Author's response to reviews

Title: Lay perceptions of predictive testing for diabetes based on DNA test results versus family history assessment: a focus group study

Authors:

Miranda Wijdenes-Pijl (m.pijl@vumc.nl)
Wybo J Dondorp (w.dondorp@maastrichtuniversity.nl)
Danielle RM Timmermans (drm.timmermans@vumc.nl)
Martina C Cornel (mc.cornel@vumc.nl)
Lidewij Henneman (l.henneman@vumc.nl)

Version: 2 Date: 2 June 2011

Author's response to reviews: see over
Re: Revision of manuscript by M. Wijdenes-Pijl et al. "Lay and professionals’ views on predictive testing for diabetes based on DNA test results or family history assessment: a qualitative study"

Dear Dr. Whiting,

We would like to thank you and the reviewers for the opportunity to revise the manuscript ‘Lay and professionals’ views on predictive testing for diabetes based on DNA test results or family history assessment: a qualitative study’, in consideration for publication in BMC Public Health. Below you will find an itemized, point-by-point reply to all of the reviewers’ comments.

Reviewer #1:
The reviewer indicates that the authors make a false comparison between professionals and lay people, since it was concluded that the professionals were mainly concerned with the low predictive value, whereas the lay participants did not receive any information regarding the low predictive value of DNA testing. Furthermore, the reviewer indicates that the opinions of the professionals are somewhat distracting and suggests to leave this group out of the study. In addition, the reviewer argues that the paper would be stronger if it focused on important, clinically-relevant questions, such as the contrast between obtaining family history vs. DNA testing for diabetes in terms of: perceived utility, perceived differences, differences in negative implications, etc.

Answer: The authors agree with the reviewer that the comparison of professionals’ opinions (although meant as experts rather than just focusing on clinicians) with lay people may be distracting. Therefore, we have decided to exclude the professionals’ opinions and also changed the focus of the paper. We have now put more emphasis on differences in perceptions between the use of DNA test results or a family history assessment to assess diabetes risk, as the reviewer suggests. As a result we have changed the title to ‘Lay perceptions of predictive testing for diabetes based on DNA test results versus family history assessment: a focus group study’. Additionally, quotations have been added to support the findings with regard to these differences. Newly added quotations are underlined in the manuscript. Also, passages or words are added throughout the manuscript to indicate and explain the new focus (comparison between both tests), which are underlined as well.

The reviewer would like to know if there were important contrasts between focus groups, particularly between patients and other participants.

Answer: There were little differences between the focus groups, except that diabetes patients perceived more benefits of genetic risk information for their family members and children, and also felt more obliged to disclose risk information to other members of the family as we have indicated in the discussion section.

The reviewer would like to see discussed the oversampling of women in the study.

Answer: We have added a remark about this in the discussion section: ‘More women than men participated in this study, which may have influenced the findings as it has been shown that women, in general, are less favourable towards genetic testing than men.’.

The reviewer stated that if the interviews were conducted in Dutch the translation/back translation methodology should be described.
The interviews were conducted in Dutch, however we believe there is no need for a translation/back translation methodology, since the analyses have been performed in Dutch as well. To ensure a proper reporting of the quotes, a Dutch to English translator has reviewed the manuscript. This has been indicated in the method section: ‘Quotations were translated from Dutch and checked by a Dutch to English translator.’.

The reviewer pointed out that the word “data” should be used as plural in a sentence.

We adjusted the sentence to ‘For these monogenic diseases there are many data available on the ethical, legal and social issues of testing for and communication of genetic risk information to individuals and families.’.

The reviewer indicates that the sentence about the predictive value of genetic variants in addition to traditional disease risk factors is not appropriate

The authors rephrased the sentence: ‘Testing based on these genetic variants alone, or in addition to traditional disease risk factors, such as obesity and hypertension, still shows limited predictive value for disease.’.

The reviewer suggested not to use the term “positive” family history.

The authors agree and deleted “positive” in the manuscript if applicable.

Reviewer #2:

The reviewer would like to see discussed in what way the recruitment by means of an advertisement in a regional newspaper had been done and whether incentives were given to the participants, since this may have caused selection bias.

The information provided in the advertisement was marginal as we have now indicated in the method section, in addition to information on the incentive: ‘Participants were recruited by means of an advertisement in a regional newspaper, inviting people between 35 and 70 years of age to participate in a group discussion about the prevention of diabetes. It was indicated that they would receive an incentive of €25 (gift card). No further information was provided.’

We thus expect that bias was limited but we have added the following to the discussion: ‘It can be expected that people who are more interested in health or who are in need of money were more prone to have responded to the study invitation.’.

The reviewer argues that the finding that predictive testing is beneficial might be misrepresented in the abstract:

We agree with the reviewer that the term beneficial does not entirely represent the findings. Therefore we have adjusted the conclusion to: ‘The results suggest that most participants believe a predictive genetic test could be used in the prevention of multifactorial disorders, such as diabetes, but indicate points to consider before these tests are applied.’.

The reviewer indicates that the uncertainty of long-term effects on motivation to adopt a healthy behaviour should be explained more clearly.

Although in our study we only assessed participants perceptions not their intentions or motivation, we now report on the conflicting evidence for this effect in the discussion section: ‘Only few studies evaluated the impact of genetic risk information on motivation (or intention) to adopt healthy behaviour and report conflicting effects on actual behaviour change. Some participants in this study believed that genetic risk information could lead to fatalism, i.e. people being less motivated to change their behaviour. However, there is no evidence for such an effect.’.

The reviewer states that the authors make a claim about the justification of a public health approach in the discussion section that is contradicted by the remainder of the results: ‘Lay participants placed more emphasis on the freedom of choice in deciding to have a DNA test, whereas for a family history assessment autonomy was considered to be less relevant. Therefore, family history assessment might be more ready for a public health setting, as has been suggested by others.’
**Answer** Instead of DNA testing the authors refer in this statement to family history assessment, as we have now made more clear in the discussion section: ‘Participants placed more emphasis on autonomy with regard to the unrequested offer of a DNA-test, as they do not want to be offered such a test unless asked for, whereas this was not brought up as a condition with regard to a family history assessment. Moreover, with regard to a family history assessment, only one person indicated that it will be important to be able to accept or reject the test, thus stressing that participation should be voluntary. In general, we conclude that being offered a family history test was far less readily considered as a potential threat to autonomy than the offer of a DNA-test. Therefore, the former type of assessment might be more ready for a public health setting.’.

The reviewer wonders if the sentence ‘one participant mentioned that a family history assessment should be voluntary, while most participants believed that the DNA test should never be performed unless asked for.’ contains twice the same meaning

**Answer** In the sentence we refer to family history assessment in the first part and DNA testing in the second. To make this contrast more clear we adjusted the sentence and added more information: ‘While most participants believed that DNA tests should never be performed [or even offered] unless asked for, no such condition was suggested with regard to a family history assessment. Moreover, only one participant mentioned that having a family history assessment should be voluntary. For this test it was even suggested that it should be actively offered to the entire population.’. Thus people request DNA tests to be only performed when asked for and family history assessment should be a voluntary decision, but it can be offered.

The reviewer would like to have more focus on differences between the views of the different stakeholders.

**Answer** This aspect is not applicable anymore, as we excluded the professionals from the report (see reviewer #1). With regard to the lay participants, there is little difference between people with a family history, people without a family history and diabetes patients, see point 2 in response to reviewer #1

The reviewer would like to have the semi-structured interview guide published as an appendix.

**Answer** Although an outline of the questions is presented in the methods section we have now added the semi-structured interview guide that could be published as an appendix.

**General**

Sentences or words that have been added to the text are underlined. In the results section we have changed the order of the themes, the themes “informational privacy” and “autonomy” were exchanged.

Instead of Miranda Wijdenes-Pijl, Lidewij Henneman will be the corresponding author, as we have now indicated in the manuscript.

We hope these amendments meet with your approval. Please do not hesitate to contact me if you have any further queries.

Yours sincerely,
on behalf of all co-authors,

Miranda Wijdenes-Pijl

Department of Public and Occupational Health
EMGO Institute, VU University Medical Center
Van der Boechorststraat 7
1081 BT Amsterdam, The Netherlands
E-mail: m.pijl@vumc.nl
Phone: +31-20-4448381; Fax: +31-20-4448387.