Prevalence of ME/CFS in Europe: results from Belgrade to Sofia meeting?

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# What has been done so far?

◆ **Online EURO-EpiME survey study**

New alternative ways about how to collect epidemiological metadata from Europe countries

◆ **Systematic literature review on the prevalence of ME/CFS across Europe**

An epidemiological approach is addressed through EUROMENE ME/CFS Epidemiology Working Group

Updated current situation regarding to EURO-EpiME survey data
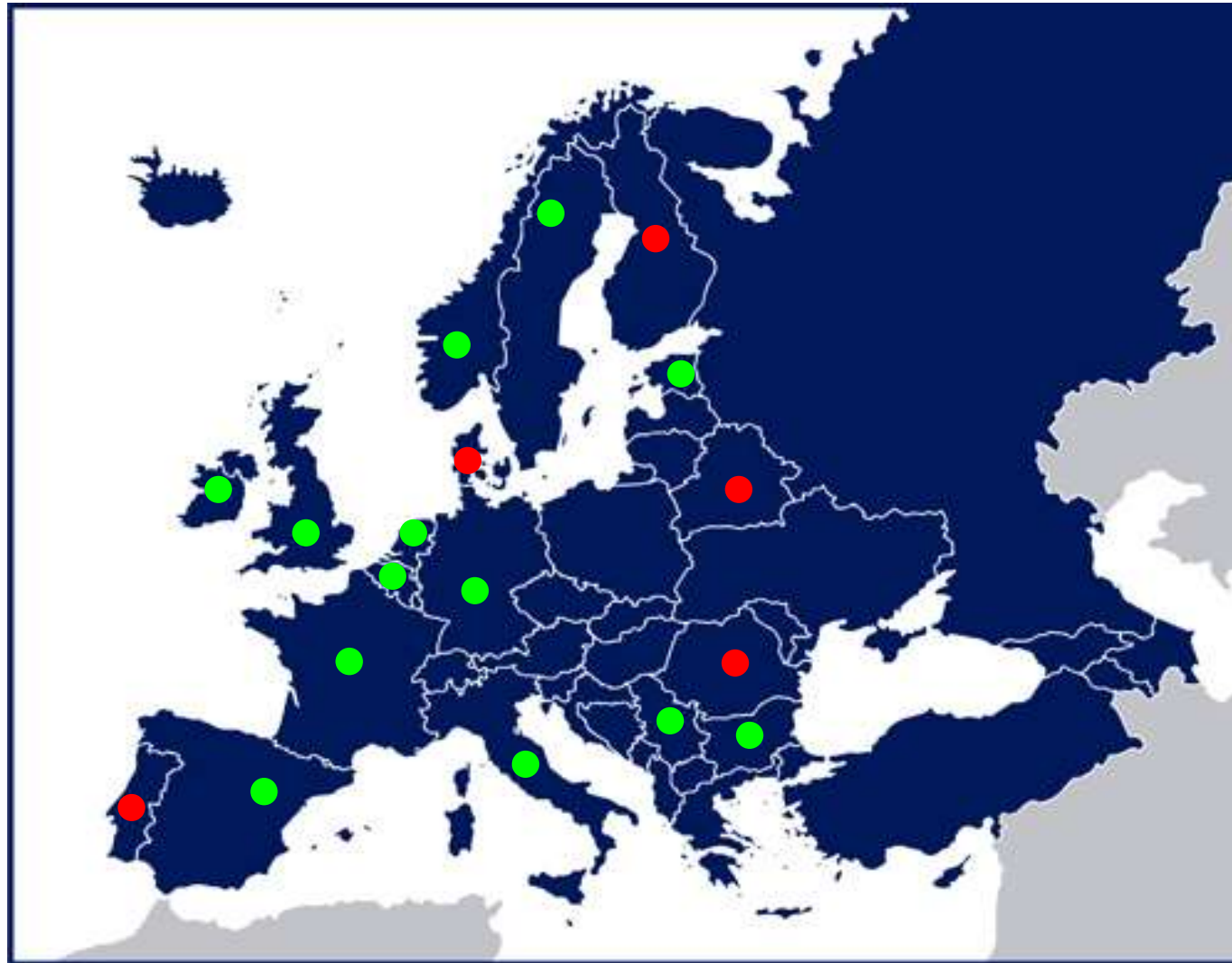
Data retrieved
- Bulgaria
- Belgium
- France
- Germany
- Italy
- Norway
- Spain
- Serbia
- Sweeden
- UK
- Ireland
- The Netherlands
- Latvia

Data no-retrieved
Belarus	Romania
Finland	Portugal
Denmark	

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Steps followed: Systematic search

- **Databases & Keywords combination**

  - **Scopus**: ({epidemiology} OR {prevalence} OR {incidence}) AND ({chronic fatigue syndrome} OR {myalgic encephalomyelitis} OR {CFS/ME} OR {ME/CFS})

  - **Web of Science**: ("epidemiology" OR "prevalence" OR "incidence") AND ("chronic fatigue syndrome" OR "myalgic encephalomyelitis" OR "CFS/ME" OR "ME/CFS")

Steps followed: Systematic search

- **<u>Databases & Keywords combination</u>**

  - **Pubmed**: ("Fatigue Syndrome, Chronic"[Mesh] AND (("Incidence"[Mesh] OR "Epidemiology"[Mesh] OR "epidemiology" [Subheading]) OR "Prevalence"[Mesh] OR "Cross-Sectional Studies"[Mesh]))

Steps followed: Extended search

- References of included papers
- Citations of included papers
- Online EUROMENE survey by e-mail (EURO-EpiME study)

Steps followed: Exclusion criteria

- Review

- Non-European studies

- Biased samples (e.g., **vaccines, virus infection**)

- Secondary or tertiary care (i.e., high-risk groups)

- Innappropriate case definition (e.g., **Oxford criteria**, **CFS/ME-like illnesses**)

- Children and adolescents
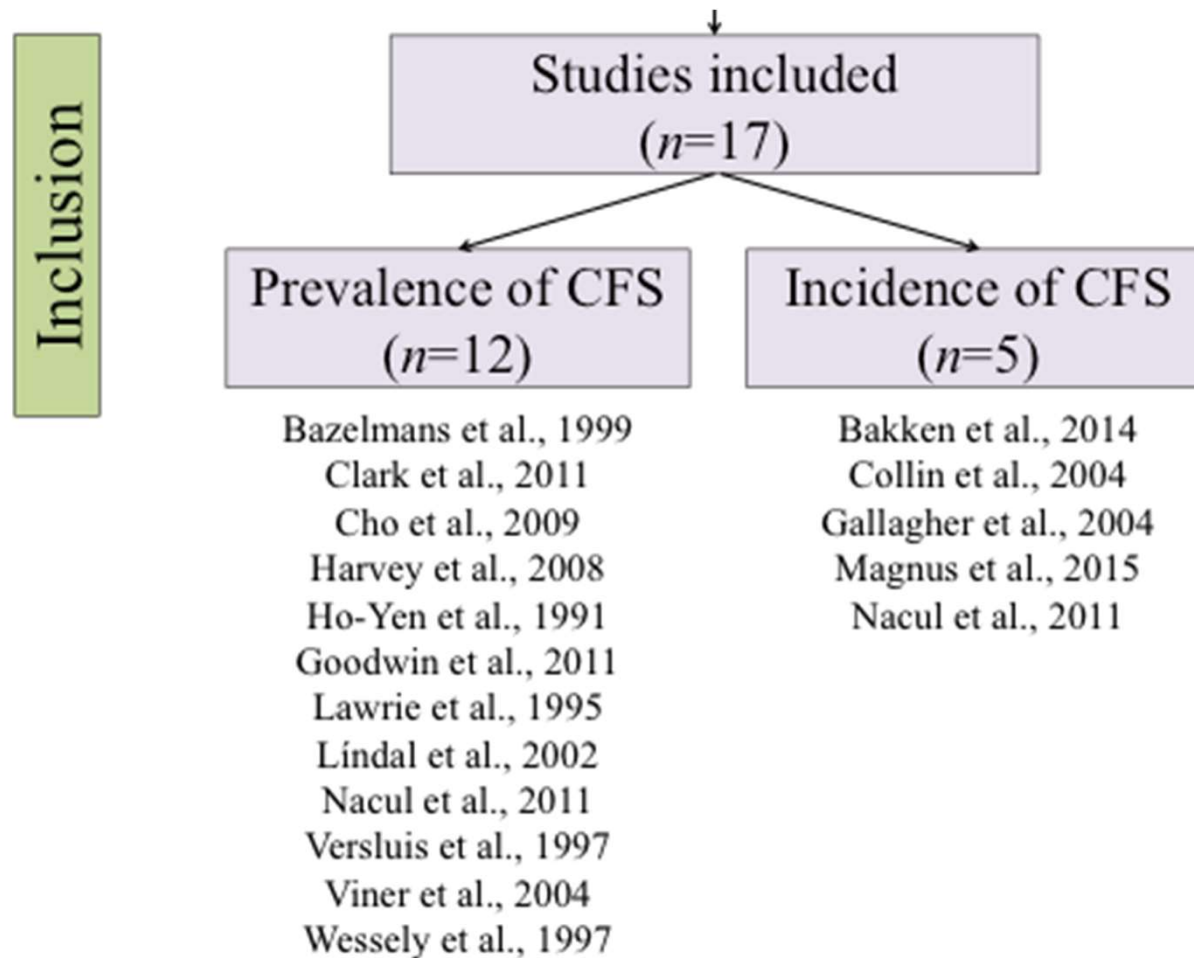
- Double reports

Steps followed: Quality assessment

- **Tool**:
  - Joanna Briggs Institute-Checklist for Prevalence Studies

- **Main advantage**:
  - Short & easy to apply

- **Main disadvantage**:
  - Not widely used

Results: Flow-chart
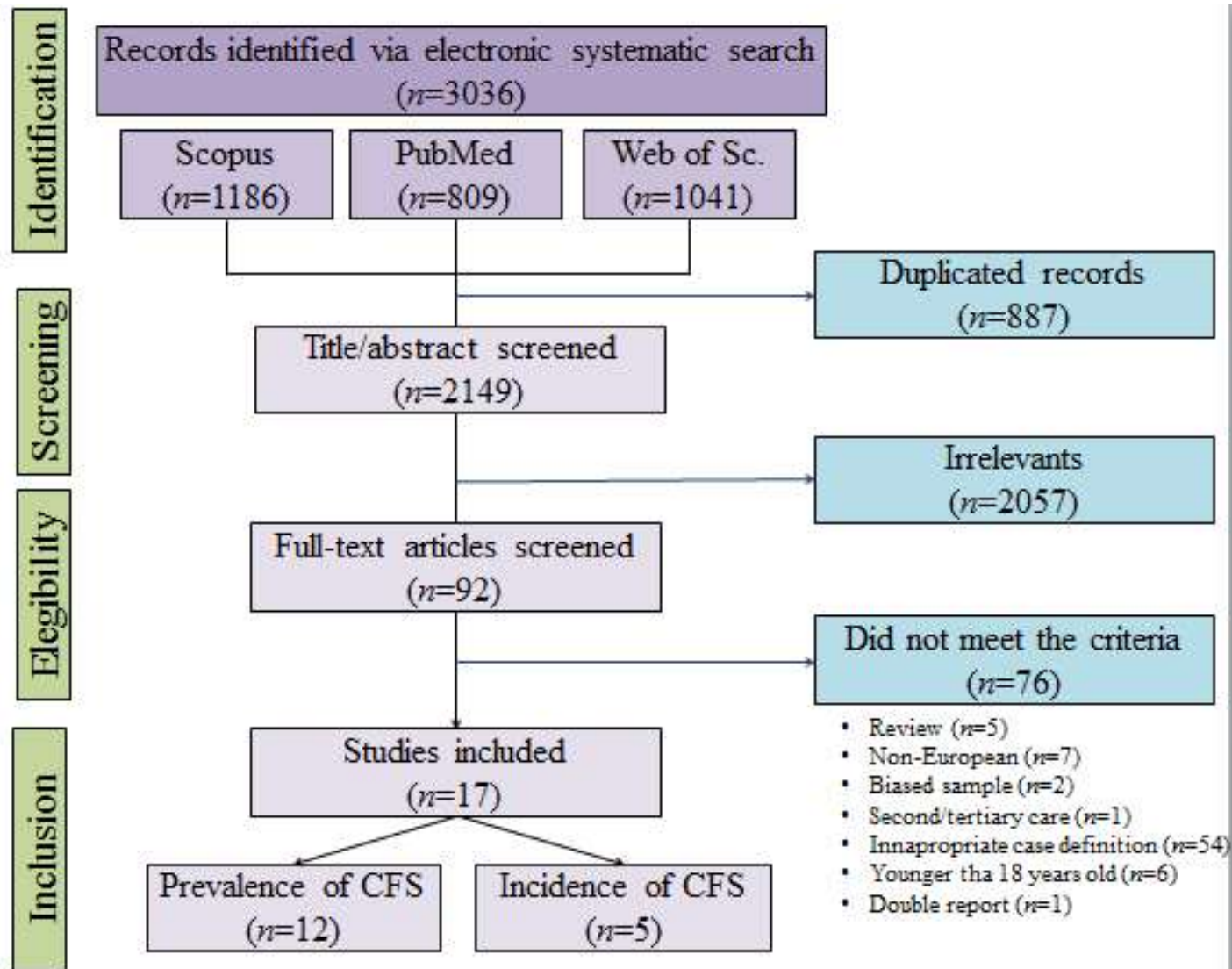
Results: Flow-chart

Point prevalence (%) of CFS/ME in Europe

Iceland, Lloyd, *n*=2471

Wessely, England, Fukuda, *n*=1985

Iceland, Sharp, *n*=2471

Cho, England, Fukuda, *n*=2459

Wessely, England, Australian, *n*=1985

Iceland, Fukuda, *n*=2471

Wessely, England, 1988CDC, *n*=1985

Harvey, Great Britain, Self-report, *n*=2973

Goodwin, Great Britain, Self-report, *n*=11419

Clark, Great Britain, Self-report, *n*=11419

Verluis, Netherlands, 1988CDC, *n*=?

Viner, Great Britain, Self-report, *n*=11261

Lawrie, Scotland, Ramsay, *n*=695

Nacul, England, any of Fukuda/Canadian/ECD, *n*=143153

Nacul, England, Fukuda, *n*=143153

Ho-Yen, Scotland, GP (undefined), *n*=?

Nacul, England, Canadian, *n*=143153

Balzemans, Netherlands, GP (undefined), *n*=?

Nacul, England, ECD, *n*=143153

Iceland, Holmes, *n*=2471

0   0.5   1.0   1.5   2.0   2.5   3.0   3.5   4.0   4.5   5.0

Point prevalence (%) of CFS/ME in Europe

Iceland, Lloyd, *n*=2471

Wessely, England, Fukuda, *n*=1985

Iceland, Sharp, *n*=2471

Cho, England, Fukuda, *n*=2459

Wessely, England, Australian, *n*=1985

Iceland, Fukuda, *n*=2471

Wessely, England, 1988CDC, *n*=1985

Harvey, Great Britain, Self-report, *n*=2973

Goodwin, Great Britain, Self-report, *n*=11419

Clark, Great Britain, Self-report, *n*=11419

Verluis, Netherlands, 1988CDC, *n*=?

Viner, Great Britain, Self-report, *n*=11261

Lawrie, Scotland, Ramsay, *n*=695

Nacul, England, any of Fukuda/Canadian/ECD, *n*=143153
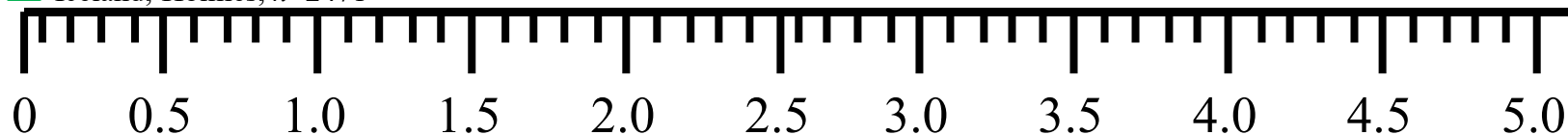
Nacul, England, Fukuda, n=143153

Ho-Yen, Scotland, GP (undefined), *n*=?

Nacul, England, Canadian, *n*=143153

Balzemans, Netherlands, GP (undefined), *n*=?

Nacul, England, ECD, *n*=143153

Iceland, Holmes, *n*=2471

**Great Britain
(as a whole or single
countries)**

0   0.5   1.0   1.5   2.0   2.5   3.0   3.5   4.0   4.5   5.0

Point prevalence (%) of CFS/ME in Europe

Iceland, Lloyd, *n*=2471

Wessely, England, Fukuda, *n*= 1985

Iceland, Sharp, *n*= 2471

Cho, England, Fukuda, *n*= 2459

Wessely, England, Australian, *n*= 1985

Iceland, Fukuda, *n*= 2471

Wessely, England, 1988 CDC, *n*= 1985

Harvey, Great Britain, Self-report, *n*= 2973

Goodwin, Great Britain, Self-report, *n*= 11419

Clark, Great Britain, Self-report, *n*= 11419

Verluis, Netherlands, 1988 CDC, *n*= ?

Viner, Great Britain, Self-report, *n*= 11261

Lawrie, Scotland, Ramsay, *n*= 695

Nacul, England, any of Fukuda/Canadian/ECD, *n*= 143153

Nacul, England, Fukuda, *n*= 143153
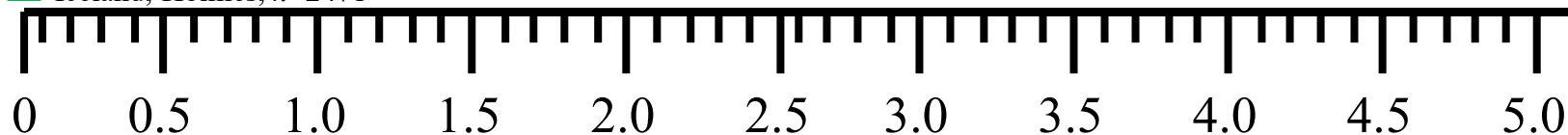
Ho-Yen, Scotland, GP (undefined), *n*=?

Nacul, England, Canadian, *n*= 143153

Balzemans, Netherlands, GP (undefined), *n*=?

Nacul, England, ECD, *n*= 143153

Iceland, Holmes, *n*= 2471

Other EU-countries

| 0 | 0.5 | 1.0 | 1.5 | 2.0 | 2.5 | 3.0 | 3.5 | 4.0 | 4.5 | 5.0 |

Point prevalence (%) of CFS/ME in Europe

Iceland, Lloyd, *n*=2471

Wessely, England, Fukuda, *n*=1985

Iceland, Sharp, *n*=2471

Cho, England, Fukuda, *n*=2459

Wessely, England, Australian, *n*=1985

Iceland, Fukuda, *n*=2471

Wessely, England, 1988CDC, *n*=1985

Harvey, Great Britain, Self-report, *n*=2973

Goodwin, Great Britain, Self-report, *n*=11419

Clark, Great Britain, Self-report, *n*=11419

Verluis, Netherlands, 1988CDC, *n*=?

Viner, Great Britain, Self-report, *n*=11261

Lawrie, Scotland, Ramsay, *n*=695

Nacul, England, any of Fukuda/Canadian/ECD, *n*=143153

Nacul, England, Fukuda, *n*=143153

Ho-Yen, Scotland, GP (undefined), *n*=?

Nacul, England, Canadian, *n*=143153

Balzemans, Netherlands, GP (undefined), *n*=?

Nacul, England, ECD, *n*=143153

Iceland, Holmes, *n*=2471

1994 CDC/Fukuda definition

| 0 | 0.5 | 1.0 | 1.5 | 2.0 | 2.5 | 3.0 | 3.5 | 4.0 | 4.5 | 5.0 |

Point prevalence (%) of CFS/ME in Europe

Iceland, Lloyd, *n*=2471

Wessely, England, Fukuda, *n*=1985

Iceland, Sharp, *n*=2471

Cho, England, Fukuda, *n*=2459

Wessely, England, Australian, *n*=1985

Iceland, Fukuda, *n*=2471

Wessely, England, 1988 CDC, *n*=1985

Harvey, Great Britain, Self-report, *n*=2973

Goodwin, Great Britain, Self-report, *n*=11419

Clark, Great Britain, Self-report, *n*=11419

Verluis, Netherlands, 1988 CDC, *n*=?

Viner, Great Britain, Self-report, *n*=11261

Lawrie, Scotland, Ramsay, *n*=695

Nacul, England, any of Fukuda/Canadian/ECD, *n*=143153

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Ho-Yen, Scotland, GP (undefined), *n*=?

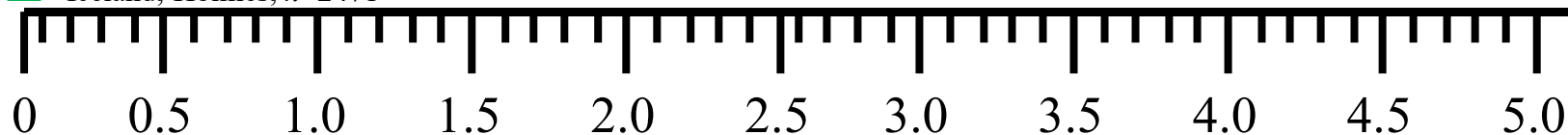Nacul, England, Canadian, *n*=143153

Balzemans, Netherlands, GP (undefined), *n*=?

Nacul, England, ECD, *n*=143153

Iceland, Holmes, *n*=2471

Self-reported CFS/ME

0   0.5   1.0   1.5   2.0   2.5   3.0   3.5   4.0   4.5   5.0
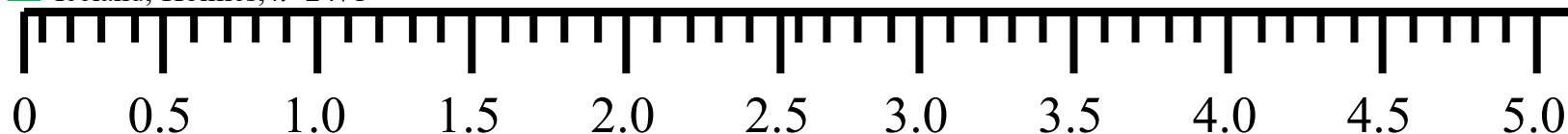
Results: Incidence

Ref Adults studies	Country	Sample, total (women, %)	Follow-up (months)	Case definition	Incidence (95% CI); cases per 100000 person-years)[1]
Gallagher et al., 2004	UK	2,400,000	84	Read coding	10 (n/a) for females 4 (n/a) for males
Nacul et al., 2011	England	143,153 (n/a)	12	Any of the following: 1994 CDC/Fukuda, 2003 Canadian, or ECD	15.0 (n/a)
Collin et al., 2017	UK	n/a (n/a)	156	Read coding	14.8 (14.5 to 15.1)
Bakken et al., 2014	Norway	22,173,710 (50%)	60	ICD-10 coding	25.8 (25.2 to 26.5)
Magnus et al., 2015	Norway	4,822,337 (50%)[2]	38	ICD-10 coding	24.96 (n/a)

Results: Quality prevalence studies

Author (year)	P1	P2	P3	P4	P5	P6	P7	P8	P9	Score
Lawrie SM et al. (1995)	1	1	1	1	UN	1	1	1	1	8
Wessely S et al. (1997)	1	1	1	1	1	1	1	1	1	9
Viner R et al. (2004)	1	1	1	1	1	0	1	1	1	8
Harvey SB et al. (2008)	1	1	1	1	1	0	1	1	1	8
Ho-Yen DO et al. (1991)	1	1	1	UN	0	0	0	0	1	4
Nacul LC et al. (2011)	1	1	1	1	1	1	1	UN	1	8
Clark C et al. (2011)	1	1	1	1	1	1	1	1	1	9
Goodwin L et al. (2011)	1	1	1	1	1	1	1	1	1	9
Cho HJ et al. (2009)	1	1	1	1	1	1	1	1	1	9
Líndal E et al. (2002)	1	1	1	UN	0	0	0	0	1	4
Bazelmans E et al. (1997)	1	1	1	0	0	0	0	0	1	4
Versluis RG et al. (1997)	PAPER NOT FOUND									

Results: Quality incidence studies

Author (year)	P1	P2	P3	P4	P5	P6	P7	P8	P9	Score
Bakken IJ et al. (2014)	1	1	1	1	1	1	N/A	1	1	8
Magnus P et al. (2015)	1	1	1	1	1	1	N/A	1	1	8
Gallengher AM et al. (2004)	1	1	1	UN	1	1	1	UN	1	7
Nacul LC et al. (2011)	1	1	1	1	1	1	1	UN	1	8
Collin SM et al. (2017)	1	1	1	1	1	1	1	1	1	9

What's the future: do we want to improve the systematic review?

- If yes,
    - Prospero registration (Ref. CRD4201-7078688)

    - Double check (e.g., review & data extraction)

    - Ask authors for further details (e.g., prevalence by gender, age ranges)

    - Better quality assessment

    - Meta-analyses: Global and specific ones

    - **Other suggestions?**

BMJ Open

The prevalence and incidence of myalgic encephalomyelitis/chronic fatigue syndrome in Europe: the EURO-epiME study from the European network EUROMENE. A protocol for a systematic review.

Journal:	BMJ Open
Manuscript ID	bmjopen-2017-020817
Article Type:	Protocol
Date Submitted by the Author:	20-Dec-2017
Complete List of Authors:	Estévez-López, Fer; University of Granada, Department of Physical Education and Sport, Faculty of Sport Sciences; Utrecht University, Department of Psychology, Faculty of Social and Behavioural Sciences Castro-Marrero, Jesus; Vall d'Hebron University Hospital, CFS/ME Unit, Universitat Autònoma de Barcelona Wang, Xia; University of East Anglia Bakken, Inger Johanne; Norwegian Institute of Public Health Ivanovs, Andrejs; Rigas Stradinas Universitate Nacul, Luis ; London School of Hygiene and Tropical Medicine Sepulveda, Nuno; London School of Hygiene and Tropical Medicine Strand, Elin; Oslo universitetssykehus Ulleval Pheby, Derek; Buckinghamshire New University Alegre, Jose; Vall d'Hebron University Hospital, CFS/ME Unit, Universitat Autònoma de Barcelona Scheibenbogen, Carmen; Charite - Universitatsmedizin Berlin Institut fur Medizin- Pflegepadagogik und Pflegewissenschaft Shikova-Lekova, Evelina; Natsionalen tsentar po zarazni i parazitni bolesti Lorusso, Lorenzo; A.S.S.T. della Franciacorta Capelli, Enrica; Universita degli Studi di Pavia Facolta di Medicina e Chirurgia Slobodan, Sekulic; Univerziteta u Novom Sadu Medicinski Fakultet Lacerda, Eliana; London School of Hygiene & Tropical Medicine Murovska, Modra; Rigas Stradinas Universitate
Keywords:	EPIDEMIOLOGY, EUROMENE, EURO-epiME, incidence, prevalence

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Read the press released article Do emotions related to alcohol consumption differ by alcohol type? An international cross-sectional survey of emotions associated with alcohol consumption and influence on drink choice in different settings

Impact Factor 2.369

Manuscripts I Have Co-Authored

STATUS	ID	TITLE	CREATED	SUBMITTED
EA: Editorial Office, BMJ Open Awaiting ME Decision	bmjopen-2017-020817	The prevalence and incidence of myalgic encephalomyelitis/chronic fatigue syndrome in Europe: the EURO-epiME study from the European network EUROMENE. A protocol for a systematic review. View Submission Submitting Author: Estévez-López, Fer Cover Letter	24-Nov-2017	20-Dec-2017

What would be the next step?

рахмат danke 謝謝 ngiyabonga spas teşekkür ederim

mersi kia ora barka welalin tack mahalo tapadh leat

Баярлалаа спасибо faafetai lava vinaka dank je misaotra matondo paldies grazzi asante manana хвала

kiitos dankie dhanyavad спасибі blagodaram gracias obrigada

nanni nandri thank you akun dankon ačiū djere dieuf ţau mochchakkeram дякую mamnun tenki

bedankt grâcie hvala mauruuru köszönöm sulpáy go raibh maith agat chokrane murakoze

enkosi bayarlalaa dziękuję chnorakaloutioun gratias ago gràcies ţaiku

sobodi děkuji sukriya kop khun krap arigatô takk dakujem trugarez

mèsi madloba sagolun najis tuke ありがとう grazie tanemirt rahmet diolch мерси mercé

didi madloba kam sah hamnida terima kasih rahmet dhanyavadagalu shukriya

তোমাকে ধন্যবাদ rahmat 감사합니다 xièxie ευχαριστώ merci