**The CISSD Project**

## Conceptual Issues in Somatoform and Similar Disorders

**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, Professor of Psychiatry, 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.**
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15.07.08

Dear Nick,

George Armstrong has asked that I send you an additional copy of my report to AfME on the CISSD Project.

A copy is enclosed herewith, together with a copy of my Coordinator's report.

With regards,

Richard

Richard Sykes

## 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.

# THE CISSD PROJECT 2003-2007

**(Conceptual Issues in Somatoform and Similar Disorders)**

**FINAL REPORT OF CO-ORDINATOR (Richard Sykes PhD, CQSW)**

Somatoform Disorders are one of the categories of "Mental and Behavioural Disorders" listed in the tenth edition of the International Classification of Diseases (ICD-10) produced by the World Health Organisation (WHO). They are also one of the categories of "Mental Disorders" listed in the fourth edition of the Diagnostic and Statistical Manual (DSM-IV) produced by the American Psychiatric Association (APA). (For a brief account of Somatoform Disorders in DSM-IV see Appendix 1).

The CISSD (Conceptual Issues in Somatoform and Similar Disorders) project was developed in order to make a background contribution to the complex task of revising the sections on Somatoform Disorders in these two influential and internationally used classifications.

## 1. Impetus for project

The impetus for the CISSD project came from 4 main sources.

The first was the frequent difficulties in communication between doctors and patients about the nature of Chronic Fatigue Syndrome (CFS). These included disagreement as to whether or not CFS should properly be considered a "mental" disorder, falling within the category of "somatoform" disorders.

The second was the evident conceptual confusions and other difficulties surrounding the concept of somatoform disorder. These had led some researchers to call for an abolition of the whole category of somatoform disorders (1).

The third was the background of the co-ordinator, which included work for a charity for people with CFS and prior training and research in linguistic philosophy (Appendix 4)

The fourth was the impending revision of the international classifications, due from 2012 onwards.

From this background it seemed reasonable to expect that there would be major benefits if clarity could be achieved and widespread agreement could be reached about how the conditions now listed as Somatoform Disorders could better be characterised and classified. This could not only facilitate international communication and research but could lead to improved communication between doctors and patients in relation to CFS and similar disorders. This led to the idea of an international and interdisciplinary group to investigate the problems and to make a preliminary contribution towards more satisfactory classifications.

## 2. Aims and evolution of the Project

In the early stages the aims of the project were defined as follows: "The production of a report by an international and multi-disciplinary expert group on *Conceptual Issues in Somatoform and Similar Disorders*. Topics to be discussed include key terms and their definitions and concepts such as psychological association and causation. Wider issues such as the distinction between physical and mental illness will also be considered. The report will set

out the conceptual problems involved, will discuss different possible solutions and will make recommendations. It will be presented to the WHO and the APA by December 2006.".

As discussions developed, they tended to concentrate on the more specialist issues relating to Somatoform Disorders rather than on the wider underlying concepts. Much attention, for example, has been given to the category of Somatization Disorder - whether the category should be retained and, if so, on the need for less restrictive criteria for the disorder.

Additionally, the ending of the project was extended from December 2006 to October 2007.

**3. Membership**

Membership of the project was open to anyone with a professional interest in the subject. The number of consultants and contacts grew from a small nucleus at the start of the project to a total of over 80. Of these, 44 played an organisational or active or advisory role. They settled into four groups. (See appendix 3 for a list of the "active" and "advisory" consultants.)

Organising Group

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

"Active" Consultants

There were 28 "active" consultants who attended workshops, or took part in formal discussions. The majority were Psychiatrists but there were also expert members from Pathology, Primary care, Psychology, and Philosophy. Among this interdisciplinary group were participants from the UK (10), the USA (7), The Netherlands (5), Germany (4), Denmark (1) and Norway (1),). They included researchers, clinicians, a patient representative and a research assistant. Some are already involved in the preparation of DSM-V.

"Advisory" consultants

There were a further 11 "advisory" consultants, from the USA (7), the UK (2) and Switzerland (2). These all discussed the project with the co-ordinator and made helpful comments and suggestions.

"Additional" consultants

The many "additional" consultants all expressed an interest in the project and a willingness to be consulted. Their interest was encouraging and most welcome.

**4. Activities**

There were three formal CISSD Project International Workshops:

- London - May 2005
- Oxford - March 2006
- Indianapolis - May 2006.

Nine CISSD Bulletins have been circulated to consultants and contacts to provide information about project developments and discussions.

A workshop entitled "Conceptual Issues in Somatoform and Similar Disorders" and chaired by the CISSD project co-ordinator, was held at the 27th European Conference of Psychosomatic Research in Cavtat, Croatia, in September 2006.

In addition, several project members have given presentations at international conferences and workshops during the life of the project.

**5. Publications**

From the London 2005 workshop, 8 articles were published in the April 2006 issue of the Journal of Psychosomatic Research. A final article, summarising the project discussions and recommendations, has been published in the July/August 2007 issue of Psychosomatics. (These are listed in Appendix 3).

**6. 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.

## 7. Support and Affiliation

The project was supported by grants from the Wellcome Trust, administered by Edinburgh University and from the Hugh and Ruby Sykes Charitable Trust, administered by the registered charity Action for ME.

As co-ordinator, I held appointments as Hon Visiting Research Associate at the WHO Collaborating Centre, Institute of Psychiatry, University of London and as Consultant to Action for ME.

## 8. Acknowledgements and Appreciation

I would like to express my most appreciative thanks to all those who gave support to the project: to the funding bodies and affiliated organisations for their indispensable support: to Natalie Banner for her most helpful research assistance; to all the consultants who not only most generously donated their time and knowledge but did so in a most friendly and co-operative way.

Most of all, my warmest thanks go to the organising group for their consistent support; to Rachel Jenkins for her invaluable help as Principal Collaborator; to John Bradfield, the Project Advisor, whose patient and perceptive comments on numerous draft documents were invaluable; to Michael Sharpe for his encouragement and work as Co-chair UK; and, above all, to Kurt Kroenke for giving us the benefit of his internationally acclaimed expertise and for chairing the project so vigorously and effectively.

My heartfelt thanks to all.

Richard Sykes PhD, CQSW , CISSD Project Co-ordinator 26.10.07

## References

1. Mayou R, Kirmayer LK, Simon G, Kroenke K, Sharpe M *Somatoform Disorders: Time for a New Approach in DSM-V.* Am J Psychiatry 2005; 162:847-855.

## Appendices

### Appendix 1 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 2 Published articles resulting from the CISSD project**

Levenson JL (Editorial) *A Rose by any other name is still a rose* J Psychosom Res 2006; 60: 325-326.

Bradfield JWB *A pathologist's perspective of the somatoform disorders* J Psychosom Res 2006; 60: 327-330.

Creed F *Can DSM-V facilitate productive research into the somatoform disorders ?* J Psychosom Res 2006; 60: 331-334.

Kroenke K *Physical Symptom Disorder: A simpler diagnostic category for somatization-spectrum conditions* J Psychosom Res 2006; 60: 335-339.

Sykes R *Somatoform disorders in DSM-IV: Mental or Physical disorders?* J Psychosom Res 2006; 60: 341-344.

Hiller W *Don't change a winning horse* J Psychosom Res 2006; 60: 345-347.

De Gucht V, Maes S *Explaining medically unexplained symptoms: Toward a multidimensional theory-based approach to somatization* J Psychosom Res 2006; 60: 349-352.

Sharpe M, Mayou R, Walker J *Bodily Symptoms: New approaches to classification* J Psychosom Res 2006; 60: 353-356.

Kroenke K, Sharpe M, Sykes R *Revising the classification of Somatoform Disorders. Key Questions and Preliminary Recommendations*: Psychosomatics 2007; 48:277-285.

**Appendix 3 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 4 Co-ordinator's background for the CISSD project**

Three factors in the background of the co-ordinator provided a basis for the project.

The first was previous work as director of Westcare UK, a Bristol based charity for people with CFS/ME which operated from 1988 to 2002 and then merged with Action for ME. It adopted a biopsychosocial approach to CFS/ME and provided services on this basis. The experience of our charity was that there was frequently conflict between doctors and patients about the nature of the patient's illness. Most patients thought that their illness had primarily an undiscovered physical cause and should be classed as a physical illness. Some doctors, though, thought that their illness was primarily a mental disorder and that its primary causes were mental – some said that it should be classed as a "somatoform disorder". Conflict on this issue sometimes led to a breakdown in communication between doctor and patient.

The second factor was work on the production of two reports (1,2), jointly authored with Professor Peter Campion, on the interface between physical and mental factors in CFS/ME. During this work it became very clear that there were major problems associated with the category of somatoform disorder and that many of these problems were of a conceptual rather than empirical nature.

The third factor was prior training, teaching and research in linguistic philosophy. Linguistic philosophy is a branch of philosophy which combines an analytic approach with an emphasis on the need to pay very careful attention to the way in which terms and concepts are used. It demonstrates that conceptual problems and disagreements are often resolved when imprecision and ambiguity in language is uncovered and corrected (3).

1. Sykes, R.D. and Campion, P. 2002 *The Physical and the Mental in Chronic Fatigue Syndrome/ME. Principles of Psychological Help.* Bristol: Westcare UK*
2. Sykes, R.D. and Campion, P. 2002 *Chronic Fatigue Syndrome/ME. Trusting Patients' Perceptions of a Multi-dimensional Physical Illness.* Bristol: Westcare UK*
3. For the relevance of linguistic philosophy to psychiatry, see, e.g., Fulford KWM *Philosophy and Medicine: The Oxford Connection.* Br J Psychiatry 1990; 157: 111-115.

Notes

*These reports are available on the Action for ME website: www.afme.org.uk or from Action for ME, Third Floor, Canningford House, 38 Victoria Street, Bristol BS1 6BY