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## Executive summary

Health Council of the Netherlands. Population Screening Act: research into familial risk in the screening programme for bowel cancer. The Hague: Health Council of the Netherlands, 2014; publication no. 2014/24.

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In this advisory report the Committee on Population Screening of the Health Council of the Netherlands assesses a license application for scientific research by the Radboudumc in Nijmegen. The study aims to ascertain if (extra) anxiety is associated with an online questionnaire form familial risk for bowel cancer within the regular population based screening programme for bowel cancer. At the request of the Minister of Health, Welfare and Sport the committee advises about the license application for this study within the framework of the Population Screening Act.

According to the guideline ([www.oncoline.nl](http://www.oncoline.nl)) familial bowel cancer more intensive screening is advised for people with an increased familial or hereditary risk for bowel cancer than in the regular national population based screening programme. The use of an online questionnaire can standardise and facilitate the detection of these families, but could also cause extra anxiety. The committee finds it useful to examine this. However, on the condition, that the control group is omitted, as it has no added value for this research.

The committee finds that the provision of information, the informed consent procedure and the complaints procedure correspond with the requirements of the WBO, on the condition that it will be clearly explained that there can be consequences for nearest family members as well.

The burden of the study is limited to filling out a questionnaire on two occasions. Screening every six years with colonoscopy means a cumulatively higher risk of complications for these people. However, even then complications

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are rare. And according to the committee, the expected benefits of more intensive screening for people with at least three times higher risk for bowel cancer than average, would outweigh the extra risk of complications. Therefore the benefit risk ratio is considered positive.

The committee has one final condition, that it at least will be registered how many people (participants and family members) with increased familial risk for bowel cancer are found by this research and how many of them conform to the guideline.

The committee recommends the Minister of Health, Welfare and Sport to grant the license under three conditions:

- 1 the control group will be omitted
- 2 it will be clearly explained that there can be consequences for nearest family members as well
- 3 it will be registered how many people (participants and family members) with increased familial risk for bowel cancer are found by this research and how many of them conform to the guideline.