

Reply to letter from G Evers-Kiebooms

The letter from Evers-Kiebooms responding to our systematic review of the psychological consequences of predictive genetic testing¹ raises four main points.

- (1) Qualitative data should be included in systematic reviews.
- (2) Other research is consistent with the findings of the systematic review.
- (3) It is unethical to carry out experimental studies (randomised controlled trials) of genetic counselling.
- (4) The review includes some unspecified inaccurate reporting.

We will discuss these points in the same order:

(1) Systematic reviews vary in their inclusion criteria, depending on the research question they are addressing. In our review, we were interested in the outcome of testing as assessed by standardised, quantitative measures of psychological functioning. We chose to do this in order to enable comparisons across studies that vary across several dimensions. Systematic reviews are just that: systematic in the way that they define and pursue their search and integration of the relevant literature.² Our search strategy used terms that maximised the chance of identifying the studies of interest, and this was confirmed by our validation check.

Systematic reviews can only be as good as the research that they review and we described some of these limitations, such as a lack of cognitive and behavioural outcomes, and study groups which combined affected with unaffected people (which were therefore omitted from our review). Qualitative studies have an important contribution to make to understanding psychological impact, and a review of this work would be very timely. The large number of reprint requests for this systematic review suggests a great interest in this area, and our review is only one, and certainly not definitive, contribution.

(2) Other studies of predictive genetic testing exist that did not meet our review criteria have also found that pre-test mood is an important determinant of post-test mood. This does not detract from the importance of any of those findings. Indeed, the more consistency between different studies carried out in different countries on different conditions using different methods, the more robust that finding is.

(3) As evidence-based health care is increasingly advocated as the most ethical approach, it becomes necessary to define what constitutes evidence. The strongest evidence about causation (eg, that a type of counselling causes a type of outcome) comes from studies that compare models of care in which only the aspects of interest are varied, whilst keeping others the same. This experimental approach is further strengthened by randomising people to these two conditions so that we can be confident that it is the type of counselling that is bringing about the outcome, not the type of person who selects the type of counselling. To deprive people of the evidence on which to base their health care choices is ethically problematic.

The studies we envisage would not deprive anyone of counselling. Rather, they might compare different amounts and types of counselling at different stages of the testing process to determine the most effective and efficient counselling for different groups of counselees. Current practice of predictive testing counselling varies widely. Without evidence to support any one type of practice, those commissioning care will understandably select the cheapest, which may not be the best, option. It is arguably unethical not to conduct experimental studies that address this issue.

(4) Whilst we acknowledge that any published research may include inaccuracies, our review was checked by three researchers and we have received no details about inaccuracies within it. We hope that our review, and this subsequent correspondence, will help to stimulate interest in, and study of, this area. Further research, building on what we know to date, will help to further our understanding of the psychological and social consequences of predictive genetic testing and how to present such testing in a way that maximises well-being and minimises harm.

Susan Michie, Theresa Marteau

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References

1 Broadstock M, Michie S, Marteau TM: The psychological consequences of predictive genetic testing: a systematic review. *Eur J Hum Genet* 2000; 8: 731-738.

2 Mulrow CD: Rationale for systematic reviews. *Br Med J* 1994; 309: 597 - 599.