Cochrane

Declaration of interests form

Instructions: You should declare and describe any financial interest relevant to your Cochrane advisory board role falling into one or more of the below categories that you have held within the time period beginning 36 months prior to submission of this declaration.

An interest is relevant for this role if you have received payment from a commercial organization with an interest in the topic of the review(s) you advise on. This means that the organization has developed (or is known to be developing), or distributes (anywhere in the world), an intervention or potential comparator related to the topic of the review(s). This applies even if the payment was made for work or advice that did not relate to the topic of the review(s).

Further details can be found in Cochrane's policy on [Conflict of Interest for Cochrane Library Content]

Name:

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?

☒ Yes ☐ No

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?

☒ Yes ☐ No

If yes, please provide details:

Editorial fees from the *Drug and Therapeutics Bulletin*; honorarium from the Cochrane Collaboration for leading Independent Advisory Groups for the update of the review on exercise and ME/CFS, and for reviews on the HPV vaccine; 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?

☒ Yes ☐ No

If yes, please provide details:

National Health and Medical Research Council (NHMRC) working group participation; GIMBE Foundation (travel for the 2023 Evidence Based Health Care Conference).

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?

☐ Yes ☒ No

If yes, please provide details:

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)?

☐ Yes ☒ No

If yes, please provide details:

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

☐ Yes ☒ No

If yes, please provide details:

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

☐ Yes ☒ No

If yes, please provide details:

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

☐ Yes ☒ No

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.

☒ Yes ☐ No

If yes, please provide details:

Cochrane reviews: I was one of the founding group of the Cochrane Collaboration, and was awarded Cochrane Emeritus membership in 2023. 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 of individual patient data on exercise therapy and CFS and was also acknowledged for assistance by the authors of the Cochrane review on exercise therapy and CFS. In June 2021, I reviewed and provided advice to the Editor in Chief on a draft Cochrane review on a vaccine-related topic (not related to ME/CFS or HPV). In 2021, I was a member of the advisory group for Cochrane Convenes, an online event on evidence synthesis for COVID-19 and changes that could help in future pandemics. Since 2021, I have led a second Independent Advisory Group for Cochrane, on update reviews on the HPV vaccine.

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 workaholism 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/027795369090191T

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