

Minutes from WG 4 meeting, France, Creteil 13th April 2018

Org/host: Elin Strand (leader, Norway) and Jerome Authier (vise-leader France)

Participants: Ruud Vermulen (Netherlands)*, Giorgos Sakkas (Grecce)*, Luis Nacul (UK), Ingrid Helland (Norway), Olli Pollo (Finland), Jose Allegre (Spain), Eliana Lacerda (UK)*, Anne Marit Mengshoel (Norway), Lorenzo Lorusso (Italy), Jerome Authier (France).

*New members from April 2018

Members not able to participate: Patricia Grabowski (Germany), Angelica Krumina (Latvia) and Magdalena Efraim (Romanien).

The following deliverables were discussed:

Deliverable 7 discussion of “Joint publication manuscript on ME/CFS European practices in diagnosis and treatment based on survey data” – deadline 24th month – April 30, 2018.”

Deliverable 11 “Evaluation scales for assessment of neurological symptoms associated with ME/CFS and usable in diagnostic”. Deadline for Deliverable preparation October 31, 2018- Jerome Authier (responsible).

Deliverable 12 “Common strategy protocol for ME/CFS diagnosis: synchronisation between centres, research component integration”

Deliverable 13 (deadline April 30, 2019). Introduction by Jose Allegre: “Stratification of CFS/ME”. Plenary discussion “Protocol and guidelines for ME/CFS subgroups detection (stratification) according to the presence of symptoms and subject to potential biomarkers variation”

During the meeting it was small group discussions as well as presentations and discussions in plenary. In the small groups, both clinical guidelines, use of questionnaires and strategy protocol for the next year were worked out. One post on patient stratification was presented. The article draft and report was reviewed and reorganization and rewriting of these papers were suggested. In addition the review of the neuropsychological aspects was presented and discussed in plenary as well as a research proposal on genetic studies of families with ME/CFS.

The first draft for the clinical guideline and a structure for assessments for research were developed. A strategy protocol was made for the work in WG4 with contents, deadlines and responsible persons for the respective tasks (see overview below). Further cooperating between the members will take place through the use of email, on future Euromene meetings and if necessary, teleconference will be set up.



Strategy protocol:

Tasks	Responsible for draft	First draft	Tele conference dates	Final draft	Synchronised document
Protocol for ME/CFS diagnostic (Includes recommendation for clinical purposes)	<u>Ingrid</u> / Giorgos	1 st Sept 2018	12 th Oct 2018	1 st Nov 2018	30 rd Nov 2018
Protocol for ME/CFS diagnostic (Includes recommendation for research purposes)	<u>Luis</u> /Olli/ Ruud	1 st Sept 2018	12 th Oct 2018	1 st Nov 2018	30 rd Nov 2018
Symptom management and relief (non-pharmacological)	<u>Anne Marit</u> /Giorgos	15 th Dec 2018	15 th Jan 2019	15 th Feb 2019	30 th Apr 2019
Symptom management and relief (pharmacological)	Jose/Olli/ <u>Patricia</u>	1 st Sept 2018	12 th Oct 2018	1 st Nov 2018	30 rd Nov 2018
Public comments (web site)	Lorenzo	16 th feb 2019	15 th March 2019	15 th April 2019	30 th April 2019
D7 Draft: European Landscape on Diagnosis etc for publication	<u>Giorgos</u> , Ruud, Anne Marit	10 th June 2018			
D 11 Draft: Neuropsychological review	<u>Jerome</u> , Jean-Dominique, Ingrid, Elin	1 st August 2018			



D 13 “Protocol and guidelines for ME/CFS subgroups detection (stratification) according to the presence of symptoms and subject to potential biomarkers variation”	WG leaders	Discuss next EUROME NE meeting			
Final WG 4 survey report	Elin	30 th April 2018			
Web side: -minutes from creteil Presentations 12th April 2018: -from Lorenzo, Ingrid, Jerome and Jose -Wg4 report from GP1 -Jasons Youtube presentation from march 2017 Final WG4 survey report	Elin/Lorenzo	May 2018			



