

## **COST action CA15111**

### **European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome**

#### **Minutes of the 13 April 2018 Work Group No 3 meeting**

**WG3 leader: Derek Pheby**

**Work Group No 3:** Socio-economics  
**Date:** Friday 13<sup>th</sup> April (09:00 to 18:00)  
**Location:** Faculty of Medicine – Alain Harf room- 8 rue du General Sarrail, F94000 CRETEIL- CEDEX, FRANCE

In attendance: Derek Pheby (DP chair), Uldis Berkis (UB), Xia Wang-Steverding (XW), Rachael Hunter (RH minutes), Jean-Dominique De Korwin (JD),  
 Apologies: Elenka Brenna (EB), Lara Gitto (LG), Dominic Trepel (DT), John Cunningham (JC),

Item	Action	Person responsible
1. Introductions and apologies		
2. Working together		
The issue of clear roles and responsibilities, deliverables, communication and timelines was discussed. Each deliverable needs a responsible person, who is working on it and what actions need to be taken.	Circulate a list of everyone in the group and their roles in the Euromene group i.e. lead; WP member; Executive member.	DP
UB highlighted that for publications to be badged as part of Euromene they need to have authors from at least three of the Cost Action countries.	Circulate publication policy. WP3 members to acknowledge they have read the policy.	DP All WP3 members
	DP to develop publication list with input from WP3 members. List to include( i) working title;(ii) responsible author; (ii) other authors (for a total three of the Cost Action countries represented, minimum; (iii) anticipated submission date.	DP All WP3 members
We agreed that e-mails were not always the easiest way to communicate, partially due to the volume of e-mails people receive. Instead a document sharing app such as Trello may help to facilitate sharing of documents and feedback.	Set up group on Trello	XW
Meeting in person can be challenging due to constraints on time and finances. We were	Confirm date of September meeting and ensure circulated to all WP3	UB

<p>unable to identify a suitable time or reason to meet before the next Euromene meeting in September. The September date also fits well with other timelines. The date is yet to be confirmed.</p> <p>It was noted that DT had offered to host the meeting in Dublin. Meeting attendees agreed that Dublin was a good option given cost and transport (particularly compared to one of the other proposed locations, London). DT should be actively encouraged to host the meeting. Sorting a date for the September meeting was identified as a priority given the need to get something in people's diaries soon.</p>	members.	
<p>3. Deliverable 15 (Summary of evaluated socio-economic impact and direct and indirect costs caused by ME/CFS in Europe: Deliverable 8 in agenda)</p>		
<p>It was agreed that EB and LG's work addressed this deliverable.</p>		
<p>We discussed the key issue, that had also been discussed at previous meetings (Berlin and Barcelona) that a cost of illness study will always be methodologically flawed without (a) a case definition of ME/CFS; (b) doctors using this to diagnose ME/CFS. As a result the work of WG3 is heavily dependent on the work being done by the other groups on epidemiology and diagnosis.</p> <p>DP had previously conducted epidemiological work in England using read codes. This could be helpful to other members of the group for identifying numbers and cases in different countries.</p>	<p>Circulate CFS/ME read codes used in Observatory project and related papers.</p> <p>Write to Fer and Jesus regarding update on WG1 epidemiology paper which was submitted to BMJ.</p>	<p>DP</p> <p>DP</p>
<p>Given the importance of case definition in cost of illness to identify the population the first step is to give a summary of the each case definition and the proportion of people that it captures. This can be related to which ME/CFS study has used this definition (which is likely to be very few),</p>	<p>DP to draft a paper of case definitions</p> <p>Circulate Jason's Barcelona presentation to WG3</p>	<p>DP</p> <p>DP</p>
<p>We discussed the work proposed by JC: summary form and "quick and dirty" paper.</p>	<p>Chase JC on proposed table and paper</p>	DP
<p>It was queried how this relates to the work proposed in Sofia assessing the position of each countries.</p>	<p>Circulate to all Euromene participants text of questionnaire (Sofia).</p>	DP
<p>4. Deliverable 16 (Common consensus protocol for economic loss estimation and forecasting due to ME/CFS) Due August -2018</p>		
<p>As part of the morning session there was a presentation on common data elements for ME/CFS conducted by <u>NIND in the US</u> . WG4 are also looking at standardising what is collected as part of research. This includes SF-36 for quality of life.</p>	<p>Enquire with EB and LG about data form they are using to collect costs.</p> <p>Pull together a draft questionnaire asking about socio-economic impact including employment status, carer, days off work and</p>	<p>DP</p> <p>RH</p>

	<p>productivity. Questionnaire to be circulate to WG3 for comments</p> <p>Share proposed socio-economic form with WG4. DP to discuss with Eliana Lacerda if the questionnaire can be included in biobank work (WG1)</p>	DP
<p>We had a brief discussion regarding our last deliverable (17 guidelines for policy makers on prevention losses due to ME/CFS in health and economy aspects in Europe). This deliverable is due August 2020 (end of year 4). We noted the paucity of evidence and that, besides the two studies we were aware of in Ireland and Italy and the mixed evidence in UK, it is very unlikely there will be sufficient evidence to address this deliverable in time. To make some head way on this though a brief study in Latvia was proposed and considered an excellent idea.</p>	<p>Send UB Latvia proposal.</p> <p>UB to send questionnaire to patients in Latvia on economic impact of ME/CFS.</p> <p>Members of WP3 to provide advice and support on questionnaire content.</p>	<p>DP</p> <p>UB</p> <p>All WP3 members.</p>
<p>Following identification of the gaps in knowledge, and the short questionnaire proposed by JC, it was agreed that a useful outcome for WP3 would be a report detailing:</p> <p>1) Summary of current issues with cost of illness studies in ME/CFS, particularly case definition and diagnosis (in countries where the illness is not recognised cost of illness studies are particularly challenging). This will link to work in deliverable 15, including case definition work by DP.</p> <p>2) Based on suggested form by JC, the systematic review by EB and LG and other work as part of deliverable 15, what work is currently happening?</p> <p>3) What future work is proposed and how that addresses the gaps (identified in (1) &amp;(2)? What are the gaps that remain?</p> <p>Other things that could be discussed are how to measure quality adjusted life years (QALYs) and suitability of EQ-5D.</p> <p>This may require some reference to Health Technology Guidance across Europe (how they assess cost-effectiveness across different countries).</p> <p>RH has offered the assistance of a Masters student in this work (and as a result will lead the project).</p> <p>The contribution of other WP3 members to satisfy cost requirements are:</p> <p>a) provide information on the work they are conducting.</p> <p>b) comment on outputs from the work</p>	<p>One page protocol on the work to be conducted.</p> <p>Report on challenges, gaps and future work required for measuring the economic impact of CFS/ME in Europe. To be delivered by September.</p> <p>UB to check that reporting in September rather than August (to fit with Masters deadline) is acceptable.</p>	<p>RH</p> <p>WP3 led by RH</p> <p>UB</p>

Next meeting: September 2018 (date TBC).

Action points completed since the meeting:

		Responsibility	Action taken
1	Circulate annotated list of WG3 members to work group.	DP	Done
2	Circulate to WG3 the diagnostic algorithm used in UK for the epidemiological studies in the Observatory project.	DP	Done
3	Write to Fer and Jesus to find out the current status of the paper from WG1 submitted to BMJ Open.	DP	Done; paper currently undergoing peer review
4	Circulate to WG3 the Observatory epidemiology papers.	DP	Done
5	Set up 'Trello' facility to enable better communication within WG3	XW	Done
6	Re-circulate to all EUROMENE participants the questionnaire developed in Sofia.	DP	Done; responses received so far from Germany, the Netherlands and Italy
7	Forward to WG3 Leonard Jason's presentation to the Barcelona meeting.	DP	Done
8	Follow up John Cullinan re his proposed draft summary paper.	DP	Done
9	Ask Eliana Lacerda for list of data items on social circumstances, etc. collected by the Biobsnk.	DP	Done
10	Request a copy of the questionnaire re resource use developed by Lara Gitto and Elenka Brenna for their study of 108 Italian patients with ME/CFS, and for their draft paper analysing the data collected using a probit model.	DP	Done
	Send to Uldis the proposed epidemiology/resource use study for Latvia.	DP	Done