

## COST ACTION CA 15111 reports on the perspective work plans for the next period and realization approaches – WG 1

### Current situation

Background: World Health Organization, Department of Health (UK), Department of Work and Pensions (UK), National Institute for Health and Care Excellence, Medical research Council, Royal Colleges all accept this is a genuine and disabling illness characterized with long term fatigue. Disease is causing significant social and economic burden.

But there is much contention over the etiology, pathophysiology, nomenclature and diagnostic criteria of chronic fatigue syndrome.

Even the numbers of prevalence could be drastically different between different studies: from 7 cases to 3000 persons on 100 000 adults.

### Current situation

Nomenclature is also not uniform:

1. Myalgic Encephalomyelitis,
2. Chronic Fatigue Syndrome,
3. Post Viral Fatigue Syndrome,
4. Systemic Exertion Intolerance Disease

### Current situation

There is over 20 clinical and research definitions: 2003/2011 Canadian criteria, 1994 CDC/Fukuda, 1991 Oxford, NICE and now 2015 IOM)

Epidemiology is the study and analysis of the patterns, causes, and effects of health and disease conditions in defined populations. It is the cornerstone of public health, and shapes policy decisions and evidence-based practice by identifying risk factors for disease and targets for preventive healthcare.

To accomplish this basic role of epidemiology in relation to chronic fatigue syndrome, uniform clinical definition of this syndrome is required.

### Current situation

The most commonly used diagnostic criteria and definition of CFS for research and clinical purposes were published by the United States Centers for Disease Control and Prevention (CDC).

The CDC recommends the following three criteria be fulfilled:

1. A new onset (not lifelong) of severe fatigue for six consecutive months or greater duration which is unrelated to exertion, is not substantially relieved by rest, and is not a result of other medical conditions.
2. The fatigue causes a significant reduction of previous activity levels.
3. Four of 8 or more of other symptoms

### Current situation

To overcome mentioned problems WG-1 planed to:

- Explore of ways to collect population based data on the prevalence of ME/CFS,
- Explore of the potential of existing cohorts,
- Review the characteristics of existing clinical databases maintained by collaborating institutions;
- Survey existing epidemiological data on ME/CFS in participating countries.

## Current situation

Collected data from Norway, Latvia, and United Kingdom are based on:

1. population-based registry data
2. analytical or observational studies
3. cross-sectional prevalence study

## Current situation

Collected data from Norway, Latvia, and United Kingdom are related to following criteria:

1. The Fukuda criteria (CDC)
2. Canadian 2003 criteria
3. Epidemiological Case Definitions

## Current situation

- Recruiting new countries is ongoing activity of WG-1 members.
- Insisting on usefulness of different set of criteria to improve sensitivity with good specificity such as CDC+2011 ME consensus+SEID

Data depositories harmonisation and data collection protocol synchronisation can greatly improve use of existing data, including Open data sources, and allow the development of coherent research strategies.

THANK YOU FOR YOUR ATENTION!

## Current situation

3. Four of the following symptoms that concurrently last six months or longer:
  - Impaired memory or concentration
  - post-exertional malaise, where physical or mental exertions bring on "extreme, prolonged exhaustion and sickness"
  - unrefreshing sleep
  - Muscle pain (myalgia)
  - pain in multiple joints (arthralgia)
  - headaches of a new kind or greater severity
  - sore throat, frequent or recurring
  - Tender lymph nodes (cervical or axillary)

## Current situation

- The CDC states other common symptoms include the following:
  - brain fog (feeling like one is in a mental fog)
  - difficulty maintaining an upright position, dizziness, balance problems or fainting
  - allergies or sensitivities to foods, odors, chemicals, medications, or noise
  - irritable bowel syndrome-like symptoms such as bloating, stomach pain, constipation, diarrhoea and nausea
  - chills and night sweats
  - visual disturbances (sensitivity to light, blurring, eye pain)
  - depression or mood problems (irritability, mood swings, anxiety, panic attacks)