribution to a complex task.

Despite its limitations, there are reasons for thinking that the impact will be considerable. In the first place the changes proposed have been backed by careful arguments and these have been tested in high-level discussions. Secondly, the recommendations were backed by the large majority of the participants, among whom were many of the foremost international experts in the field. Thirdly, seven of the CISSD project participants have now been invited to join the formal DSM revision groups. Fourthly, many of the consultants, including myself, have been involved in other workshops and conferences internationally and will continue to be involved in further international conferences

Impact in relation to CFS/ME

Although the focus of the project was Somatoform Disorders in general rather than CFS, the project is likely to have significant influence on the classification of CFS. Some of the difficulties in classifying CFS as a Somatoform Disorder, and hence a mental disorder, are now appreciated and debated by a large number of the leading experts in the field, several of whom are on the relevant committees that will debate and construct the next revision of DSM-IV. The issue of patient participation is clearly on the agenda and it seems reasonable to expect that the views of patients will be given greater weight than in the past. I was able to make limited personal contributions to this process in discussions with individual experts and with papers presented at international conferences.

While it is not a foregone conclusion that in the next international revisions CFS will be classified as a "general medical condition" or physical disorder and not as a mental disorder, the CISSD project will increased the likelihood that CFS and CFS?ME will be so classified.

6. Concluding Review

In spite of starting as an unofficial project with a limited budget the CISSD Project developed into a high calibre international venture that attracted many of the leading experts in the field. It produced a published report which made a number of recommendations and highlighted some key issues for Somatoform Disorders generally.

Three of its recommendations are relevant and important for CFS and strengthen the case for classifying CFS as a physical rather than as a mental disorder. Two of the key issues highlighted are also very relevant and important.

The final impact of the project will not be known until the international revisions are produced from 2012 onwards. In the meantime there are good reasons for thinking that the CISSD project will be influential in shaping final decisions both about CFS and about the category of Somatoform Disorders overall. The project's recommendations were backed by detailed arguments and were supported by leading experts, several of whom are directly involved in revising the international classifications.

The work of the CISSD project has increased the likelihood that CFS will eventually be classified as a "general medical condition" (as a physical disorder), rather than as a mental disorder. It also has the potential to make a significant contribution to future international communication and research in the field of Somatoform Disorders.

The support of Action for ME is gratefully acknowledged.

Richard Sykes December 07

Notes

Note 1. I am most appreciative of the help given by Professor John Bradfield, former Professor of Histopathology at Bristol University, in compiling this report. In addition, he has made numerous other most valuable contributions as Project Advisor to the CISSD Project.

Note 2. There are, most confusingly, a few exceptions to this rule in ICD-10. For example, Irritable Bowel Syndrome is classified both as a disorder of the Digestive System (K 58) and as a Somatoform Autonomic Function Disorder (F45.32) – a mental disorder.

Note 3. The situation is more complex in ICD-10, since ICD-10 includes, besides Somatoform Disorders, a further possible pigeonhole for CFS/ME. This is the subcategory of "Neurasthenia" which ICD-10 includes in addition to the category of Somatoform Disorders. While the project did not specifically address the problems associated with Neurasthenia, there are some strong objections to the subcategory of Neurasthenia and it is possible that this subcategory will be omitted in the next revision of ICD-10.

Appendices

Appendix A Somatoform Disorders in DSM-IV

DSM-IV introduces the category of **Somatoform Disorders** in the following way:*
"The common feature of the **Somatoform Disorders** is the presence of physical symptoms that suggest a general medical condition (hence the tern *somatoform*)and are not fully explained by a general medical condition, by the direct effects of a substance, or by another mental disorder... .The grouping of these disorders in a single section is based on clinical utility..... rather than on assumptions regarding shared aetiology or mechanism."

The individual somatoform disorders are introduced as follows:*
"**Somatization Disorder** (historically referred to as hysteria or Briquet's syndrome) is a polysymptomatic disorder that begins before age 30 years, extends over a period of years and is characterized by a combination of pain, gastrointestinal, sexual, and pseudoneurological symptoms.
Undifferentiated Somatoform Disorder is characterized by unexplained physical complaints, lasting at least 6 months, that are below the threshold for a diagnosis of Somatization Disorder.
Conversion Disorder involves unexplained symptoms or deficits affecting voluntary motor or sensory functions that suggest a neurological or other general medical condition. Psychological factors are judged to be associated with the symptoms or deficits.
Pain Disorder is characterized by pain as the predominant focus of clinical attention. In addition psychological factors are judged to have an important role in its onset, severity, exacerbation or maintenance.
Hypochondriasis is the preoccupation with the fear of having, or the idea that one has, a serious disease based on the person's misinterpretation of bodily symptoms or bodily functions.
Body Dysmorphic Disorder is the preoccupation with an imagined or exaggerated defect in physical appearance.
Somatoform Disorder Not Otherwise Specified is included for coding disorders with somatoform symptoms that do not meet the criteria for any of the specific Somatoform Disorders."

*From *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*, Washington, DC. American Psychiatric Association, 1994.

(The characterisation of Somatoform Disorders in ICD-10 is along the same lines though there are some important differences.)

Appendix B How does the WHO currently classify CFS/ME?

"CFS/ME" (Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis or Myalgic Encephalopathy) is the composite name used by the UK Department of Health and other organizations to refer to a condition that has been named and defined in a variety of ways. Generally speaking, "CFS" tends to be preferred by health professionals, "ME" by patients.

Background
The main WHO (World Health Organization) classification of diseases and disorders is the *International Statistical Classification of Diseases and related Health Problems* (ICD). This classification is a classification of all disorders and related health problems and contains one chapter, chapter V, which is concerned solely with "mental and behavioural disorders". The classification is revised periodically: the latest revision is the tenth revision (ICD-10) which was published in 3 volumes; *Vol I: A Tabular List* in 1992, *Vol 2: Instruction Manual* in 1993 and *Vol 3: Index* in 1994.

Also produced from 1992 onwards was a separate series of volumes that dealt solely with mental and behavioural disorders, the subject of chapter V of ICD. Although the glossary provided by chapter V of ICD was considered adequate for use by coders or clerical workers, it was not recommended for use by health professionals. The first and central volume of the additional series was *The ICD-10 Classification of Mental and Behavioural Disorders. Clinical descriptions and diagnostic guidelines (CDDG),* produced in 1992, which was intended for general clinical, educational and service use. (Other volumes in this series included *The ICD-10 Classification of Mental and Behavioural Disorders. Diagnostic Criteria for Research (DCR),* and *Diagnostic and Management Guidelines for Mental Disorders in Primary Care: ICD-10 Chapter V Primary Care Version.)*

Is CFS/ME classified as a neurological or as a mental disorder in ICD-10?
CFS and CFS/ME are not listed in ICD-10 and of the 4 related conditions that are listed (post-viral fatigue syndrome, benign myalgic encephalomyelitis, neurasthenia, fatigue syndrome), 2 are listed as neurological disorders and 2 as mental disorders. On the one hand "post-viral fatigue syndrome" is classified as a neurological disorder with the code number G33.3. In CDDG this is said to include "benign myalgic encephalomyelitis". Although the adjective "benign" has long since been dropped and although most users of the term *ME* now say that *ME* should stand for *Myalgic Encephalopathy*, rather than *Myalgic Encephalomyelitis* (since there is no evidence of encephalomyelitis), this would appear to be a good reason for saying that ME is implicitly classified as a neurological disorder. (Since G33.4 is the code for encephalopathy, it would seem that this code rather than G33.3 is now the more appropriate code for ME.)

On the other hand "neurasthenia" is classified as a neurotic disorder with the code number F48.0 and CDDG states that this includes "fatigue syndrome". So it could be argued that CFS should be classified as a neurotic, and hence, a mental disorder. A case could also be made for coding some cases of CFS as F45 Somatoform Disorders, either as F45.1, the code for Undifferentiated Somatoform Disorder or as F45.3, the code for Somatoform Autonomic Dysfunction, or as F45.9, the code for Somatoform Disorder, Unspecified. All these are codes for mental disorders.

This presents a problem for CFS/ME. If ME is stressed, then it could be argued that CFS/ME should be classified as a physical disorder, since benign myalgic encephalomyelitis is classified as a neurological disorder. On the other hand, if Chronic Fatigue Syndrome is stressed then it could be argued that CFS/ME should be classified as a mental disorder, since fatigue syndrome is classified as a neurotic disorder.

Developments since 1992

In 2004 the *WHO Guide to Mental and Neurological Health in Primary Care, Second Edition*, was published by the Royal Society of Medicine Press. This was described on the cover and in the frontispiece as "Adapted for the UK, with permission, from *Diagnostic and Management Guidelines for Mental Disorders in Primary Care: ICD-10 Chapter V Primary Care Version.*".

In this volume the main term used is Chronic Fatigue Syndrome (CFS), which is said to be also referred to as ME (Myalgic Encephalomyelitis or Myalgic Encephalopathy) or as CFS/ME, and this is coded as G93.3. G.93.3 is the code for post-viral fatigue syndrome, a neurological disorder.

So does this settle the matter? Is CFS/ME now officially classified by the WHO as a neurological, not as a mental disorder?

Unfortunately the matter is not quite so simple, for a number of reasons. In the first place the 2004 publication is described as "adapted for the UK, with permission". This means that it is not applicable in countries outside the UK, in Germany or France etc.. It does not have international applicability. Secondly, even in the UK it applies only to Primary Care (GP level). It does not claim to be applicable to Secondary Care (hospital level).

Thirdly, even in the UK it does not claim to be an official WHO classification. It is an initiative of the UK WHO Collaborating Centre, one of many of the Collaborating Centres worldwide, and is backed by the English Department of Health and a number of other organizations and individuals. It is not an authoritative WHO classification but is intended simply to provide helpful recommendations which UK GPs may use or not use as they wish. In the UK a GP may use any of a number of competing classifications. These include the International Classification of Health Problems in Primary Care (ICHPPP), the Read Codes, and a triaxial classification. They can also choose not to use a classification system at all.

Summary

"CFS" and "CFS/ME" are not listed in ICD-10 and this leaves room for debate as to how they should be listed. The UK WHO Collaborating Centre, with the support of the Department of Health and other organizations, proposed in 2004 that they should be coded as G33.3, the code for a neurological disorder. These proposals are undoubtedly encouraging for the ME patients' organizations, who will hope that this initiative will be confirmed in the next revision of ICD-10, but they are not yet official recommendations by the WHO. There remains confusion and debate about how CFS/ME fits in to the official WHO classification.

A note on DSM-IV.

DSM-IV is the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, produced by the American Psychiatric Association. It has been extensively researched and is in widespread use worldwide.

In DSM-IV there is equally no mention of CFS, but neurasthenia is mentioned and is subsumed under Undifferentiated Somatoform Disorder, one of the Somatoform Disorders. There is an extensive overlap between the symptoms of neurasthenia and of CFS and consequently some argue that this is where CFS should be placed. Against this it could be argued that CFS or ME or CFS/ME should be classified as G93.3 in ICD and hence should not have a place in a manual of mental disorders at all.

So for DSM-IV, too, there is the same uncertainty as to how CFS/ME should be classified.

Appendix C Presentations by Richard Sykes at Professional Conferences

1. 28 June 2005 Leeds
Distinguishing between mental and physical disorder. Some proposals.
At the Conference "The concept of Disease" sponsored by the British Society for the Philosophy of Science, the Society for Applied Philosophy and the University of Leeds

2. 17 September 2005 Oxford
The Distinction between physical and mental disorders: Redefine or Discard?
At the Ninth Annual Conference "Reconstructing Consciousness, Mind and Being" of the Consciousness and Experiential Psychology Section of the British Psychological Society

3. 19 May 2006 Heidelberg, Germany
Somatoform Disorders: mental or physical disorders?
At the Congress/Symposium: "Functional/somatoform disorders. Concepts and Management." organized by the Klinik fur Psychosomatische und Allgemeine Klinische Medizin, Heidelberg University

4. 30 September 2006 Cavtat, Croatia
Chair of Workshop on "Conceptual Issues in Somatoform and Similar Disorders".
Presentations: *Emerging proposals from the CISSD project.*
and *Somatoform Disorders.: What are patients concerns and do they matter?*
At the 26th European Conference of Psychosomatic Research.

5. 20 April 2007 London
Conceptual Issues in the Classification of ME/CFS
At the Annual Meeting of the Melvin Ramsay Society.

6. June 2007 Maastricht, The Netherlands
Somatoform Disorders in the DSM V: Physical or Mental Disorders?
At the 13th Triptych Congress, "Psychosomatics in the 21st century" organized by the Department of Psychiatry, Maastricht University

Appendix D List of consultants

Organising Group (5)

Chairman: Prof Kurt Kroenke, Professor of Medicine, Regenstrief Institute, Indianapolis, USA
Co-Chair (UK): Prof Michael Sharpe, Professor of Psychological Medicine, Edinburgh Univ
Principal Collaborator: Prof Rachel Jenkins, WHO Collaborating Centre, Institute of Psychiatry, London Univ
Project Advisor Prof John Bradfield, former Professor of Histopathology, Bristol Univ
Co-ordinator: Dr Richard Sykes, Hon Visiting Research Associate, Institute of Psychiatry, London Univ

"Active" Consultants (28) – who attended one or more of the three workshops or were significantly involved in discussions or publications.

UK (10)
Prof Derek Bolton, Professor of Philosophy and Psychopathology, Institute of Psychiatry, London University
Dr Richard J Brown, Lecturer in Clinical Psychology, University of Manchester
Frankie Campling, Patient Representative, Oxford
Dr Rachel Cooper, Lecturer in Philosophy, Lancaster University
Prof Francis Creed, Professor of Psychological Medicine, Manchester University
Dr Richard Kanaan, Clinical Lecturer, Institute of Psychiatry, London University
Prof Richard Mayou, Professor of Psychiatry, University of Oxford
Dr Ruth Taylor, Senior Lecturer in Liaison Psychiatry, London University
Professor Michael Trimble, Professor of Behavioural Neurology, Institute of Neurology, London
Research Assistant Natalie Banner

USA (7)
Prof Arthur Barsky, Prof of Psychiatry, Harvard Medical School, Boston, Mass.
Dr Charles Engel, Assoc Prof of Psychiatry, Uniformed Services University, Washington, DC
Prof Javier Escobar, Prof of Psychiatry, Robert Wood Johnson Medical School, New Jersey
Prof James Levenson, Prof of Psychiatry, Medicine and Surgery, Virginia Commonwealth University, Richmond, Virginia
Prof Kathryn Rost, Prof in Mental Health, College of Medicine, Florida State University
Dr Robert C. Smith, Prof of Medicine and Psychiatry, Michigan State University, East Lansing, Michigan
Prof Mark Sullivan, Prof of Psychiatry, Washington University, Seattle

Germany (4)
Prof Dr Peter Henningsen, Prof of Psychosomatic Medicine, University Hospital, Munich
Prof Dr Wolfgang Hiller, Psychological Institute, University of Mainz
Prof Dr Bernd Löwe, Director, Institute for Psychosomatic Medicine and Psychotherapy, Hamburg
Prof Dr Winfried Rief, Professor of Psychology and Psychotherapy, Marburg

The Netherlands (5)
Dr Ingrid Arnold, Department of Public Health and Primary Care, Leiden University Medical Center
Dr Veronique de Gucht, Department of Clinical and Health Psychology, Leiden University
Prof dr Stan Maes, Professor of Health Psychology, Leiden University
Prof Dr Philip Spinhoven, Faculty of Social Sciences, Leiden University
Dr Margot de Vaal, Department of Public Health and Primary Care, Leiden University Medical Center

Denmark (1)
Prof Per Fink, Professor of Psychiatry, Aarhus University Hospital

Norway (1)
Dr Kari Ann Leiknes, Research Fellow, Institute of Basic Medical Sciences, Oslo University

"Advisory" consultants (11) – who have offered helpful comments and suggestions.

USA (7)
Prof Caroline Doebbeling, Research Scientist, Regenstrief Institute, Indiana University School of Medicine, Indiana
Dr Michael First, Research Psychiatrist, Biometrics Research Department, New York State Psychiatric Institute, New York, NY

Prof Robert D Martin, Assistant Professor of Psychiatry, Albert Einstein College of Medicine, Long Island Jewish Medical Center Campus, New York, NY
Prof Christian Perring, Associate Professor of Philosophy, Dowling College, Long Island, NY
Dr Claire Pouncey, Cornell Hospital, New York, NY
Prof Jennifer Radden, Professor of Philosophy, Massachusetts University, Boston
Prof John Z Sadler, Professor & Director Undergraduate Medical Education, Dept of Psychiatry, UT Southwestern, Dallas, Texas

UK (2)
Prof Bill Fulford, Professor of Philosophy and Mental Health, Warwick University, Coventry
Prof Peter Campion, Professor of Primary Care, University of Hull

Switzerland (2)
Prof em Dr med Martha Koukkou, University Hospital of Clinical Psychiatry, Bern
Prof Norman Sartorius, WHO Expert Advisory Council, Geneva

Appendix E Some Consultants' Comments

1. "Thanks for all your efforts Richard. You gave birth to CISSD, and now it's graduated and left home, and you should be a very proud father. One very clear measure of the success of CISSD is the number of CISSD participants who have been appointed to the DSM V Somatoform Disorders Work Group (Sharpe, Creed, Barsky, myself). I fully expect more of them will be enlisted as consultants or members of the work group (our first meeting is a week from now in DC)."

James L. Levenson, M.D.
Professor of Psychiatry, Medicine, and Surgery
Virginia Commonwealth University School of Medicine
Box 980268
Richmond, VA 23298-0268, USA

2. "Richard: You are to (be) congratulated on this extraordinary achievement. I hope you will write about your experience of preparing this advice for the DSM process, from the public sector and involving broad involvement. Please keep me appraised of progress, and certainly feel free to ask for my assistance."

John Z. Sadler, M.D.
Daniel W. Foster Professor of Medical Ethics
Professor of Psychiatry & Clinical Sciences
Director, UT Southwestern Program in Ethics in Science and Medicine
Director, Center for Values in Medicine, Science, & Technology
The University of Texas at Dallas
Co-Editor: Philosophy, Psychiatry, & Psychology
Department of Psychiatry

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3. "Congratulations on such a successful and productive project. Let's keep our fingers crossed that DSM-V and other efforts lead to a more rational diagnostic system."

Charles C Engel, MD, MPH
Colonel, Medical Corps, US Army
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F. Edward Hebert School of Medicine
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4. "I am convinced that the discussions within CISSD will, in the end, prove to be helpful also for the patients. I have learned a lot!"

Prof. Dr.med. Peter Henningsen
Head, Dept. of Psychosomatic Medicine
University Hospital of the Technical University
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5. "Many congratulations for putting together such a stimulating programme"

Richard J. Brown PhD, ClinPsyD
Lecturer in Clinical Psychology
University of Manchester

6. "A terrific effort, well done."

Dr Richard Kanaan
Clinical Lecturer
Institute of Psychiatry
London University

Appendix F Main recommendations

Recommendations were made on 3 main types of issues – Category Issues, Terminological Issues, and Stakeholder Issues. The full recommendations are given in the article by Kroenke K, Sharpe M and Sykes R *Revising the classification of Somatoform Disorders. Key Questions and Preliminary Recommendations* in: Psychosomatics July/August 2007; 48:277-285. A very brief summary is given below.

Category Issues

One of the key category issues is whether the whole category of **Somatoform Disorder** should be abolished, as some advocated. Agreement was not reached on this key issue. Consequently, in addition to some unequivocal recommendations, some *qualified* recommendations are made, dependent on whether or not the category of **Somatoform Disorder** is retained.

Unequivocal category recommendations

1. The category of **Pain disorder** should be deleted. All pain symptoms should be coded on Axis III with concomitant psychiatric co-morbidity coded on Axis I.
2. The category of **Undifferentiated Somatoform Disorder** should be deleted.
3. Revised criteria are needed for **Hypochondriasis.**

Qualified category recommendations (Either A or B)

A If the category of **Somatoform Disorder** is retained,

- A1 The criteria for **Somatization Disorder** should be made more inclusive (less restrictive).
- A2 The diagnosis of a **Somatoform Disorder** (or other psychiatric disorder) should not be made solely on the basis that the symptoms of the disorder are medically unexplained. Positive "psychological" criteria are also needed.

Or B If the category of **Somatoform Disorder** is abolished,

- B1 **Hypochondriasis** could be placed with the Anxiety disorders.
- B2 **Conversion Disorder** could be placed with Dissociative disorders.
- B3 **Body Dysmorphic Disorder** could be placed with Obsessive-Compulsive Disorder.
- B4 **Somatization Disorder** could be regarded as a combination of Personality Disorder and Affective or Anxiety disorder.

Terminological Issues

1. Where possible, language that gives offence to patients should be avoided..
2. **"Hypochondriasis"** should be replaced by **"Health Anxiety Disorder"**.
3. Replacement terms are needed for **"Pseudoneurological"**, **"Doctor Shopping"**.
4. The terms **"Somatoform"**, **"Somatization"**, **"Functional"** need review.

Stakeholder Issues

1. An important question is to what extent the views of patients and of non-psychiatric clinicians should be considered.

These recommendations and the July/August 2007 Psychosomatics article (referred to above) will be brought to the attention of the Revision Committees of the WHO and the APA. We trust that they will make a positive contribution to the difficult task of producing a more satisfactory classification of the conditions now classified as Somatoform Disorders.