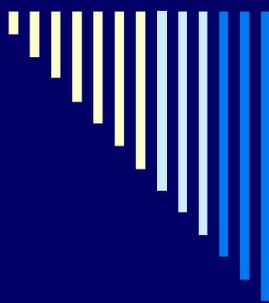


Working Group 3 – Socio-  
Economics  
Report to COST Action 15111  
Management Committee  
Sofia, 8<sup>th</sup> February 2018

Derek Pheby

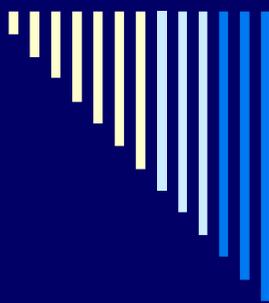
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## Progress to date (1)

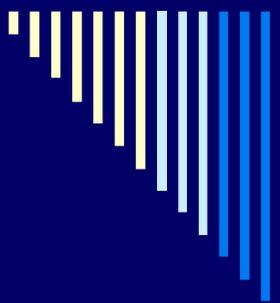
- Milestone 1 – Survey data on direct and indirect economic loss due to ME/CFS in Europe.
  - Achieved by due date of October 2017
  - *See: Brenna E, Gitto L. The economic burden of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME): an initial summary of the existing evidence and recommendations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

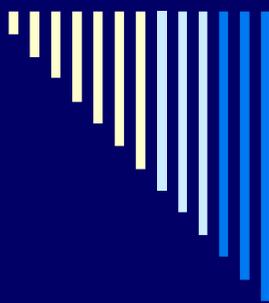
- Presentation made to Annual Conference of European Society for Person Centred Healthcare, London, 27<sup>th</sup> October 2017.
  - 
  - Silver Medal of Society awarded jointly to Elenka Brenna, Lara Gitto, Lorenzo Lorusso and Derek Pheby.
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## Current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

- Deliverable 15 due April 2018:
  - 
  - 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%.

- 

### Lack of consistency of case definitions

- Few cost-of-illness studies

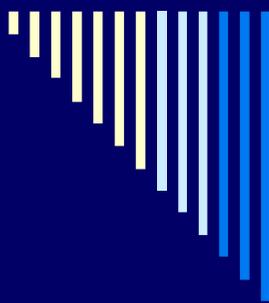
- A variety of case definitions used, varying markedly in inclusiveness.

- Consequently, wide range of estimated costs identified world-wide.

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## 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).

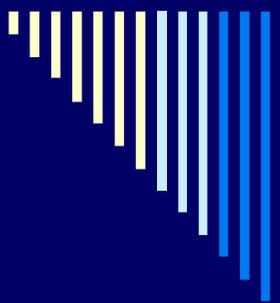


### Differences in organization and funding of health care between countries.



Therefore comparative assessment of economic implications very problematic.

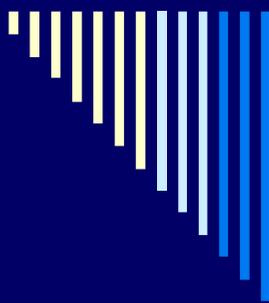
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## Current Position (4)

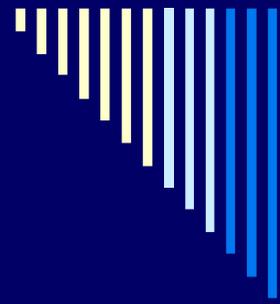
- Welcome insights from other Working Groups, e.g.:-
  - 
  - Working Group 1: Comprehensive review on epidemiology of ME/CFS in Europe.
  - Working Group 4: Recommendations on standardised diagnostic criteria for ME/CFS in Europe (not due until April 2020, too late for our deadlines).
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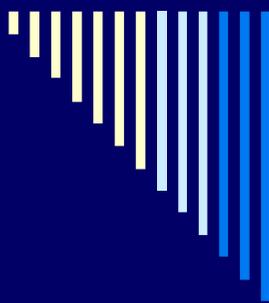
# Ways Forward (1)

- Reviewing comparability and ‘market penetration’ of different case definitions.
  - 
  - 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*
  -
-



## 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](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.

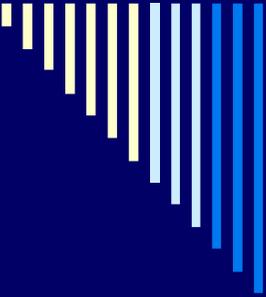


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## Ways Forward (3)

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)?
-

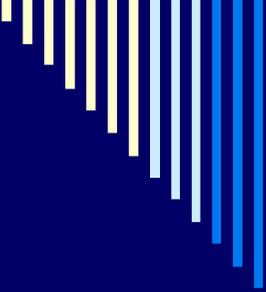


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## Ways Forward (4)

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?
-

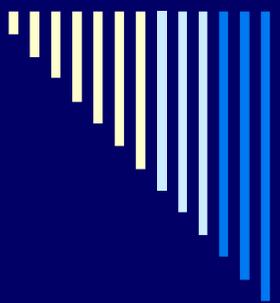


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# Outstanding Questions (1)

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

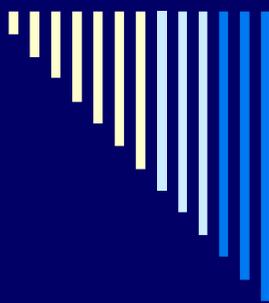
- ❑ Substantial lacunae in available data.
  - ❑ Modelling may fill gaps, but may involve dubious assumptions.
-



## 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.



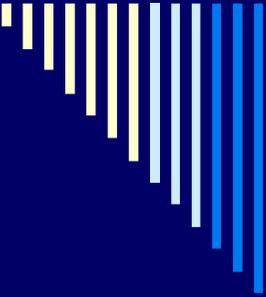


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# Other Work in Progress

- 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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