

Working Group 3 – Socio-
Economics
Report to COST Action 15111
Management Committee
Sofia, 8th February 2018

Derek Pheby



Progress to date (1)

- Milestone 1 – Survey data on direct and indirect economic loss due to ME/CFS in Europe.
 - Achieved by due date of October 2017
 - *See: Brenna E, Gitto L. The economic burden of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME): an initial summary of the existing evidence and recommendations for further research. European Journal for Person Centred Healthcare (2017); 5(3) 413-420.*
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Progress to date (2)

- Presentation made to Annual Conference of European Society for Person Centred Healthcare, London, 27th October 2017.
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 - Silver Medal of Society awarded jointly to Elenka Brenna, Lara Gitto, Lorenzo Lorusso and Derek Pheby.
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Current Position (1)

- Deliverable 15 due April 2018:
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 - Summary of evaluated socio-economic direct and indirect costs caused by ME/CFS in Europe.
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Current Position (2) – Problems in achieving deliverable 15

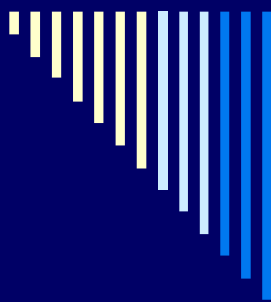
Lack of comprehensive case ascertainment.

- Everywhere substantially less than 100%.
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Lack of consistency of case definitions

- Few cost-of-illness studies
- A variety of case definitions used, varying markedly in inclusiveness.
- Consequently, wide range of estimated costs identified world-wide.





Current Position (3) – Problems in achieving deliverable 15 (continued)

Impact of case definitions on prevalence estimates.

- Tenfold difference in prevalence between inclusive and exclusive case definitions (Jason, 2017).



Differences in organization and funding of health care between countries.



Therefore comparative assessment of economic implications very problematic.



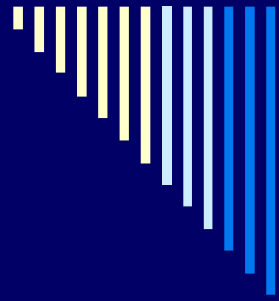
Current Position (4)

- Welcome insights from other Working Groups, e.g.:-
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 - Working Group 1: Comprehensive review on epidemiology of ME/CFS in Europe.
 - Working Group 4: Recommendations on standardised diagnostic criteria for ME/CFS in Europe (not due until April 2020, too late for our deadlines).
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Ways Forward (1)

- Reviewing comparability and ‘market penetration’ of different case definitions.
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 - Brurberg et al (2014) useful in identifying case definitions in current use.
 - - *Brurberg KG, Fønhus MS, Larun L, et al. Case definitions for chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): a systematic review. BMJ Open 2014;4:e003973.doi:10.1136/bmjopen-2013-003973*
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Ways Forward (2) - Information on national variations in funding health care for ME/CFS

- None specific
- Rachael Hunter has spotlighted a summary of the overall funding position for health care in Europe [OECD, Health at a Glance: Europe 2016, available at http://www.oecd-library.org/social-issues-migration-health/health-at-a-glance-europe-2016/financing-of-health-care_health_glance_eur-2016-37-en].
- Xia Wang has some relevant information from other EU and World Bank projects.
- As far as we can tell, no European country collects information routinely on the costs of health care for people with ME/CFS.



Ways Forward (3)

We need country-specific information on patterns of care for people with ME/CFS, i.e.:-

- ❑ Is referral of such patients to specialist care always via GPs?
 - ❑ Do GPs have lists of registered patients?
 - ❑ What proportion of people with ME/CFS present to a GP?
 - ❑ What proportion of patients with ME/CFS who present to a GP are referred to specialist care?
 - ❑ What proportion of patients with ME/CFS self-refer to specialist services?
 - ❑ What constitutes “specialist care” for ME/CFS in each country?
 - ❑ Is there specific national guidance on treatment pathways (as for example in England via NICE)?
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Ways Forward (4)

Other questions:

- ❑ To what extent do GPs in different European countries recognise ME/CFS as a genuine clinical entity?
 - ❑ How confident are they of diagnosing it?
 - ❑ What proportion of patients with ME/CFS who consult their GPs are in fact diagnosed by them?
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Outstanding Questions (1)

How can we obtain data at the patient level in different countries in order to determine informal care costs?

- ❑ Substantial lacunae in available data.
 - ❑ Modelling may fill gaps, but may involve dubious assumptions.
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Outstanding Questions (2)

- Elenka Brenna and Lara Gitto: questionnaire to 100 patients, seeking information about
 - symptoms,
 - quality of life (using Euro-Q-5),
 - other aspects of social and family life, current therapies and costs.
- But:
 - problems of representativeness (participants self-selected),
 - survey on a small scale
- useful start nevertheless, and may establish methodology which can be used in other countries.





Other Work in Progress

- Comparative review of cost-of-illness studies.
 - Identified need for primary research, eg.:
 - Pilot studies of the cost implications of patient journeys in different countries, to test and validate a data collection methodology.
 - The prevalence and cost study proposed for Latvia, which could provide a model which could possibly be replicated in other small jurisdictions with similar centralised systems.
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Looking Further Ahead

- Deliverable 16: Common consensus protocol for economic loss calculation due to ME/CFS.
 - Deadline: August 2018
 - Need group meeting to resolve this.
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