Author's response to reviews

Title: Genetic Discrimination and Life Insurance: A Systematic Review of the Evidence

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Author's response to reviews: see over
To the Editors:

We would like to express our gratitude to the referees and the editors for allowing this dialogue and providing us with their valuable insights. Please find below a point-by-point response to the peer review comments.

Referee 1 (Prof. Mark Rothstein)

Comment 1 (The online search might have been too narrow)

We believe that our online search (see table 1 for results) is complete and does include research from a variety of scholarly fields and peer reviewed publications. The 2004 survey on public attitude conducted by Rothstein and Hornung was part of our initial search results. However, this study had to be excluded because it did not provide empirical data on the occurrence of genetic discrimination, but rather on the fear of it.

Comment 2 (Given the current US law it should be no surprise that the issue is more one of concerns about discrimination than of actual discrimination)

This comment speaks directly to the observation made in our conclusion, that at this point in time: “targeted policies and careful monitoring of the situation as it evolves is likely the most adequate course of action.”
Comment 3 (importance of the new genomics/personalized medicine context)

We agree with this important observation and have added the following line to our paper (p.8): “This is particularly concerning given that the amount of genomic information in the typical individual’s medical record is likely to increase tremendously in the next few years as whole-genome sequencing costs are reduced and personalized medicine becomes more common in clinical settings”, to introduce this point in our text.

Referee 2 (Prof. Peter Lee)

Comment 1 (reordering and clarifications required in the “Methods” section)

The methods section now starts with the criteria for selecting the appropriate studies for analysis, as suggested in this comment.

Comment 2 (methodology used for literature search needs to be clearer and more detailed to be reproducible)

The presentation of the methodology has been clarified and further detailed to ensure that readers could reproduce the searches. The methodology was also segmented into the 3 main steps with more details. The corresponding Figure 1 has been expanded to reflect those changes.

Comment 3 (need more information about endpoint(s) of the study and validation criteria)

The data extraction process was made according to 6 principal end-points referred to as “pre-selected themes” in the manuscript: (1) identify the scope and context of the study, (2) identify whether the study focuses on a single or multiple genetic conditions, (3) assess how genetic discrimination (GD) was construed or defined, (4) assess the conclusions provided on the occurrence of GD in the context of life insurance, (5) determine whether a formal
validation process was used (or disclosed) to assess the occurrence of GD, and (6) take into account how often peers cited the publication as a reference.

Comment 4 (separate the results from the discussion in the main body of the text)
We have chosen not to present the results and the discussion in two distinct sections. Because our study addressed several themes (see themes in answer to preceding comment), such separation could negatively impact the readability of the manuscript forcing readers to go from results to discussion for each of the different topics. Nevertheless, results and discussion were generally put in separate paragraphs to avoid creating any confusion for the readers.

Comment 5 (expand table 1 to include information on findings of genetic discrimination in each individual studies)
Table 1 has been revised to reflect individual results from themes not previously presented in other tables and figures (i.e. whether the study was specific to life insurance, whether authors provided a validation process and conclusions concerning the evidence of GD). Additional information concerning the legal framework in the country of each study has also been added to Table 1.

Moreover, as suggested in this comment, results from studies on single genetic condition have been included in the text (page 10) in the following paragraph: “Among the 19 studies dealing with a single genetic condition (see Table 1), a significant number of studies (47%) concluded that there was sufficient evidence raising serious concerns about GD. Half of these studies concerned Huntington’s Disease. A second important category (42%) found that while GD existed it was of rare occurrence. Finally, a minority of studies (11%), concluded there was no evidence of GD.”

Referee 3 (Prof. Lisbeth Tranebjaerg)
We took note of this referee’s positive feedback regarding our manuscript and have no additional comments to express about her report.

Once again, we would like to take the opportunity to thank all the referees for their constructive comments on our study. In reviewing our manuscript, we have taken into account the vast majority of the comments and followed the instructions of the MOOSE guidelines; this has resulted in a substantial improvement in our manuscript.

Sincerely,

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