

Declaration of interests form

Instructions: You should declare and describe any present or past affiliations or other involvement in any organisation or entity that might lead to a real or perceived conflict of interest. You should report relationships that were present during the last 36 months. You should declare potential conflicts even if you are confident that your judgement is not influenced. Further details can be found in Cochrane's policy on [conflict of interest and Cochrane Reviews](#).

Name: Hilda Bastian

1. Financial interests

a) Received research funding: any grant, contract or gift, commissioned research, or fellowship from any organisation related to health care or medical research (for example Cochrane, a non-governmental organisation, a pharmaceutical or medical device company, a healthcare charity or a patient advocacy group) to conduct research?

- No
 Yes

If yes, please provide details:

PhD university fees waived via Australian Government Research Training Program Scholarship.

b) Had paid consultancies: any paid work, consulting fees (in cash or kind) from an organisation related to health care or medical research?

- No
 Yes

If yes, please provide details:

Editorial fees from the *Drug and Therapeutics Bulletin*; honorarium from the Cochrane Collaboration for leading the Independent Advisory Group for the update of the review on exercise and ME/CFS; blogging payment from PLOS (Public Library of Science); writing for WIRED and The Atlantic.

c) Received honoraria: one-time payments (in cash or kind such as travel expenses) from an organisation related to health care or medical research?

- No
 Yes

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Better health.**

If yes, please provide details:

Virginia Commonwealth University (speaking fee and travel); University of Utah (speaking fee and travel); University of Bristol (travel) World Federation of Science Journalists (travel); National Health and Medical Research Council (NHMRC) working group participation.

d) Served as a director, officer, partner, trustee, employee or held a position of management with an organisation related to health care or medical research?

- No
 Yes

If yes, please provide details:

Senior Clinical Scientist, National Center for Biotechnology Information (NCBI) at the U.S. National Library of Medicine (U.S. National Institutes of Health) until April 2018.

e) Possessed share-holdings, stock, stock options, equity with an organisation related to health care or medical research (excludes mutual funds or similar arrangements where the individual has no control over the selection of the shares)?

- No
 Yes

If yes, please provide details:

f) Received personal gifts from an organisation related to health care or medical research?

- No
 Yes

If yes, please provide details:

g) Had an outstanding loan with an organisation related to health care or medical research?

- No
 Yes

If yes, please provide details:

h) Received royalty payments from an organisation related to health care or medical research?

- No
 Yes

If yes, please provide details:

2. Non-financial interests

Do you have any other interests that would reasonably appear to be related to the primary interest? Such interests could include, but are not limited to, publicly declaring any strong opinions about this health area, unpaid membership of committees, advisory boards or patient advocacy groups in this health area, and being a named author of a study that might be included in this review.

No

Yes

If yes, please provide details:

Cochrane reviews: I was one of the founding group of the Cochrane Collaboration, although I am no longer a member of the organization; my PhD research included several studies of, or related to, Cochrane reviews. I have written blog posts criticizing and supporting Cochrane reviews, and actions of the Cochrane Collaboration. One of my PhD supervisors, Paul Glasziou, was an author of a now-withdrawn protocol for a Cochrane review on ME/CFS. **Update on 2 June 2021:** Glasziou was also acknowledged for assistance by the authors of the Cochrane review on exercise and ME/CFS.

ME/CFS: I have written two blog posts expressing strong opinions about the Cochrane review on exercise therapy and chronic fatigue syndrome (at the PLOS Blog, Absolutely Maybe). Those posts list disclosures related to ME/CFS and the Cochrane Collaboration more broadly and that list follows.

Additional non-financial disclosures, as listed in:

1. February 2019: <https://blogs.plos.org/absolutely-maybe/2019/02/08/consumer-contested-evidence-why-the-me-cfs-exercise-dispute-matters-so-much/>

2. October 2019: <https://blogs.plos.org/absolutely-maybe/2019/10/03/its-a-start-the-amended-version-of-the-cochrane-review-on-exercise-and-cfs/>

I was a health consumer advocate (aka patient advocate) from 1983 to 2003, including chairing the Consumers' Health Forum of Australia (CHF) from 1997 to 2001, and its Taskforce on Consumer Rights from 1991 to 2001. I have not experienced CFS/ME and nor has anyone close to me.

However, at the time I first encountered CFS activists, I had a relevant personal frame of reference. I had to leave my occupation several years prior after a severe bout of repetitive strain injury (RSI) following a stretch of workaholicism as a teenager. Then, RSI was regarded by some medical practitioners as malingering or psychological, rather than a physical condition. (You can read about the controversy around Australia's RSI epidemic [here](#), [here](#), and here [[PDF](#)].)

As then editor-in-chief of a consumer health information website based on systematic reviews at the NIH, I was pressured about the inclusion of systematic reviews on GET and CBT and approach to CFS consumer information, but not by CFS activists.

I was the consumer representative from the foundation of the Cochrane Collaboration in 1993, and leader of Cochrane's Consumer Network from its formal registration in 1995 to 2003. I was the coordinating editor of a Cochrane Review group from 1997 to 2001.

One of the authors of the planned Cochrane individual patient data review, the *protocol* of which was withdrawn, is my PhD supervisor, Paul Glasziou. We have not discussed it and have not discussed anything related to this post while I was considering, researching, and writing it.

Links:

Australia's RSI epidemic:

https://link.springer.com/chapter/10.1007/978-1-349-27625-7_9

<https://www.sciencedirect.com/science/article/abs/pii/S027795369090191T>

<http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.1013.9945&rep=rep1&type=pdf>

Withdrawn Cochrane IPD protocol:

<https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD011040.pub2/full>