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# The Effect of Presenting Information about Invasive Follow-Up Testing on Individuals' Noninvasive Colorectal Cancer Screening Participation Decision: Results from a Discrete Choice Experiment



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#### ABSTRACT

Objectives: Many national colorectal cancer screening campaigns have a similar structure. First, individuals are invited to take a noninvasive screening test, and, second, in the case of a positive screening test result, they are advised to undergo a more invasive follow-up test. The objective of this study was to investigate how much individuals' participation decision in noninvasive screening is affected by the presence or absence of detailed information about invasive follow-up testing and how this effect varies over screening tests. Methods: We used a labeled discrete choice experiment of three noninvasive colorectal cancer screening types with two versions that did or did not present respondents with detailed information about the possible invasive follow-up test (i.e., colonoscopy) and its procedure. We used data from 631 Dutch respondents aged 55 to 75 years. Each respondent received only one of the two versions (N = 310 for the invasive follow-up test information specification version, and N = 321 for the no-information specification version). Results: Mixed logit model results show that detailed information about the invasive follow-up test negatively affects screening participation decisions. This effect can be explained mainly by a decrease in choice shares for the most preferred screening test (a combined stool and blood sample test). Choice share simulations based on the discrete choice experiment indicated that presenting invasive follow-up test information decreases screening participation by 4.79%. **Conclusions:** Detailed information about the invasive follow-up test has a negative effect on individuals' screening participation decisions in noninvasive colorectal cancer screening campaigns. This result poses new challenges for policymakers who aim not only to increase uptake but also to provide full disclosure to potential screening participants.

Keywords: colorectal cancer, conjoint analysis, public health, preferences, The Netherlands.

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### Introduction

Many national colorectal cancer (CRC) screening campaigns have a similar structure in that, first, individuals are invited to take a noninvasive screening test (e.g., fecal occult blood test [FOBT]), and, second, in the case of a positive screening test result, they are advised to undergo a more invasive follow-up test (e.g., colonoscopy). Previously, in the literature on participants' CRC screening preferences, little emphasis has been placed on this multilayered character of national campaign-based CRC screening. Several studies investigated the preferences of the general public for noninvasive screening tests only [1–5]. For example, Nayaradou et al. [4] studied the French public's preferences for noninvasive screening tests while Benning et al. [1] recently

studied preferences for innovative noninvasive screening tests in The Netherlands. Other studies simultaneously elicited preferences for noninvasive screening tests and invasive tests by allowing individuals to also choose direct invasive "follow-up" testing without participating in noninvasive screening first [6–11]. Marshall et al. [9], for example, found that the greatest impact on uptake might be achieved if all endorsed CRC screening tests were available, including FOBT, double contrast barium enema, flexible sigmoidoscopy, colonoscopy, and computed tomography colonography, instead of limiting the choice to FOBT.

Likewise, in several recent studies in which CRC screening preferences of the Dutch population were investigated [6,8,11], individuals also had a direct choice between noninvasive (i.e., FOBT) and invasive tests (i.e., flexible sigmoidoscopy or

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colonoscopy). Van Dam et al. [11], for example, found that improvements in the awareness on CRC mortality reduction and the use of shorter screening intervals may increase screening participation in such a setting. Furthermore, Hol et al. [8] found that a flexible sigmoidoscopy and colonoscopy were preferred over FOBT by both naive as well as previously screened subjects and that risk reduction (RR) dominated screening preferences. Moreover, by comparing the results of a labeled and unlabeled discrete choice experiment (DCE), De Bekker-Grob et al. [6] found that the use of a labeled design increased the validity of the results but that the use of labels also reduced the attention given to the attributes. For a more exhaustive overview of previous DCE-based studies about CRC screening, we refer to Table 1.

A possible limitation of the aforementioned studies is that, in Europe, large-scale CRC screening campaigns more commonly use a multilayered approach in which noninvasive screening tests are followed by a more invasive follow-up test (colonoscopy) in case of a positive screening test result [12]. This screening procedure is also used in the Dutch screening campaign that recently started in 2014. Therefore, in this research, we extend previous analyses by investigating an intermediate approach that varies how much information about possible invasive follow-up testing is provided to participants in a noninvasive screening context without offering the option to directly choose such an invasive test. Specifically, we were interested in knowing how much individuals' participation decisions in noninvasive screening are affected by the presence or absence of detailed information about invasive follow-up testing and how this effect varies over screening tests. Despite the fact that most of the earlier studies on noninvasive screening implicitly addressed the issue of follow-up testing by including attributes such as the number of false-positives or unnecessary colonoscopies [1-5,9,10,13,14], none of these focused on how providing detailed information about a future invasive follow-up test (e.g., colonoscopy) affects individuals' participation decision in campaign-based noninvasive CRC screening-in this study, two separate versions of a discrete choice survey were used to explicitly address this issue. One notable exception is Marshall et al. [10] who included an attribute about the possible need for follow-up testing in their DCE and investigated how physician assessments of patients' preferences differed from actual preferences. They did not, however, provide specific information about the follow-up test and there was also no contrast made between presenting detailed follow-up test information to respondents or not. Note, furthermore, that the attribute "need for follow-up testing" was found to be nonsignificant in their study.

We propose that in individuals' willingness to participate in screening, the possible need to undergo a more invasive follow-up test is likely to also be of influence. The reason is that the consideration of future consequences has been found to play a role in forming intentions regarding screening participation [15]. In particular, we predict that providing extensive information about the follow-up test affects individuals' screening participation decisions. It is likely that individuals will more carefully consider this type of information for their participation decision when it is explained in detail and that this may lower the probability of participation, in particular when the follow-up test is invasive. More specifically, it may lower the probability of participating in more sensitive and less specific tests (e.g., a combi test) because this type of test is more likely to lead to (unnecessary) follow-up testing.

In short, this article specifically addresses the issue how presenting information about the possible future invasive follow-up test affects individuals' decision to participate in noninvasive screening by means of a DCE in the field of CRC screening. Screening for this disease provides a suitable context for our research because it matches the typical multilayer character of

screening quite well (i.e., a noninvasive screening test followed by an invasive follow-up test in case of a positive screening test result). Furthermore, the yearly prevalence and mortality rates for CRC are high enough that several countries provide regular screening invitations to the population.

Based on the fact that individuals have rather limited knowledge about CRC screening and the embarrassing and uncomfortable nature of follow-up testing [16–18], we hypothesize that when individuals are extensively informed about the invasive follow-up test (i.e., colonoscopy), screening uptake in our DCE context may be lower than in the situation in which this is not the case. Moreover, we predict that there is a negative moderating effect of follow-up test information on the preference for the combi test relative to the blood and stool tests due to the combi test's higher likelihood of providing false-positive test results. We particularly focus on the effect that the presentation of detailed follow-up test information has on expected screening uptake because of the relatively low expected CRC screening participation rates in The Netherlands [19,20].

#### **Methods**

#### DCE

DCEs measure individuals' preferences for goods and services [21–23]. The technique is increasingly used for health care purposes, such as the evaluation of health care interventions [24]. It describes interventions in terms of specific attributes (i.e., characteristics), which each take on different (attribute) levels. The levels of the attributes are varied on the basis of an experimental design that defines a series of tasks that describe two or more interventions from which individuals are asked to choose the one that they prefer the most [21–23]. A DCE has several advantages over less complicated methods such as alternative survey designs because it enables one to investigate many types of questions [25] related to, for example, the relative importance of and trade-offs between attributes or the prediction of market shares (i.e., the percentage of people expected to choose a particular screening test relative to other available tests).

#### Selection of attributes and attribute levels

In the two follow-up test specification versions of the survey, the attribute follow-up test was either present or absent, and it presented information about the type of follow-up test that is conducted in the case of a positive screening test result (see below for further specification). This attribute was included to be able to address our main research question whether presenting detailed follow-up test information affects individuals' screening participation decision. We based the attributes of the three screening tests on a review of studies that have previously measured preferences for CRC screening tests by means of discrete choice and conjoint analysis methods. The attributes that we selected are sensitivity, the number of unnecessary colonoscopies (i.e., false-positive test results), the RR of CRC death, the scientific level of evidence, and the follow-up test used after a positive screening test result. The first three attributes are used most frequently in the reviewed studies [2-11,13,14], and their importance was also confirmed by experts in the field (n = 3). Strength of the evidence is also relevant in health care decisions [5,26,27], and therefore the fourth attribute was included to indicate this aspect of the test. Individuals may consider the scientific evidence of CRC screening tests in their screening participation decision [28].

The attributes' levels were selected using the previously described review of studies and were also validated with opinions of the three earlier mentioned experts in the field of CRC screening. Furthermore, we studied CRC-related mortality-risk data from

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