Reviewer's report

Title: Impact of informed-choice invitations on diabetes screening knowledge, attitude and intentions: an analogue study

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Reviewer: Karsten Juhl Jørgensen

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General comments

There is no doubt that fear of reduced participation has led to screening invitations that emphasize benefits, directly encourage participation, and leave out information on important harms, and that this is going on today despite official statements that informed choice is the objective. This is certainly true in mammography screening and cervical cancer screening. The current manuscript therefore adds important data that can help dispel this practice and hopefully lead to more open and honest information about screening in the future.

However, the authors do not discuss how informed choice is a personal right in healthcare, rather than an option (although they do provide the relevant reference to the GMC). This right to information is particularly strong in screening where the health provider approaches the individual rather than the individual approaching the provider asking for their assistance. This right is independent from the question if full information changes the choice of the individual and thorough information should be given regardless. I think this point should be made clear in the manuscript.

I also miss a discussion of the evidence for diabetes screening. The authors state that they have written an evidence-based leaflet. But the evidence in this field is not strong. I particularly miss a reference to the 2008 systematic review on screening healthy adults for type 2 diabetes from the U.S. Preventive Services Task Force (Ann Intern Med 2008; 148(11):855-68). They conclude that: ’Direct evidence is lacking on the health benefits of detecting type 2 diabetes by either targeted or mass screening, and indirect evidence also fails to demonstrate health benefits for screening general populations. Persons with hypertension probably benefit from screening, because blood pressure targets for persons with diabetes are lower than those for persons without diabetes.’

In some places the authors generalise their findings too much. E.g. they begin their Discussion section with the following statement: ‘These results suggest that informed choice invitations that increase knowledge alone have little effect on attitudes or intentions, and would therefore be unlikely to reduce screening attendance. Attitudes and intentions to attend for screening were strong regardless of invitation type. Invitation type had a small indirect effect on intention, mediated by knowledge, but attitudes towards screening were the main
predictor of intention, and were unaffected by invitation type. The DICISION trial also found no difference in uptake by invitation type. I realise that caveats are mentioned further into the discussion, but I still think that this opening statement should be modified.

Evidently, whether the screening information will change attendance is highly dependent on whether or not the leaflet confirms previous beliefs. Since most people believe that screening for disease ('catching it early') is overwhelmingly good, it would take strong arguments to change that view. There may or may not be such strong arguments against diabetes screening, and these may or may not have been included in the leaflet intended to provide informed choice. The findings in this study may simply be due to the evidence based leaflet confirming already held positions, but now with the added bonus of some knowledge behind that view.

But if we look at a screening programme where there are certainly room for serious doubt, namely mammography screening, the result from this study may not be applicable. We have written and presented an evidence-based leaflet about mammography screening, which we presented in the BMJ last year (Gøtzsche PC BMJ 2009 Jan 27;338:b86. doi: 10.1136/bmj.b86). The leaflet is freely available in English and 12 other languages on our web site (www.cochrane.dk). Had the authors conducted a similar study using the official NHS BSP leaflet and our leaflet, I am not convinced that they would have reached the same results. A discussion of how the chosen information and the framing of this information may have affected the results would be welcome.

When the authors refer to evidence from other trials of the impact of informed choice on screening participation, it would seem fair to mention that the screening programmes explored in those studies were very diverse. E.g. prostate cancer screening and colorectal cancer screening are fundamentally different, with prostate screening aiming to advance the time of diagnosis of already developed cancers. Contrary, colorectal cancer screening primarily intends to identify pre-cancerous lesions (polyps). The balance between benefits and harms is therefore also very different, particularly concerning overdiagnosis, which in the opinion of many experts make prostate cancer screening an unattractive idea, while overdiagnosis is less frequent in colorectal cancer screening. The balance for colorectal cancer screening may therefore seem more favourable, and this difference could explain why informed choice in prostate cancer screening reduced uptake, but not so for colorectal cancer screening.

Specific comments

Page 4: The heading 'Method' is in the same fond and size as other headlines, yet there is no text under this headline. Is there text missing or is it meant as an overall headline for the subsequent ones?

Page 5: The method of enrolling patients by using research representatives in the street (perhaps those in need of diabetes screening are more prone to stay at home due to competing illnesses or obesity?), the need to accept a visit in your
home (selection bias), the quota of 50% with no more than basic school education (representative sample?), drawing information leaflets from a randomised pile (was the order of the pamphlets visible, and could there be a selection at this stage?), verbal rather than written questionnaires (more screening-positive responses in order to ‘please’ the interviewer?), receiving a 5 pound compensation (selection bias), and the hypothetical nature of the screening programme (no one actually had to stand by their claimed intention to participate) are all clear potential sources of bias. This should be thoroughly discussed as such. Currently, only the hypothetical nature of the screening programme is mentioned as a limitation in the Discussion.

Page 6: When describing the informed choice leaflet, it would be helpful with a short description of which benefits and harms were mentioned, and how they were described, and why (were absolute or relative risks used, were there information about how participants will risk having to take medicine for the rest of their lives, which has potential side-effects, and that there is a substantial possibility that they will be taking this medicine without any benefit to their health? Etc.). Why did you choose the information you did, and why did you present it in the way you did? I realise that you have presented the actual leaflets in a previous publication but this publication should be informative enough to evaluate this on its own.

Page 8: I would like some explanation for using detailed scales to indicate likelihood of participation. In real life, there are only two options: you attend, or you do not. There is no option of partial participation.

Page 9, last paragraph: ‘278 participants viewed one of the invitations designed to facilitate informed choice.’ This could be misunderstood as if there were more than one leaflet intended to promote informed choice. As I read your previous description, there was only one, or am I mistaken?

Page 10: ‘Intentions were slightly higher in the informed choice group’. Intentions to attend?

Page 13: There is an unfinished reference to Fox?

Reference 20 lacks a journal title.

I would like to note that the type of statistics and statistical modelling used are not all that familiar to me. The Editor may want to seek a more statistically qualified assessment of this part of the manuscript.

**Level of interest:** An article of importance in its field

**Quality of written English:** Needs some language corrections before being published

**Statistical review:** Yes, but I do not feel adequately qualified to assess the statistics.
Declaration of competing interests:

I declare that I have no competing interests.