# Willingness to pay for preconception expanded carrier screening: a discrete choice experiment

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# Summary

**Objectives**

At the moment, 1% of European couples are at risk of having a child with an autosomal recessive disease (ARD). For most of these couples, this risk is unknown as being only a carrier of an ARD is not a threat. Preconception expanded carrier screening (ECS) aims to provide couples information regarding their carrier status for their reproductive decision making. However, there are still barriers to undergo ECS in the Netherlands and not much research is available regarding to willingness to pay (WTP) and the preferences regarding the features of an ECS. To fill the current knowledge gap, the objective of this study is to gain insight in the WTP for ECS and individuals' their preferences.

**Methods**

A discrete choice experiment (DCE) was constructed to get information of the trade-offs individuals make across 5 attributes that are believed to be important features of ECS: price, information provision, diseases screened, accuracy and provider. The data gained from the DCE was analyzed using two mixed logit models, one including demographic interaction effects and one without.

**Results**

In total, 481 individuals between 18 and 40 years with a child wish and whom are open to ECS participated in the DCE. The price attribute dictated the respondents choice the most, followed by the accuracy. It was estimated that participants were willing to pay €1165.20 for the best rated ECS available in the Netherlands. Having knowledge of ECS prior to the DCE and having a partner were the respondent characteristics that increased the WTP the most and having a degree in higher education or having children had the largest decrease.

**Conclusions**

The WTP is higher than estimations done in the past. In addition, the WTP for ECS is higher than current costs of ECS for most of the sample. Being informed about ECS was shown to increase the WTP substantially. However, there is still a demand for commercial screenings that are less expensive, accurate, transparent than screenings offered by university hospitals, which may be a reason for concern.

# Table of contents

# 1. Introduction

Each year, more than 7 million children are born worldwide with a congenital disease, not including diseases that are expressed later in life. Most of these congenital diseases have a genetic cause, and are therefore called genetic congenital diseases[1]. Many of the children are born completely unexpectedly with genetic congenital diseases, due to the diseases having a autosomal recessive origin (ARDs)[2]. It is believed that 0.8-1% of European couples are at risk of having a child with an ARD[3].

Getting a child with an ARD is virtually always caused by both the parents carrying one or more mutated genes. A lot of parents are not informed about being a carrier of an ARD as being a carrier alone is not a threat to the individual. However, if both partners are carriers of the same ARD, a probability exists for offspring to be affected by this disorder[2].

Most individuals carry multiple ARDs of which the represented diseases differ in severity. It is estimated that on average individuals carry more than 2 genes that can cause ARDs, of which 0.29 have a possibility of causing sterility or childhood death[3,4]. One prevalent disabling and life-shortening example is Cystic Fibrosis (CF), which affects the lungs and digestive system. Of those of Northern European descent, 1 in 25 individuals carry CF[5].

Many ARDs cause disabilities to those affected and a burden to their loved ones[6,7,8]. For this reason, many efforts have been and are being done to provide opportunities in terms of early treatment to those affected and to battle the overall incidence of ARDs. This is for a big part done by providing technologies that analyse whether individuals are carrier of an ARD, as they are caused genetically.

One of these technologies is Next Generation Sequencing (NGS), which has been introduced and developed during the last two decades to the point where it is being implemented in clinical and even commercial settings. Due to NGS, mapping genomes has become faster, less expensive and more accurate[1].

These developments make way for expanded carrier screening (ECS), where the genome of couples with a child-wish gets screened to check whether they are carriers of the same ARD[2]. This screening gives couples insight in the existence of a probability of having a child with an ARD. Therefore, ECS test-results can be particularly informative for reproductive decision making[2].

The objective of ECS is to inform couples about the existing risks of having a child with an ARD. This can be done prenatally (after conceivement) or preconceptionally (before conceivement)[2]. Both possibilities occur in healthcare or in research context, although the utilization of this screening in the Netherlands is still lagging behind compared to other countries. Currently there are multiple countries that fully implemented ECS in their health care system, such as Israel, Italy, Australia and the United States[10].

At the moment, there are only guidelines and reimbursements available regarding preconception ECS for high-risk groups in the Netherlands. This has proven to be effective for these groups in terms of informing couples about the possibility of affected offspring[11]. Couples are thought to have a higher risk of having a child with an ARD when the individuals are family from each other, if someone or his/hers ancestors originate from an area or country with a higher ARD incidence, if ancestors belonged to the Ashkenazi Jewish population or if carriership or a hereditary disease runs in the family[12].

However, preconception ECS has also proven to be effective and feasible when targeted at the general population in the Netherlands[12]. There is a lot to be gained for this group as hereditary diseases also occur outside of high-risk groups. In the Netherlands, ECS is (limitedly) available to the public from two university hospitals and commercially (direct-to-consumer)[13,14,15]. Even so, these available screenings are not in any way reimbursed and have a cost of €450 to €675 per person when done in one of the two university hospitals.

Moreover, studies show that the majority of the Dutch population has a positive attitude towards preconception ECS when informed about this option, even though there are barriers for couples to actually undergo ECS[16]. One of these barriers is the pricing. The median of the willingness to pay (WTP) for ECS for couples in reproductive age, is estimated to be €75[17]. Since the median WTP is less than the cost of ECS, implications are shown in the

accessibility of ECS. However, this WTP evaluation is based on a fixed ECS offer, with no information about what aspects might affect the WTP[17].

Previous research shows that the costs and WTP of preconception ECS are partly influenced by characteristics/attributes of the test, such as the provider of the test, test accuracy and what support/counselling couples get[17,18]. How the WTP is affected by these attributes is currently unknown. If there is a deeper understanding in the valuation of the different characteristics of ECS by couples with a child-wish, a balance could be created in the couples' wishes and costs, and give providers better insights in couples their preferences. Tailoring ECS to the preferences of couples could make ECS more accessible for them, thereby providing more couples with an informed choice.

To fill the current knowledge gap regarding the valuation of preconception ECS and its features in monetary terms, the aim of this research is to provide insight in the WTP for preconception ECS of individuals with a child-wish and who are open towards ECS. Therefore, the main research question is formulated as:

> What is the willingness to pay for preconception expanded carrier screening and its features of individuals with a child-wish and who are open towards ECS?

Furthermore, it is also believed that the demographic characteristics of an individual have an effect on how preconception ECS is valued in terms of WTP. As the accessibility of preconception ECS for the general population of the Netherlands is still believed to have implications, this study also aims to address which and to what extent respondent characteristics have an effect on this valuation in terms of WTP.

At last, this study addresses whether changes are needed in the pricing and features of currently available preconception ECS. As discussed earlier, previous studies have evaluated the WTP to be much lower than the actual current pricing of preconception ECS[17]. To re-evaluate this observation, this study will look into how individuals value currently available screenings and screening feature compositions that could possibly be offered in the future.

# 2. Background

## 2.1 Genetic testing and screening

Genetic tests are a tool to extract hereditary information from a person. The first genetic tests were done in the second half of the previous century and involved counting the number of chromosomes, the molecules that hold hereditary information. As time progressed, the technology regarding genetic testing became more advanced, making it possible to map whole human genomes. This advancement ultimately led to the possibility to link human traits to their hereditary information. These human traits also involved disorders of which was found that they had a genetic origin. This information influx is still ongoing and has already proven to be a substantial support in healthcare[19,20].

To utilize information from genetic testing in health care, the technology also had to progress in practical ways. DNA sequencing had to become less costly, faster and more precise[9,20]. These developments were accelerated by the arrival of Next Generation Sequencing (NGS) which involved high-throughput approaches to sequence DNA. During the last two centuries a lot of improvements were made in NGS, bringing genetic testing to the point of using it in health care, where it is used to pinpoint disorders or diseases a person suffers from and finding the right treatment[20]. Next to finding diseases a person already suffers from, genetic testing is also being used to prevent the consequences of diseases by providing early or prior treatment or informing (prospective) parents about the risk of getting a child with a hereditary disease. This latter option is called screening and can be applied during (prenatal) or before pregnancy (preconception)[21].

With regards to genetic screening concerning pregnancy, a commonly executed type of screening in the Netherlands is the non-invasive prenatal testing (NIPT), a prenatal screening method where the parents get information about whether their baby has any congenital disorders after conceivement. NIPT analyses cell free DNA in the maternal blood which is drawn with a needle and syringe and is considered safe to the fetus and mother[22]. Although the NIPT is considered as an advantageous screening compared to other prenatal screenings due to its non-invasive nature, it only screens for nondisjunction conditions (conditions due to chromosomal abnormalities) such as Down, Patau and Edwards syndrome[22]. Other prenatal genetic tests that are more diagnostic in nature and often deployed after positive

results in a NIPT, such as chorionic villus sampling and amniocentesis, also share this limited amount of tested congenital disorders[21].

Preconception screening (PCS) is different to prenatal screening in terms of the techniques utilized, the genetic diseases that are tested, the outcome and when in the pregnancy the screening is applied[20,21]. Preconception screening is executed before conceiving and allows for more decisions and options for action that can be made than prenatal testing only. Additionally, it allows the parents to get a risk assessment that can later be verified using a prenatal test. PCS is processed the same way as many genetic tests, with a great variability in the NGS techniques that can be used and what diseases it tests for. The NGS techniques available are different in terms of processing speed, costs and accuracy[20]. Even though the way preconception carrier screening is carried out can vary, the goal of PCS is specific as it functions as a tool for couples to make an informed decision about getting pregnant.

Most preconception carrier screening programs test for more than one congenital disorder and are therefore called preconception expanded carrier screenings (ECS)[21]. Preconception ECS has been included in the health care system in several countries, and has already proven itself in terms of decreasing the overall burden of disease, to those affected and to their loved ones. In addition to a decrease in the burden of disease, the screening is also cost-effective[6,7,8], although calling it cost-effective is still controversial and a point of ethic discussion[23]. Being able to test for the possibility of conceiving a baby with one of the many tested congenital diseases can lead to complex decisions.

Due to prospective parents being informed about the possibility of having a child with a congenital disorder, a congenital disease can be diagnosed and in some cases treated early, decreasing the burden of disease and therefore future health-related costs in many cases. Being informed about the risk also gives couples the choice of not getting a baby (with the current partner), adopting a child or getting pregnant through in vitro fertilisation (IVF) and select an embryo without a genetic abnormality[21]. The latter mentioned choices have to be made before conceiving.

## 2.2 Genetic disorders

A genetic disorder is a disorder that one is born with and that could manifest itself at birth or later in life. Genetic disorders that are present at birth are called genetic congenital disorders and most of these disorders are due to mutated genes inherited from one's mother and father. In general, inherited congenital disorders can be categorised as autosomal recessive, autosomal dominant, X-linked or Y-linked[24].

X- and Y-linked genetic disorders are caused by mutations on the sex chromosomes and can be dominant or recessive of nature. Autosomal dominant disorders need only one mutated gene to manifest, coming either from the mother of the father. In virtually all cases, the risk of conceiving a child with an autosomal dominant disorder is clear beforehand, as either the mother or father (or both) suffer from the same disorder[24]. For autosomal recessive disorders, two versions of the same mutated gene, inherited from both the mother and the father, are needed for the disorder to manifest. When a person inherits only one mutated gene that is linked to an autosomal recessive disorder, he or she is called a carrier[21,24].

Being a carrier of an autosomal recessive genetic disorder (ARD) does not bring implications for the person carrying it, as the disorder is not expressed in their phenotype. However, being a carrier can bring implications when the person is planning to have a child with someone who is carrier of the same disease. When two partners both are carrier of the same ARD, the chance of their child having that disorder is 25% in case of autosomal recessive genetic disorders[2]. It is estimated that each person carriers on average 1-2 or more ARDs that can cause severe disorders or prenatal death, of which 0.29 cause sterility or death before reproductive age[5]. These numbers and more disease-specific numbers vary for each region in the world. For instance, the number of people who are carrier of sickle cell anaemia, a severe disorder that affects the amount of red blood cells, is more than 30 times higher for Africans than for other populations[25].

While the risk of getting off-spring with a congenital disease can be perceived as small for some, the implications that risk holds can be very serious and live threatening. There are many different types of ARDs, differing in age of onset, severity, and whether treatment is possible or not. A preconception carrier screening can test for all possible ARDs, but the diseases ECS tests for in the end depend on the incidence of a particular disease in a country, carrier frequency, the severity and how much scientific knowledge about the genes that cause

the disease is deemed as enough. In addition, it also depends on the social-ethical considerations within a country whether they are more conservative or pro-active in terms of screening. For instance, in Australia panels are used that test for more than 400 ARDs[26], while in the Netherlands panels of 50 ARDs are currently used[27].

Preconception ECS is aimed at testing for the presence of ARDs and X-linked recessive disorders because the risk for disorders that are genetically dominant in nature is already clear, as at least one of the parents should already be expressing that disorder in their phenotype[24].

### 2.3 Currently available carrier screening programs

In some countries preconception ECS programs have already been implemented in their public health care system and/or are offered by private companies. At first, carrier screening programs were aimed at high-risk groups in which certain disorders were relatively more present than in other groups. Israel for instance initiated in 1971 their first carrier screening program for Tay Sachs disease, aimed at the Ashkenazi Jewish community where this lethal disease was very common[28]. Much later due to ethical issues, in the 2000s, carrier screening for high-risk groups were offered in the Netherlands[29].

During the last two decades more room became available to offer carrier screening programs to the general public due to lower costs, a more open look towards such screening and because there is still a lot of prevenTable suffering in lower risk groups. Currently there are multiple countries that implemented preconception ECS to their health care system, such as Israel, Italy, Australia and the United States (US)[10]. Of these countries, Israel is the only country that has implemented a national program regarding genetic carrier screening[10,30]. Other countries offer preconception ECS through private providers, which also means that out-of-pocket payments have to be made[31,32].

In the Netherlands several options are available regarding preconception ECS. Two university hospitals offer the screening. The Amsterdam University Medical Center offers a screening that tests for 50 ARDs and asks for €650 for each person that undergoes the screening[15]. The preconception ECS offered by the University Medical Center Groningen tests for 70 ARDs for €950 per couple[14]. Even though carrier screening for the general public is available in the Netherlands, there are not many people that actually undergo the screening.

The low uptake is thought to be due to couples being uninformed about the possibility of a preconception ECS. Other causes might be the out-of-pocket payments that have to be made, as the screening is not in any way covered by health insurance for the general public, and other practical hurdles in the way the screening is organized[16]. To make preconception ECS more accessible and to ultimately implement it population-wide, the current hurdles have to be overcome by tailoring preconception ECS to the wishes of informed couples that are interested.

### 2.4 Preferences of couples regarding preconception expanded carrier screening

There have been several studies regarding the preferences towards preconception expanded carrier screening (ECS) of the Dutch population. Most recently, a qualitative study by Bijsterbosch was reported, where the most important aspects/attributes of preconception ECS were investigated by conducting interviews with 11 individuals with partners who recently had a child or were planning to[18]. Important aspects that were discussed with the participants were the costs, test reliability, the providers of the screening, the time that couples have to await the test-result, the guidance/counselling, whether the test has to focus on the combined or individual results and what disorders the screening should test for[18].

According to this study, test reliability was the most important aspect followed by the support/counselling, severity of the diseases screened and the costs. These aspects affect whether the participants would undergo ECS. The study mostly gave insight in the reasoning behind the indicated preferences of the participants. Many aspects seemed to be intertwined in some way, such as the costs and the test reliability. Participants were suggesting that they would allow higher costs, as they felt that higher costs would mean that the test would be more reliable[18].

Another study, by Plantinga et al., evaluated various preferences for preconception ECS through a survey among 500 individuals in reproductive age with a partner. During the survey design an explorative qualitative interview study was held with 20 potential preconception ECS users to explore which factors influenced participation in ECS. The following aspects/attributes were found to be important: the provider of the test, support/counselling, what diseases are screened, costs and information provision[17]. Finally, the following aspects were evaluated using a survey with the 500 participants: type of

guidance, hereditary diseases screened, provider of the screening and the willingness to pay (WTP)[17]. Noticeable findings were that most of the respondents preferred a face-to-face consult (37%), the general practitioner (GP) to be the provider (44%) and 58% of the respondents were willing to pay for the screening, with an amount ranging from €5 to €5000 and a median of €75 per couple. Furthermore, a complementary study investigated the preferences towards couple-based vs. individual ECS test-result. Plantinga et al. felt the need to research this, as the regular procedure in the US entails an individual ECS test-result is, while it has almost no function in predicting offspring risk[33].

In the US, Clarke et al. assessed the WTP for preconception ECS of couples and woman who were planning to undergo ECS. The proposed ECS tested for the carrier status of 728 autosomal recessive, mitochondrial or X-linked conditions. The participants (n=309) were asked how much they were willing to pay for ECS using 5 categories (0$, $1-20, $21-100, $101-300, $301-1000+). Most of the participants (40%) were willing to pay between $21 and $100, followed by $101 to $300 (29%)[34].

### 2.5 Commercial vs noncommercial ECS offers

Previous WTP studies regarding preconception ECS outline that the WTP is far lower than the current prices of preconception ECS in the Netherlands by medical providers [14,15,17,34]. Commercial companies offer direct-to-customer preconception ECS for lower prices than medical-based instances, with more disorders and diseases that are being tested for[16].

In the Netherlands there is a commercial provider of genetic tests that also gives information on carrier status. The costs of such a test are €169 per person which is substantially lower than current medical-based offerings and the test can be easily purchased online without guidance of a professional[10]. The pricing, number of conditions that are screened, low practical barriers and the amount of additional information that is given might persuade individuals to purchase a preconception ECS from a commercial provider[13].

Whether the availability of commercial genetic tests for health-related purposes is a positive development is disputed. The commercial genetic tests are not approved by a health authority and no information is given on what technologies are being used or the accuracy of their genetic tests. Commercial genetic test providers have no minimum standards in what DNA

sequencing technologies have to be utilized, as long as disclaimers are given that the results should not in any way be used for medical and reproductive decisions. However, the projected outcomes and test characteristics might imply to individuals that there are health-benefits and that the results can be used for risk evaluation and reproductive decisions[35]. These assumptions might ultimately mislead individuals and/or couples that are aiming for informed decision-making regarding pregnancy, as no guarantees are given by the commercial providers.

### 2.6 Conclusion from current literature regarding preconception ECS

Current Dutch literature gives an idea about what the population thinks are important attributes of preconception ECS. These are the attributes reliability, price, diseases being screened, guidance during ECS, the provider of the screening and whether the screening should be focused on the individual or on the couple[16,17,18,33]. However, there are no adequate WTP studies regarding preconception ECS in the Netherlands and International WTP studies are scarce and it is unclear whether they apply to the Netherlands. Overall, available literature suggests that the WTP is lower than the actual price[16,17,33], which might push individuals towards commercial direct-to-customer offers, but it is hard to tell the true WTP of couples/individuals that are open to preconception ECS in the Netherlands. In the study by Plantinga et al. it cannot be fully concluded because there is not much information available about the WTP range and the WTP rates[33].

Clarke et al. reports more information on WTP but cannot be used as an example because the study is based in the United States. Additionally, the findings may not reflect actual behaviour because the respondents were already planning to undergo ECS and may have had more insight in the actual price[34].

Besides the mentioned weaknesses of the current available studies, another weakness is that making certain claims regarding the WTP for preconception ECS may not be fully plausible or valid, as results vary across different test characteristics[18].

There have been no studies of which the design allows the evaluation of utility and trade-offs regarding the different preferences. To fill this knowledge gap, the method of choice for this study is a discrete choice experiment (DCE).

### 2.7 Method of choice: Discrete choice experiment

A DCE is a method in which the utilities or preferences of (the attributes of) a health commodity are derived indirectly. The term 'utility' can be seen as a type of value, that is used to measure the extent of goal-achievement. Utility can also be translated in monetary terms, such as WTP[36]. Preferences can be defined as "statements made by individuals regarding the relative desirability"[37]. Measuring preferences allows researchers and policy makers to assess the (un)desirability of certain products, situations or states and make informed choices.

The experiment itself consists of a series of choice-tasks in which participants have to make choices between a set of hypothetical offers. A hypothetical offer is described using attributes that characterize the offer. Each attribute has different 'levels', by which the offers vary. In WTP DCE studies, price or costs is always one of the attributes, which allows the translation of utilities into monetary values. An example of a choice-task is asking a participant if he/she prefers paying €1000 for an ECS test with 100% reliability or €200 for an ECS test with 95% reliability. This way one can determine with statistical models how much an individual is willing to pay for a higher reliability and vice versa[38].

DCE is an indirect method, because the utility is derived from certain trade-offs respondents have to make and not asked directly as in the contingent valuation method (CVM). DCE also fixes some limitations CVM has. Ethical protesting (not stating true WTP or preferences) is less of an issue in DCEs as respondents are more inclined to make a decision between the offers when they have choices[39]. DCEs also have practical advantages compared to other valuation methods such as time trade-off. Firstly, the task complexity is lower due to a lower chance for a respondent to feel indifferent about the two choices. This makes respondents answer more corresponding their real behaviour compared to stated preferences. Secondly, many choice tasks per respondent are feasible without the respondent becoming fatigued, providing a higher statistical power[38]. At last, a DCE can be conducted in unattended surveys which means more individuals can participate in a given timeframe than other methods. For the current study, DCE is thought to be the right research method because of its feasibility and the amount of vignettes that can be assessed thoroughly and compared to each other

(including price), making it a perfect tool to assess the trade-offs individuals make and compose an ECS according to their preferences.

DCEs are considered a reliable option to obtain preference utilities and WTP for health technologies[40,41]. DCE studies on ECS and WTP of ECS are currently lacking. Instead, Table 1 lists current studies regarding screening, DCE, preferences and WTP.

**Table 1-** Summary DCE studies

| **Author and year** | **Study** | **Attributes** |
|---|---|---|
| Hill 2012[42] | Women's and health professionals preferences for Down syndrome prenatal tests | Accuracy, waiting time results, risk of miscarriage, information from test |
| Barrett 2017[43] | Women's and HPs preferences for Down syndrome non-invasive prenatal testing | Accuracy, cost, risk of miscarriage, waiting time results, information provided |
| Buchanan 2019[44] | Preferences and WTP of HPs for screening of inherited cardiovascular disease | Costs, Counselling, Reliability, Sensitivity regarding pathogenic mutations |
| Regier 2009[45] | Preferences and WTP of families of affected children for prenatal idiopathic developmental disability screening | Incidence positive screening, Time waiting for results, Costs |
| Hill 2004[46] | Preferences of Adult Patients, CF Carriers and HPs for CF prenatal screening | Accuracy, waiting time results, no miscarriage risk |
| Hall 2006[47] | Participation factors for Tay Sachs and CF prenatal screening of the general community and an Ashkenazi Jewish | Doctor recommendation, individual or couple result, Provider, False-negative probability, cost, Risk CF with mild symptoms vs severe, screening uptake within community |

Table 1 shows that many attributes are in line with findings regarding preconception ECS preference studies such as costs and accuracy[18,33]. But some attributes differ, due to different types of screenings that are being studied. What preconception ECS does not have in common with many other types of screening is that safety is not an issue, as the treatment is mostly carried out before conceiving and involves a non-invasive genetic test[42,43,46].

Additionally, the most important attributes seem to differ between health professionals and mothers. Health professionals seem to value screening reliability while mothers think safety is more important[42,43]. Nevertheless, risk-groups and communities or general populations seem to make similar trade-offs[47].

The studies that included WTP show higher values of WTP than the earlier discussed preconception ECS studies show[33,45], which may be due to the respondents having experience with disability and therefore are more aware of the burden or implications of disease[48]. At last, the most mentioned limitations were regarding hypothetical bias, attributes not being inexhaustible and samples not representing the target population and that stratification should have been done. Additionally, one of the studies used 7 attributes[47], which may cause the participants to fatigue, decreasing the reliability of the results[49].

# 3. Research methods

### 3.1 Discrete choice experiment

The method of choice for this study will be a discrete choice experiment (DCE). As discussed in the background (page 14), respondents in a DCE have to make choices between hypothetical offers. A DCE consists of multiple choice tasks and each choice task contains multiple offers, each consisting of at least two mutually exclusive options. The respondents are invited to choose the option which they prefer most[38].

**Figure 1-** Example DCE choice task

| Attribute | **Test option 1** | **Test option 2** | **Test option 3** |
|---|---|---|---|
| *Costs* | €500 | €1000 | Opt-out |
| *Accuracy* | 80 out of 100 tests have a correct result | 95 out of 100 tests have a correct result | |
| | Select | Select | Select |

In figure 1, an example of a choice task is shown. A respondent has to make a choice out of three options: options 1, 2 or opt-out. Options 1 and 2 of the choice task are made out of two attributes: costs and accuracy. Each attribute has multiple levels that make possible options vary between choice taks. The 'Costs' attribute has for instance two levels shown in this choice task: €500 and €1000. The respondent is asked whether he/she prefers a test that costs €500 with an accuracy of 80% or a test that costs €1000 with an accuracy of 95%. There is also an opt-out option (Option 3), which a respondent can choose if both other options do not comply with his or hers preferences. The respondent will choose the opt-out option if for example €500 euro is thought to be more than he or she is willing to pay for a test regardless of the accuracy, or if 95% accuracy is thought to be too low.

Discrete choice models are based on the Random Utility Theory, which assumes that utility (U) can be determined by a systematic alement (V) and an error-term ($\varepsilon$) that consists of unobserved heterogenity[50]:

$$U = V + \varepsilon$$

In a choice task, respondents are expected to choose the option that gives them the most utility. When multiple choice tasks are incorporated, with multiple respondents conducting the DCE, the choice data can be used to estimate the overall utility associated with each level of an attribute and determine which attribute levels are most preferred by the group of respondents. These estimations can then be used to design a preconception ECS offer that fits the preferences of the sample that conducted the DCE.

Multiple models exist to analyze DCE data and estimate the utilities of the attribute levels. In a full-factorial experimental design all possible combinations of attributes and levels are incorporated. While this type of design guarantees that the effect of each factor can be studied, it is not feasible for respondents when more than three attributes with multiple levels are incorporated in a DCE. However, one does not need a full-factorial design to estimate the utilities of the attribute levels efficiently. Instead, a d-efficient DCE design with Bayesian uniform priors was used in this study, to assure that as much as possible information can be extracted within a limited number of choice-tasks. Even though there might be a loss of orthogonality, meaning a loss in equality in the number of appearances of each level in an attribute, a d-efficient design is the most efficient and produces the smallest error terms[38].

To be able to estimate the attribute level utilities using the raw choice data of each respondent, statistical models are used. The three most commonly used statistical models are: the conditional logit model, the latent class model and the mixed logit model.

### 3.1.1 Conditional logit model

The conditional logit model is almost identical to a binary/multinomial logistic regression analysis. In the model it is assumed that individuals have the same preferences, except for random error, which is called homogenous error variance[51]. Consequently, this model is a fixed-effects model and shifts all fixed individual heterogeneity to the random error-term.

The conditional model is the model of choice when data regarding the trade-offs made in the DCE have to be analyzed, rather than individual heterogeneity[52]. The model is mostly used in pilot experiments with small study groups to create d-efficient designs, that later can be used for experiments with larger samples and other statistical models of choice that require larger sample sizes.

The utility function that is created for each alternative in a conditional logit can be described as:

$$Uj = Vj + \varepsilon$$

Where Vj is the part of the utility that is explained by the model, ε the error-term/unexplained utility. It is assumed that respondents choose the alternative with the highest utility and the probability that a respondent chooses a certain option can be calculated using the following formula:

$$\text{Prob}(Y = j) = \exp(Vj) / \sum \exp(Vk)$$

The exponential of the utility of j is divided by the sum of the exponential of all the possible options. Nevertheless, this statistical model is not thought to be suited for the current study as it is thought different respondents have different preferences in ECS.

### 3.1.2 Latent class model

The latent class model assumes that there are a fixed number of respondent groups, each with different preferences. The preferences within each subgroup are assumed to be identical. With this model it is possible to determine differences in preferences between the most important groups. Every subgroup has their own utility function and it is assumed that each subgroup makes the same choices in a DCE, except for random error.

Each subgroup (class) represented in the latent class model has to have a sufficient sample size to allow estimations. If there are too few respondents in a class, this makes interpretation difficult as it affects the significance of the levels. Furthermore, each latent class estimation represents a standard conditional logit model. However, each subgroup has its own latent scale, which hampers a direct comparison of the coefficients between subgroups (classes)[53]. The existence of multiple utility functions is also reflected in the utility function of the latent class, which displays that each group has their own utility function (U1, U2 and U3):

$$U = X'\beta 1 + \varepsilon, U2 = X'\beta 2 + \varepsilon, U3 = X'\beta 3 + \varepsilon, \ldots$$

### 3.1.3 Mixed logit model

In the mixed logit model the assumption is made that each individual has its own preferences. All individuals together form a distribution that is constucted with each individual's preference distribution. All individuals have their preferences set up around the mean in order to form a normal distribution. The mean and standard deviation of the distribution represent the average preference of the group and the amount of heterogeneity within in the group.

The model estimates individual level preferences and average population preferences without assuming inter-individual homogeneity in preferences. Often the mixed logit model is preferred over the other mentioned models used in DCEs, as it has the advantage that "random taste variation, unrestricted substitution patterns, and correlation in unobserved factors over time" can be taken into account[54]. The utility function of for an alternative in a mixed logit can be described as:

$$U_{ij} = X'_j\beta_i + \varepsilon_{ij}$$

Where the utility (U) for alternative *j* is derived from invidual *i*. In this formula it is seen that the β is specific to the individual *i*, meaning that an individual has its own preferences.

### 3.2 Survey structure

Table 2 displays/outlines the structure of the DCE survey. The survey started of with a short introduction to the survey, followed by a obligated informed consent. Next, the respondent has to answer demographic questions and gets introduced to preconception ECS and the various characteristics of such a screening, to be able to conduct the DCE later in the survey.

**Table 2**- Survey structure

| **Survey part** | **Explanation** |
|---|---|
| Introduction | The respondent gets introduced to the survey and is explained shortly what carrier screening is, what the aim of the study is and by whom the survey is conducted. |
| Informed consent | The respondent is asked to give consent and states that he or she understands that:<br>- Participation to the study is voluntarily.<br>- Answers will be treated anonymously in the research report.<br>- Individual answers wont be appointed in the respearch report.<br>- The survey is targeted at individuals between 18 and 40 years old that wish to have (more) children withing 10 years. |
| Child-wish question | Question regarding whether the respondent wants (more) children and how soon he or she would want them. |
| Questions regarding demographic data of respondent | Questions are asked questions regarding the sex, age, education, income, ethnicity, descent mother, descent father, amount of children, in what province the respondent lives and whether the respondent has a partner. |
| Question regarding the Non-invasive prenatal test (NIPT) | Question whether the respondent has made use of a NIPT before, or is planning to with a possible pregnancy. |
| Explanation carrier screening and aim of study | Informational text about what preconception ECS entails, what choices can be made with the results of such a screening and the aim of the study. |
| Question regarding whether the respondent heard of preconception ECS before | *See first column.* |
| Question regarding whether the respondent would consider a free ECS offer that is fully reliable | This question is included to evaluate whether the respondent is not against the idea of a preconception ECS. If the respondent is, he or she gets excluded from the survey later on. |

| | |
|---|---|
| Explanation genetic disorders | Informational text about what (autosomal recessive) genetic disorders are, with a distinction in 'mild' and 'severe' genetic disorders. Examples of genetic disorders are given. |
| Questions regarding experiences with genetic disorders | Question asked about whether knows people that suffer from a genetic disorder. If the question is answered with 'Yes', follow-up questions ask whether there are cases of such disorders in the respondents family and whether the respondent has a genetic disorder himself/herself. |
| Exercise choice tasks with introduction of the attributes and levels | The following atrributes get introduced using an informational text and a exercise choice task that includes the attibutes one by one: provider, costs, type of guidance, what disorders are screened and the reliability of the test. |
| Dominant strategy | To evaluate whether the respondent understands how a DCE should be answered, a choice task has to be answered with a dominant strategy. |
| Discrete choice experiment | The DCE itself with 14 choice tasks. |
| Attribute ranking | Exercise where the respondents have to rank the attributes in order of importance. |
| Feedback questions | Questions where is asked whether the survey was understandable, what could be improved and what their overall experience was conducting the survey. |

In general, there were three main paths that a repondent could go through. If the respondent's age was outside the range of 18 to and including 40 years old or did not have a child-wish within 10 years, the respondent is directly forwarded to the exclusion page, where he or she was informed that the study was not intended for that respondent. The age criterion is in line with studies in the past[12,17], people older than 40 years have limited options for pre-implantation genetic testing in the Netherlands[16]. The child-wish criterion exists to gain some certainty in that the respondent can empathize with potential decision-making regarding preconception ECS.

The second path in the survey consisted of respondents that were excluded due to not being open towards preconception ECS. This question was located later in the survey as the respondent first has to be informed about what the screening procedure entailed. In addition, the respondent was excluded later to collect socio-demographic data on the respondents who were not open towards preconception ECS.

The third path of the survey was for respondents between 18 and 40 years old with a child-wish and are open towards ECS. These respondents took part in the DCE and got included in the WTP and preference analysis in this study.

### 3.3 Validity and reliability

#### 3.3.1 Dominant strategy

To check whether the respondents understand what is asked from them, a control choice task with a dominant strategy was added to the survey. This choice task asked the repondent whether they prefer a preconception ECS for €50 with an accuracy of 100% or a screening for €500 with an accuracy of 50%. If the respondent chose the more expensive and less reliable second option, a follow-up question was given where the respondent was asked whether he was certain he wanted the more expensive and less reliable screening. If the respondent failed the dominant question for the second time it was assumed that he or she was not able to perform the DCE and was therefore excluded.

#### 3.3.2 Survey answer time measurement

To ensure that participants took part in the experiment seriously, the average duration of taking the survey was measured. The median duration was around 9 minutes and the mean around 19 minutes. There was a large difference between the mean and the median due to some respondents pausing during the survey. Participants that were allowed to take part in the DCE were excluded if they finished the survey within 4 minutes, as it was deemed as impossible to answer the survey this fast seriously.

#### 3.3.3 Ranking exercise

A ranking exercise was added where respondents have to rank the attributes in terms of importance. Afterwards it was possible to see whether they applied the same ranking during the choice tasks. This comparison gave insight in the differences between direct (ranking exercise) and indirect (DCE) valuation methods.

### 3.3.4 Pilot survey

Prior to the final survey, a pilot survey was handed out to 31 respondents. This pilot survey served as a method to see whether respondents understood what was asked from them, to gather priors and to receive feedback on the survey and improve it accordingly.

The priors were imported in Ngene to create a d-efficient design[55] (Appendix VI). Using a conditional logit model with the results of the pilot study, the standard deviation and coefficients of the priors were derived. These priors were used to create a d-efficient DCE design for the final survey.

### 3.3.5 Think-aloud sessions

There were four think-aloud sessions conducted during the pilot study. The participants were asked to vocalize their train of thought during the execution of the survey. The sessions gave insight in how respondents experience the survey, whether survey parts were unclear and how respondents made certain trade-offs.

### 3.3.6 Inclusion criteria

Only participants were included that were:

- Minimally 18 years old and maximally 40 years old.
- Were planning to have (more) children within 10 years.
- Were open towards preconception ECS.

Whether respondents fitted the criteria was estimated using the answers to the corresponding questions (see Table 2, page 21). Participants that got excluded due to being younger than 18 or older than 40 years old or were not planning on having children within 10 years took the first survey path (page 22). Participants who stated not to be open towards ECS took the second path in the survey.

### 3.3.7 Extra warnings and information

Before the start of the DCE in the survey, the respondents were notified of certain characteristics that do not differentiate between the different options and levels within the choice tasks. The following points were appointed:

- The hypothetical offer of a preconception ECS would always be executed before conceivement.
- In order to perform the screening blood has to be taken from both partners.
- The couple will always be able to decide for themselves what will be done with the outcome of the screening.
- A positive test (both partners being carrier of the same disease) will always be followed up by a consultation with a geneticist.

These remarks were made before the DCE, to be certain that all respondents had the same idea about the characteristics that were not treated in the informational text or were easily forgotten or misinterpreted. Most points were added due to misconceptions that came to light during the think-aloud sessions and feedback questions in the pilot survey.

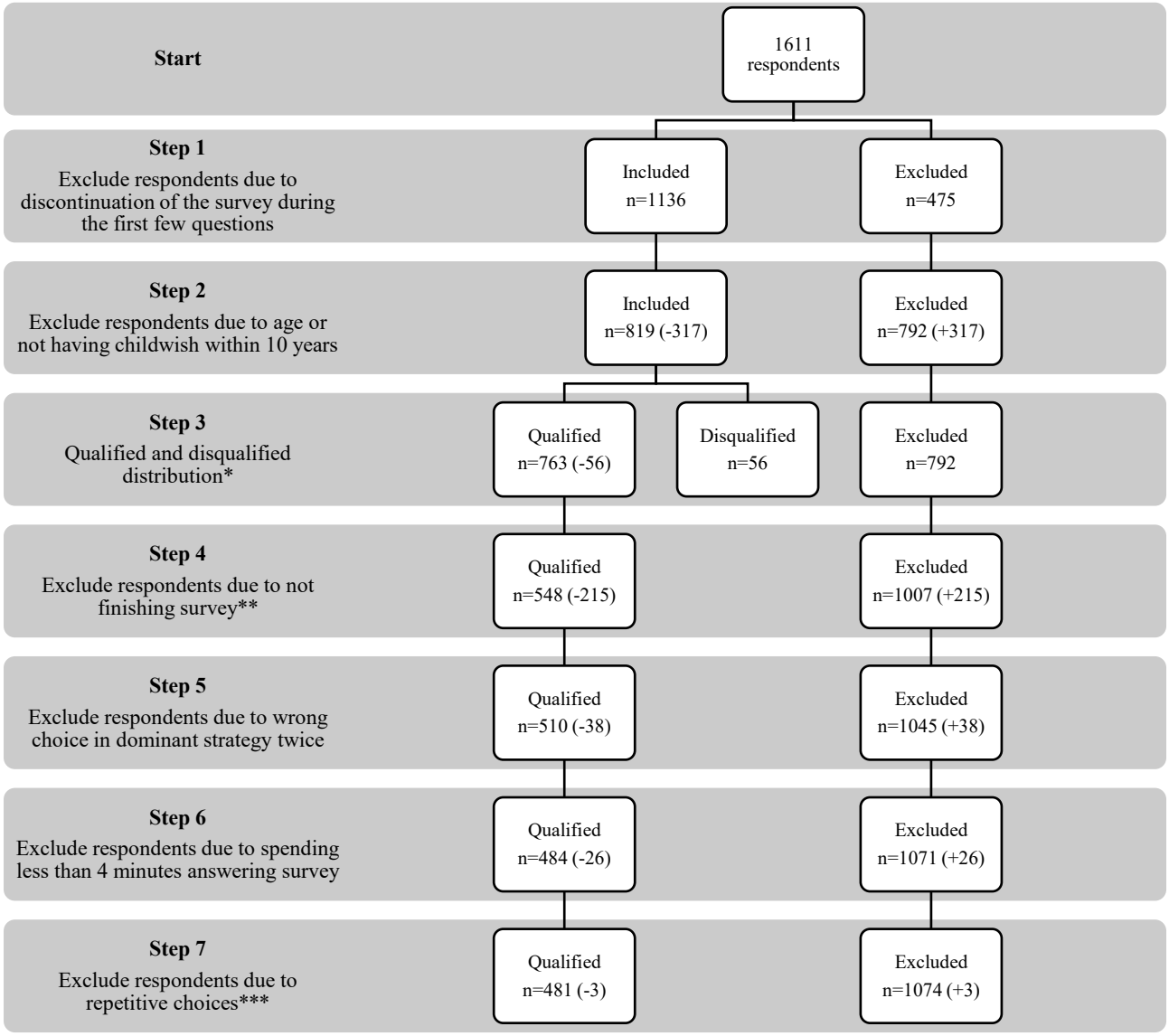
### 3.3.8 Duplicate choice-tesk

To access information on whether respondents might alternate their preferences during the DCE, a duplicate choice-task was added. The last choice-task from the DCE was identical to the first one. This duplicate choice-task was also added to get preliminary indication in the test-retest reliability.

### 3.3.9 Exclusion and inclusion amounts

In figure 2 the amount of respondents are displayed that got excluded or moved to another group during each of the exclusion steps (Appendix IV). Most of the steps were appointed in this subchapter (3.3) and extra information can be found in the caption of the figure.

**Figure 2**- Inclusion and exclusion amounts




* Disqualified= the respondent had an child wish and was aged between 18 and 40 years but was not open towards ECS.
** In this step qualified respondents were excluded due to discontinuing the survey during or before the DCE.
*** In this step qualified respondents were excluded due to always choosing the first or the second option in the DCE

### 3.4 DCE Attibute and levels

#### 3.4.1 Attribute and level selection

The attributes and levels were chosen folowing previous studies by Plantinga et al. and Bijsterbosch, where the important characteristics of preconception ECS were investigated. In the studies, these characteristics were studied in terms of the preferences that exist within these characteristics. In Plantinga et al. this was done quantitatively and in Bijsterbosch qualitatively[17,18]. Both studies did not give information on how the different characteristics relate to each other, such as is done in a DCE. In Bijsterbosch, test reliability was seen as the most important aspect followed by the support/counselling, severity of the diseases screened and the costs[18]. The same attributes were incorporated in the study by Plantinga et al. after an explorative qualitative interview study was held with 20 potential preconception ECS users to explore which factors influenced participation in ECS[17].

Another substantial guidance in the level and attribute selection were the results of the pilot survey preceding this DCE study that was held among 30 respondents. This gave insight in how respondents make certain trade-offs and what changes should be made in the attributes and levels to make the results of the final survey as much corresponding to the preferences of the respondents.

At last, consultation was done with experts in the field of preconception ECS in the Netherlands, mostly from Erasmus University and University of Groningen. During these consultations the current study with its choice of attributes and levels was discussed.

#### 3.4.2 Pilot survey and design choice tasks

Prior to the final survey, a pilot survey was done. The pilot survey functioned as a method to gain feedback on the survey, and to create a balanced d-efficient design for the final DCE. The results of the pilot survey were analyzed using a conditional logit model. This model gave preliminary information on the coefficients and standard errors of the various attributes and levels. These preliminary coefficients and standard errors were also used as priors for the final DCE design (Appendix VI), to gain as much information as possible on the trade-offs respondents make, using a limited number of choice-tasks.

The pilot DCE itself was also designed using priors for d-efficiency (Appendix V). These priors were made using own knowledge and current literature. For instance, it is possible to give higher priors (higher utility derived from a certain characteristic) for the lower cost values than higher values, because people prefer lower costs. Table 3 shows the attributes and levels used in the pilot survey.

**Table 3-** Attributes and levels of the pilot survey

| **Attribute** | **Information** | **Levels** |
|---|---|---|
| *Information provision* | The way information about the screening is provided to the couple. | Brochure |
| | | Website |
| | | Provider of the test |
| *Types of diseases screened* | What diseases are being screened for in the preconception ECS. | Serious diseases with early onset |
| | | Serious diseases with early onset + late onset |
| | | Serious diseases with early onset + late onset + mild diseases |
| | | Serious diseases + mild diseases + Genetic predispositions |
| *Provider* | By who or which instance the preconception ECS is provided. | Midwife |
| | | General Practitioner |
| | | Medical specialist |
| | | Commercial company |
| *Accuracy* | The probability of receiving a wrong result from the screening due to a false-positive or a false-negative. | Wrong result in 1/100 cases |
| | | Wrong result in 5/100 cases |
| | | Wrong result in 10/100 cases |
| *Costs (per couple)* | The costs a couple has to pay for a preconception ECS. | €50 |
| | | €200 |
| | | €500 |
| | | €1000 |

### 3.4.3 Changes made according to pilot survey

***Changes made in the survey***

A lot of (small) changes were mode to the pilot survey according to the feedback gained in the pilot survey. Many of them consisted of texual changes, to explain the concept of a ECS and genetic congenital diseases better to the participants of the survey. An extra page was

also added where certain matters were appointed which had to be take into account before the DCE (3.3.7, page 25).

Moreover, questions were added to gain more valuable information about the respondents. Respondents were asked whether they knew someone with a genetic congenital disease or whether they had one themselves. In addition, a question was added asking respondents whether they were open towards prenatal screening, to be able to study whether respondents had different views on prenatal and preconception screening.

At last, it was chosen to move the ranking exercise (3.3.3, page 23) after the DCE because it was thought that respondents also learned about their preferences during the DCE and not just before.

***Changes made in the attributes and levels***

Less levels of 'Types of diseases screened' were included in the final survey as it was observed that respondents found it difficult to understand the levels and the difference between them. Due to this misunderstanding respondents of the pilot survey had difficulty with including the attribute in their decision-making.

The lowest level of the 'Accuracy' attribute was changed, as it was observed that this attribute had too much power in the decision-making of the respondents, resulting in respondents only considering this attribute. This power was not thought to be reflecting the true preferences when choosing for an ECS in real-life as numbers relating to accuracy are most of the time not explicitly given and the focus is also on other attributes. The way this attribute was described in the survey was also altered and it was stated that if screening results were positive, further consultations and research would be done on those results.

At last, the lowest level of the attribute 'Costs' was removed, because non-invasive prenatal testing (NIPT) in the Netherlands costs €175, which provides less advantages than preconception ECS[56]. It was not deemed as plausible that preconception ECS would be less costly than NIPT.

### 3.4.4 Final DCE attributes and levels

Table 3 displays the choice of attributes and levels that were incorporated in the final DCE.

**Table 3**. Attributes and levels of the final survey

| Attribute | Information | Levels |
|---|---|---|
| *Information provision* | The way information about the screening is provided to the couple. | Brochure |
| | | Website |
| | | Provider of the test |
| *Types of diseases screened* | What diseases are being screened for in the preconception ECS. | Serious diseases |
| | | Serious diseases + mild diseases |
| | | Serious diseases + mild diseases + Genetic predispositions |
| *Provider* | By who or which instance the preconception ECS is provided. | Midwife |
| | | General Practitioner |
| | | Medical specialist |
| | | Commercial company |
| *Accuracy* | The probability of receiving a wrong result from the screening due to a false-positive or a false-negative. | Wrong result in 1/100 cases |
| | | Wrong result in 5/100 cases |
| | | Wrong result in 9/100 cases |
| *Costs (per couple)* | The costs a couple has to pay for a preconception ECS. | €200 |
| | | €500 |
| | | €1000 |

***Information provision***

This attribute entails how information about the details of the screening or screening results is given. The level 'website' is added as most commercial companies offer preconception ECS online and display the results on their website. The option of a brochure was added, as was done in previous research, which showed similar results to the level 'website'[12,14].

***Types of diseases screened***

In this attribute a distinction is made between mild and severe diseases. Mild diseases are for instance described with conditions such as blindness, which is not life-threatening but may decrease the quality of life. Severe diseases are diseases that are life-threatening or/and have a big impact on an individual's health-related quality of life, such as sickle-cell anemia which decreases the life expectancy drastically or pontocerebellar hypoplasia which additionally results in mental retardation. Severe diseases are also known for having no or limited

treatment options. Genetic predispositions are human characteristics such are hair-type, athleticism or eye-color. The latter category is added to measure the preferences by respondents towards such options that are technically possible, sometimes offered in ECS tests, but potentially unethical.

***Provider***

In the provider attribute, all possible providers of preconception ECS are included as levels. The provider is the point of contact for the screening, and is the one that communicates possible positive results and where individuals go to when requesting preconception ECS. Commercial companies are also included as a level, as it is nowadays possible to purchase carrier status screening online (direct-to-customer).

***Accuracy***

The accuracy attribute stands for the probability of undergoing preconception ECS and getting a result that is not correct. This could be for instance because the genetic test wrongly screens the DNA of a participant, telling that he or she is a carrier of one of the many diseases (false-positive), or that the genetic test does not discover that the individual is a carrier (false-negative). For the levels, professionals who work in the field of preconception ECS were consulted. It was chosen not to describe the levels according to specificity and sensitivity as this is complicated in ECS and because respondents may not be able to understand it.

***Costs (per couple)***

The costs focus on the total costs of preconception ECS for a couple, as preconception ECS is designed to provide the possibility of an informed-decision for the couple and not for the individual. The prospect of a possible health insurance coverage of the screening is not taken into account, as this would lead to too many options, depending on the precise health insurance coverage arrangements and different health insurance plans of individuals.

***Opt-out***

The opt-out possibility is not an attribute but a third choice in every choice-task. An opt-out is included in the DCE because in real-life an individual will also always have a choice to not undergo preconception ECS. Individuals are not forced to undergo an ECS. The utility outcomes of this option also function as a way to estimate the utility of what is seen as a bare minimum of an ECS according to the respondent preferences and the added attributes and levels.

### 3.5 Data collection

As the research methods used in this study needed sufficient statistical power to draw conclusions, various methods were used to gather respondents. At first, acquaintances and family were approached directly or using social-media. As these respondents were mostly comparable in terms of demographics, several Dutch online forums concerning pregnancy were consulted and forum threads were made that linked to the survey.

At last, services of Dynata were deployed. Dynata is a global online market research firm that provides researchers with qualified survey respondents. Additionally, it was requested to gather mostly respondents that belonged to certain demographic groups, to get a more stratified respondent sample. The differences between the sample gathered from Dynata and the others were also included in the results section.

### 3.6 Evaluation statistical models (data analysis)

The mixed logit model was chosen as the statistical model to analyse the data of the DCE with. This model was chosen after consideration of all the possible models. The conditional logit model quickly fell out of this consideration, as it was believed that different individuals had different preferences and that this variation had to be analysed. The possibility of the latent class model was also taken into consideration. With the current data, it was estimated that at least eight classes had to be incorporated in the model to achieve the best statistical fit. But this not deemed as feasible as this would decrease the sample size per class drastically and cause problems in terms of the statistical power. In addition, using a latent class model with eight or more classes would also make the analysis of the results very complex.

Two different mixed logit models were used to gain information on the preferences and WTP of the respondents. In both models, the price attribute was included as a continuous variable, as the different price levels had a linear relationship (Appendix I). In the first mixed logit only the different levels and opt-out were added to assess the mean utility and WTP, without taking respondent characteristics into consideration. Whether or not the standard deviation of a level was also added to the model depended on its significance ($P \leq 0.01$). This model was later used to analyse what the mean respondent of the sample was willing to pay for currently available and possible screenings in the Netherlands. Additionally, this model was used to calculate the uptake probabilities for these screenings.

The second mixed logit model had interaction effects added where the different levels were linked to different respondent characteristics. The following respondent characteristics were taken into consideration during the making of this model: log function of income, having a degree in higher education, number of children at the moment, having a partner, born outside of the Netherlands, being younger than 25 years, knowing someone with a congenital genetic disorder, knowing what ECS is prior to the DCE, planning on having a child within 1 year and being religious. As it was not possible to evaluate all possible interaction terms at once due to the number of variables, it was evaluated per attribute which respondents characteristics would be added to the model (see Appendix II). During the evaluation of all the mixed logit models with interaction effects, significant ($p \leq 0.05$) were noted and added to the final model. Afterwards, some interaction terms were still removed from the final model as they were not statistically significant ($p \leq 0.01$), due to the addition of interaction effects of different attributes.

During the optimalisation of the mixed logit with interaction terms, it was also evaluated how some respondent characteristics should be included. Mixed logit models were taken into consideration with a log function of income or a binary variable for income, consisting of whether an individual had an above average income (€3000+ per month). The same was done for the age of the respondents, where the age in years and a binary variable was taken in consideration, consisting of a respondent being older or younger than 25 years.
After evaluating the different models, it was chosen to further evaluate the log function of income and whether the respondent was younger or older than 25 years.

At last, for every mixed logit model a goodness-of-fit measure was taken into consideration, this was the log-likelihood.

### 3.7 Supporting software

- For the data analysis and the deployment of the various statistical models, Stata 16 was used[57].
- To create a d-efficient DCE design, priors acquired from the pilot survey were imported in Ngene (made by ChoiceMetrics). Ngene computed the most efficient design[55].
- The survey was hosted and created using Lighthouse studio 9.11.0 from Sawtooth[58].

# 4. Results

## 4.1 Respondent characteristics

The sample characteristics are summarized in Table 4 and Table 5.

Within the sample all characteristics were represented, and the included respondents answered all the questions. The total sample consisted of more women than men (69.8% vs 29.8%). The mean age was 29.0 years, which seems like a balanced value as it is exactly the mean of the ages that were allowed to participate in the survey.

On average, the respondents had 0.61 children and most were planning on having (more) children within 5 years. The majority of the sample had a partner at the time of answering the survey (73.4%). In terms of educational level, the vast majority had a degree in higher education (59.8%) with higher education being higher vocational training (HBO) or academic education (WO). The latter proportion was a little bigger than the Dutch mean where 47.6% of the Dutch population between 15 and 45 years old has a degree in higher education[59].

**Table 3**- Respondent characteristics part one

| | | Qualified n=481 | | Disqualified** n=56 | | Total n=537 | | |
|---|---|---|---|---|---|---|---|---|
| | | Count (%) | Mean (SD) | Count (%) | Mean (SD) | Count (%) | Mean (SD) | Pearson Chi2 (*p*) |
| *Gender* | Male | 142 (29.5%) | | 18 (32.1%) | | 160 (29.8%) | | 3.6 (0.17) |
| | Female | 338 (70.3%) | | 37 (66.1%) | | 375 (69.8%) | | |
| | Prefer not to tell | 1 (0.2%) | | 1 (1.8%) | | 2 (0.4%) | | |
| *Age (years)* | Total | 481 (89.6%) | 28.9 (5.85) | 56 (10.4%) | 29.5 (6.15) | 537 (100%) | 29.0 (5.88) | |
| | 18-23 | 92 (19.1%) | | 12 (21.4%) | | 104 (19.4%) | | 2.9 (0.90) |
| | 24-29 | 165 (34.3%) | | 15 (26.8%) | | 180 (33.5%) | | |
| | 30-35 | 149 (30.1%) | | 19 (33.9%) | | 168 (31.3%) | | |
| | 36-40 | 75 (15.6%) | | 10 (17.9%) | | 85 (15.8%) | | |
| *Number of children* | Total | 481 (89.6%) | 0.59 (1.02) | 56 (10.4%) | 0.77 (1.03) | 537 (100%) | 0.61 (1.02) | |
| | 0 | 311 (64.7%) | | 29 (51.8%) | | 340 (63.3%) | | 4.8 (0.57) |
| | 1 | 95 (19.8%) | | 16 (28.6%) | | 111 (20.7%) | | |
| | 2 | 56 (11.6%) | | 8 (14.3%) | | 64 (11.9%) | | |
| | 3 | 11 (2.3%) | | 2 (3.6%) | | 13 (2.4%) | | |
| | 4 ≥ | 8 (1.6%) | | 1 (1.8%) | | 9 (1.7%) | | |
| *When children* | Within 1 year | 114 (23.7%) | | 10 (17.9%) | | 124 (23.1%) | | 1.0 (0.62) |
| | Within 1-5 years | 246 (51.1%) | | 31 (55.4%) | | 277 (51.6%) | | |
| | Within 5-10 years | 121 (25.2%) | | 15 (26.8%) | | 136 (25.3%) | | |
| *Partner* | Yes | 356 (74.0%) | | 38 (67.9%) | | 394 (73.4%) | | 1.0 (0.32) |
| | 0-1 year | 34 (7.1%) | | 3 (5.4%) | | 37 (6.9%) | | 1.7 (0.89) |
| | -3 years | 73 (15.2%) | | 9 (16.1%) | | 82 (15.3%) | | |
| | 4-5 years | 76 (15.8%) | | 9 (16.1%) | | 85 (15.8%) | | |
| | 6-7 years | 58 (12.1%) | | 4 (7.1%) | | 62 (11.6%) | | |
| | 8-9 years | 28 (5.8%) | | 3 (5.4%) | | 31 (5.8%) | | |
| | 10+ years | 212 (44.1%) | | 28 (50.0%) | | 240 (44.7%) | | |
| | No | 125 (26.0%) | | 18 (32.1%) | | 143 (26.6%) | | |
| *Education* | Primary school | 2 (0.4%) | | 1 (1.8%) | | 3 (0.6%) | | 16.4 (0.01)* |
| | Pre-vocational secondary education (VMBO) | 13 (2.7%) | | 2 (3.6%) | | 15 (2.8%) | | |
| | Senior general secondary education (HAVO) | 18 (3.7%) | | 4 (7.1%) | | 22 (4.1%) | | |
| | Pre-university education (VWO) | 18 (3.7%) | | 0 (0%) | | 18 (3.4%) | | |
| | Intermediate vocational training (MBO) | 132 (27.4%) | | 26 (46.4%) | | 158 (29.4%) | | |
| | Higher vocational training (HBO) | 178 (37.0%) | | 17 (30.4%) | | 195 (36.3%) | | |
| | Academic education (WO) | 120 (24.9%) | | 6 (10.7%) | | 126 (23.5%) | | |

*= P ≤ 0.05

**= The disqualified group were individuals that passed the age requirements and were planning on having children within 10 years, but stated that they were not open towards ECS.

Table 5 (next page) shows further information about the respondent characteristics. The mean income was €2554 with a standard deviation of €1980. Furthermore, the median income was €2500 with the first and third quartile being €1500 and €2500 respectively. The majority of the sample stated not to be religious (70.8%) and the biggest proportion that was religious was Christian. A substantial part of the sample lived in South- or North-Holland (40.1%), which is in line with the population distribution in terms of the provinces in the Netherlands[59].

Additionally, 43% knew somebody with a congenital genetic disorder and 9.1% had one themselves. At last, 69.3% of the sample were interested in prenatal diagnosis or had prenatal diagnosis in the past and 50.3% had heard of ECS prior to the survey.

There were three characteristics that were found to have significantly different frequencies when comparing the qualified and disqualified groups. The religion characteristic was estimated to be significantly different ($p$=0.02) due to a relatively higher number of religious individuals in the disqualified group. The frequencies in the religion composition of the two groups were not found to be significantly different. Next, the educational level was estimated to be significantly different ($p$=0.01) with a higher proportion of the disqualified group having a degree in intermediate vocational training (MBO) and a lower proportion having a degree in WO when compared to the qualified group. At last, there were relatively less individuals interested in prenatal diagnosis in the disqualified group when compared to the qualified group ($p$=0.01).

**Table 4**- Respondent characteristics part two

| | | Qualified n=481 | | Disqualified** n=56 | | Total n=537 | | |
|---|---|---|---|---|---|---|---|---|
| | | Count (%) | Mean (sd) | Count (%) | Mean (sd) | Count (%) | Mean (sd) | Pearson Chi2 (*p*) |
| *Individual monthly income (€)* | Total | 481 (89.6%) | 2567.57 (1973) | 56 (10.4%) | 2437.50 (2059) | 537 (100%) | 2554.00 (1980) | |
| | 0-1000 per month | 77 (16.0%) | | 9 (16.1%) | | 86 (16.0%) | | 2.1 (0.95) |
| | 1001-2000 per month | 116 (24.1%) | | 17 (30.4%) | | 133 (24.8%) | | |
| | 2001-3000 per month | 165 (34.3%) | | 19 (33.9%) | | 184 (34.3%) | | |
| | 3001-4000 per month | 60 (12.5%) | | 5 (8.9%) | | 65 (12.1%) | | |
| | 4001-5000 per month | 32 (6.6%) | | 3 (5.4%) | | 35 (6.5%) | | |
| | 5001-7500 per month | 18 (3.7%) | | 1 (1.8%) | | 19 (3.5%) | | |
| | 7501-10000 per month | 6 (1.3%) | | 1 (1.8%) | | 7 (1.3%) | | |
| | 10001+ per month | 7 (1.5%) | | 1 (1.8%) | | 8 (1.5%) | | |
| *Religion* | Yes | 107 (22.2%) | | 19 (33.9%) | | 126 (23.5%) | | 7.7 (0.02)* |
| | Christianity | 63 (58.9%) | | 13 (68.4%) | | 76 (60.3%) | | 1.2 (0.87) |
| | Islam | 26 (24.3%) | | 3 (15.8%) | | 29 (23.0%) | | |
| | Judaism | 2 (1.9%) | | 0 (0%) | | 2 (1.6%) | | |
| | Hinduism | 7 (6.5%) | | 1 (5.3%) | | 8 (6.4%) | | |
| | Other | 9 (8.4%) | | 2 (10.5%) | | 11 (8.7%) | | |
| | No | 349 (72.6%) | | 31 (55.4%) | | 380 (70.8%) | | |
| | Prefer not to tell | 25 (5.2%) | | 6 (10.7%) | | 31 (5.8%) | | |
| *Province* | South-Holland | 114 (23.7%) | | 16 (28.6%) | | 130 (24.2%) | | 4.4 (0.96) |
| | North-Holland | 78 (16.2%) | | 6 (10.7%) | | 84 (15.9%) | | |
| | North-Brabant | 73 (15.2%) | | 8 (14.3%) | | 81 (15.4%) | | |
| | Gelderland | 65 (13.5%) | | 7 (12.5%) | | 72 (13.6%) | | |
| | Groningen | 19 (3.9%) | | 1 (1.8%) | | 20 (3.7%) | | |
| | Other | 132 (27.4%) | | 18 (32.1%) | | 150 (27.9%) | | |
| *Born in* | The Netherlands | 451 (93.8%) | | 51 (91.1%) | | 502 (93.5%) | | 0.8 (0.66) |
| | Other European country | 15 (3.1%) | | 2 (3.6%) | | 17 (3.2%) | | |
| | Non-European country | 15 (3.1%) | | 3 (5.4%) | | 18 (3.4%) | | |
| *Know someone with congenital genetic disorder* | Yes | 212 (44.1%) | | 19 (33.9%) | | 231 (43.0%) | | 4.7 (0.09) |
| | In family | 107 (22.2%) | | 8 (14.3%) | | 115 (21.4%) | | 0.3 (0.86) |
| | Self | 47 (9.8%) | | 2 (3.6%) | | 49 (9.1%) | | 2.7 (0.26) |
| | No | 230 (47.8%) | | 35 (62.5%) | | 265 (49.4%) | | |
| | Not certain | 39 (8.1%) | | 2 (3.6%) | | 41 (7.6%) | | |
| *Prior knowledge ECS* | Yes | 244 (50.7%) | | 26 (46.4%) | | 270 (50.3%) | | 0.4 (0.54) |
| | No | 237 (49.3%) | | 30 (53.6%) | | 267 (49.7%) | | |
| *Interested in prenatal diagnosis* | Yes | 361 (75.1%) | | 11 (19.6%) | | 372 (69.3%) | | 72.3 (0.00)* |
| | No | 120 (24.9%) | | 45 (80.4%) | | 165 (30.7%) | | |

*= P ≤ 0.05

**= The respondents that were added to the disqualified group were individuals that passed the age requirements and were planning on having children within 10 years, but stated that they were not open towards ECS.

### 4.2 Differences between respondents from Dynata and others

**Table 5**- Differences in respondent characteristics from Dynata versus others

| | | Qualified others | | Qualified Dynata | | |
|---|---|---|---|---|---|---|
| | | Count (%) | Mean (SD) | Count (%) | Mean (SD) | Pearson Chi2 (*p*) |
| *Gender* | Male | 14 (14.7%) | | 128 (33.2%) | | 12.8 (0.00)* |
| | Female | 81 (85.3%) | | 257 (66.6%) | | |
| | Prefer not to tell | 0 (0%) | | 1 (1.8%) | | |
| *Age (years)* | Total | 95 (19.8%) | 26.9 (4.90) | 386 (80.2%) | 29.4 (5.97) | |
| | 18-23 | 24 (25.3%) | | 68 (17.6%) | | 17.7 (0.00)* |
| | 24-29 | 45 (47.4%) | | 120 (31.1%) | | |
| | 30-35 | 18 (18.9%) | | 131 (33.9%) | | |
| | 36-40 | 8 (8.4%) | | 67 (17.4%) | | |
| *Amount of children* | Total | 95 (19.8%) | 0.38 (0.86) | 386 (80.2%) | 0.64 (1.05) | |
| *Partner* | Yes | 71 (74.7%) | | 285 (73.8%) | | 0.03 (0.86) |
| *Education* | Finished higher schooling (HBO or WO) | 78 (82.1%) | | 220 (56.7%) | | 20.4 (0.00)* |
| *Religion* | Religious | 15 (15.8%) | | 92 (23.8%) | | 2.85 (0.09) |
| *Individual monthly income (€)* | | 95 (19.8%) | 2016 (1883) | 386 (80.2%) | 2703 (1974) | |

*= P ≤ 0.05

As can be deducted from Table 6, there were some differences between the respondents that were gathered from Dynata and the other respondents. There were significantly less females and higher educated individuals in the Dynata sample when compared to the other group ($p \leq 0.01$). In addition, the mean age in the Dynata sample was 2.5 years higher than the other group, alongside with the mean income per month and the mean amount of children which were significantly higher.

### 4.3 Mixed logit model with willingness to pay

**Table 6-** Mixed logit model without interaction terms

| Attribute | Level | | β-coefficient | SE | Lower CI | Upper CI | WTP | Lower CI | Upper CI |
|---|---|---|---|---|---|---|---|---|---|
| *Accuracy* | *91% (Base case)* | | 0 | | | | | | |
| | *95%* | Mean | 0.543*** | 0.085 | 0.377 | 0.709 | €174.37 | €120.99 | €227.75 |
| | | SD | - | - | - | - | | | |
| | *99%* | Mean | 1.579*** | 0.126 | 1.333 | 1.826 | €498.93 | €461.32 | €536.55 |
| | | SD | 1.684*** | 0.117 | 1.454 | 1.914 | | | |
| *Provider* | *Commercial (Base case)* | | 0 | 0 | | | | | |
| | *Midwife* | Mean | 0.447*** | 0.089 | 0.273 | 0.621 | €143.48 | €87.69 | €199.28 |
| | | SD | - | - | - | - | | | |
| | *General Practitioner* | Mean | 0.451*** | 0.112 | 0.232 | 0.671 | €134.91 | €123.10 | €146.72 |
| | | SD | 0.125*** | 0.125 | -0.924 | -0.433 | | | |
| | *Specialist* | Mean | 0.366*** | 0.100 | 0.170 | 0.562 | €102.20 | €85.97 | €118.43 |
| | | SD | -0.867*** | 0.114 | -1.090 | -0.643 | | | |
| *Information provision* | *Counselling (Base case)* | | 0 | 0 | | | | | |
| | *Website* | Mean | -0.404*** | 0.074 | -0.549 | -0.259 | -€129.63 | -€176.11 | -€83.16 |
| | | SD | - | - | - | - | | - | - |
| | *Brochure* | Mean | -0.300*** | 0.074 | -0.444 | -0.155 | -€96.16 | -€142.45 | -€49.87 |
| | | SD | - | - | - | - | | | |
| *Diseases tested* | *Package 1 (Base case)* | | 0 | 0 | | | | | |
| | *Package 2* | Mean | 0.146 | 0.075 | -0.002 | 0.292 | €51.83 | €39.34 | €64.32 |
| | | SD | 0.674*** | 0.105 | 0.468 | 0.880 | | | |
| | *Package 3* | Mean | 0.276* | 0.112 | 0.056 | 0.496 | €104.53 | €68.18 | €140.89 |
| | | SD | 1.638*** | 0.114 | 1.413 | 1.862 | | | |
| *Price* | *Continuous (€)* | Mean | -0.003*** | 0.0002 | -0.003 | -0.003 | - | - | - |
| | | SD | -0.004*** | 0.0002 | -0.004 | -0.003 | | | |
| *Opt-out* | | Mean | -1.641*** | 0.192 | -2.017 | -1.264 | -€531.36 | -€609.24 | -€453.48 |
| | | SD | 3.170*** | 0.206 | 2.767 | 3.573 | | | |
| *Log-likelihood* | | -4666.4 | | | | | | | |

*= P ≤ 0.05, ** = P ≤ 0.01 , ***= P ≤ 0.001
The sign of the SD is irrelevant and can be interpreted as being positive. Some attributes did not have a significant SD and therefor the attribute was taken as fixed.
A confidence interval of 95% was used.
Meaning of levels and attributes is explained in the Method section.

### 4.3.1 Mean

***Price***

The price seemed to be the attribute with the biggest effect in the choices made within the DCE, considering that the levels included in the DCE were €200, €500 and €1000 (which were statistically proven to be related linearly). An ECS having a price of €1000 would give a negative β-coefficient of ~-3, indicating a substantial drop in utility.

***Accuracy***

After the price attribute, the attribute that dictated the DCE preferences of the sample the most was the accuracy. The utility and WTP gained from 99% accuracy (compared to the base case) was the highest among all levels. On average, the WTP for a screening with 99% accuracy was €498.93 higher than a screening with 91% accuracy. Linearity could not be statistically proven within this attribute, so no claims can be made for screenings with accuracies below 91%.

***Information provision***

A counselling visit was the most preferred type of information provision prior to ECS. The β-coefficients for the levels regarding brochure and website were not proven significantly different from each other in this model.

***Provider***

Within the provider attribute, the 'General Practitioner' level was given the highest WTP and utility value by the sample. However, within this model, this level seemed not to be significantly different from the midwife and specialist levels. The base case, a commercial company being the provider, was the least desirable provider by the sample.

***Diseases tested***

The levels within the attribute 'Diseases tested' were the only levels of which the mean was not fully significant ($P \leq 0.001$), meaning no definitive claims can be made considering these levels other than the effect measured not being fully statistically significant different from the base case (Package 1).

### 4.3.2 Standard deviation

The following levels had a significant standard deviation (SD): opt-out, price, package 2, package 3, specialist, GP and 99% accuracy. Significant standard deviations indicate that there are variations within the sample towards the utility derived from certain levels. This is especially true for the opt-out level. The SD of the opt-out level indicates that some respondents in the sample preferred not having an ECS at all with the given characteristics or who might have not been so open towards ECS as stated at the start of the survey.

Other levels that were highly variable within the sample were having a specialist as the provider of the screening and the levels within the 'Diseases tested' attribute. Although the mean β-coefficients of the latter one were not fully significant, from the SD can be derived that the respondents within the sample look differently towards having an ECS that tests also for genetic dispositions and mild diseases.

At last, the standard deviation of the price attribute was also significant, meaning that spending one euro for ECS had differences in terms of total utility for different respondent groups in this sample.

### 4.4 Mixed logit model with interaction effects

Table 8 shows the results of the mixed logit with interaction effects.

Some of the effects that have been appointed in the previous section (4.3) can be linked to certain respondent characteristics. For instance, when comparing the mixed logit without and with interaction terms, it can be discerned that much less of the level estimations have a significant SD in the latter model. This is due to the addition of the interaction effects, which account for this variation.

The following respondent characteristics were found to have interactions with one or more levels: having a degree in higher education, number of children at the moment, having a partner, knowing what ECS is prior to the DCE and planning on having a child within 1 year. These interactions were compared to the base case subsample which consists of respondents who did not have a degree in higher education, had no children, did not want a child within 1 year (but later), did not know what ECS entailed prior to the DCE and who did not have a partner.

**Table 7-** Mixed logit model with interaction terms

| Attribute | Level | | B-coefficient | SE | Lower CI | Upper CI | WTP |
|---|---|---|---|---|---|---|---|
| *Accuracy* | *91% (Base case)* | | | | | | |
| | *95%* | Mean | 0.286** | 0.105 | 0.080 | 0.491 | €145.79 |
| | | SD | - | - | - | - | |
| | *99%* | Mean | 1.141*** | 0.151 | 0.844 | 1.437 | €611.27 |
| | | SD | 1.241*** | 0.138 | 0.971 | 1.511 | |
| *Provider* | *Commercial (Base case)* | | | | | | |
| | *Midwife* | Mean | 0.629*** | 0.088 | 0.457 | 0.801 | €320.95 |
| | | SD | - | - | - | - | |
| | *General Practitioner* | Mean | 0.644*** | 0.098 | 0.451 | 0.836 | €328.27 |
| | | SD | - | - | - | - | |
| | *Specialist* | Mean | 0.549*** | 0.090 | 0.373 | 0.725 | €280.04 |
| | | SD | - | - | - | - | |
| *Information provision* | *Counselling (Base case)* | | | | | | |
| | *Website* | Mean | -0.666*** | 0.098 | -0.859 | -0.474 | -€339.79 |
| | | SD | - | - | - | - | |
| | *Brochure* | Mean | -0.603*** | 0.095 | -0.790 | -0.416 | -€307.57 |
| | | SD | - | - | - | - | |
| *Diseases tested* | *Package 1 (Base case)* | | | | | | |
| | *Package 2* | Mean | 0.205** | 0.067 | 0.074 | 0.337 | €102.16 |
| | | SD | -0.691*** | 0.086 | -0.860 | -0.522 | |
| | *Package 3* | Mean | 0.199* | 0.098 | 0.007 | 0.392 | €122.29 |
| | | SD | 1.507*** | 0.104 | 1.302 | 1.712 | |
| *Price* | *Continuous (€)* | Mean | -0.002*** | 0.0002 | -0.002 | -0.002 | |
| | | SD | - | - | - | - | |
| *Opt-out* | *Interaction effect* | Mean | -0.308 | 0.329 | -0.954 | 0.337 | -€100.07 |
| | | SD | 2.728*** | 0.162 | 2.409 | 3.046 | |
| *High education # 95% accuracy* | *Interaction effect* | Mean | 0.506*** | 0.127 | 0.258 | 0.754 | €133.18 |
| | | SD | - | - | - | - | |
| *High education # 99% accuracy* | *Interaction effect* | Mean | 0.646*** | 0.197 | 0.260 | 1.031 | €187.50 |
| | | SD | -1.076*** | 0.241 | -1.549 | -0.603 | |
| *N children # midwife* | *Interaction effect* | Mean | -0.161** | 0.057 | -0.272 | -0.050 | -€81.90 |
| | | SD | - | - | - | - | |
| *Child within 1 year # specialist* | *Interaction effect* | Mean | -0.490*** | 0.142 | -0.769 | -0.211 | -€250.09 |
| | | SD | - | - | - | - | |
| *High education # website* | *Interaction effect* | Mean | 0.474*** | 0.126 | 0.227 | 0.722 | €124.77 |
| | | SD | - | - | - | - | |
| *High education # brochure* | *Interaction effect* | Mean | 0.443*** | 0.119 | 0.211 | 0.676 | €116.66 |
| | | SD | - | - | - | - | |
| *Prior knowledge ECS # price* | *Interaction effect* | Mean | 0.001** | 0.0002 | 0.001 | 0.001 | |
| | | SD | - | - | - | - | |
| *High education # price* | *Interaction effect* | Mean | -0.002*** | 0.0003 | -0.002 | -0.001 | |
| | | SD | -0.003*** | 0.0002 | -0.004 | -0.003 | |
| *N children # opt-out* | *Interaction effect* | Mean | 0.675*** | 0.161 | 0.360 | 0.989 | €365.83 |
| | | SD | 1.880*** | 0.223 | 1.443 | 2.317 | |
| *Prior knowledge ECS # opt-out* | *Interaction effect* | Mean | -0.858*** | 0.307 | -1.459 | -0.256 | -€968.23 |
| | | SD | - | - | - | - | |
| *Has partner # opt-out* | *Interaction effect* | Mean | -1.413*** | 0.351 | -2.101 | -0.725 | -€720.79 |
| | | SD | - | - | - | - | |
| *Log-likelihood* | -4675.4085 | | | | | | |

*= P ≤ 0.05, ** = P ≤ 0.01 , ***= P ≤ 0.001

The following respondent characteristics were taken into consideration during the making of this model: log function of income, having a degree in higher education, number of children at the moment, having a partner, born outside of the Netherlands, being younger than 25 years, knowing someone with a congenital genetic disorder, knowing what ECS is prior to the DCE, planning on having a child within 1 year and being religious. Not all of these characteristics were taken into consideration in this model, as not all were found to have significant (P ≤ 0.01) effects. The sign of the SD is irrelevant and can be interpreted as being positive. Some attributes did not have a significant SD and therefor the attribute was taken as fixed. A confidence interval of 95% was used. Meaning of levels and attributes is explained in the Method section.

**Higher education**

Having a higher educational level was the characteristic with the most level-interactions. These respondents gave more value than the base case group for the higher accuracy levels and ECS information being provided by a brochure or website. In addition, this subsample also had a larger utility decrease for every € that had to be spent on a potential screening compared to the base case respondent characteristics. This effect on the pricing of the screening indicates that this subsample has a lower WTP than the base case group.

**Number of children**

The number of children the respondent had, had an effect on the midwife and opt-out levels. For every child a respondent had they preferred having a midwife as the provider of the screening less and preferred having no test at all to a greater extent (compared to the base case group). However, the latter interaction effect was found to have a significant SD, meaning that within this subgroup there was a great variation in how opt-out was valued.

**Expecting a child within one year**

Respondents who expected a child within one year only were found to have a negative interaction with the preference consisting of having a specialist as the provider of the screening.

**Prior knowledge of ECS**

In terms of WTP, having prior knowledge of ECS had the greatest effect within this model. This subgroup preferred having an opt-out significantly less and had a lower utility decrease for every € spent on a screening than the base case group.

**Having a partner**

The subgroup consisting of respondents who had a partner at the time of answering the survey preferred the opt-out option much less than the base case group and were overall willing to pay more for an ECS.

### 4.5 Willingness to pay comparisons across expanded carrier screenings

#### 4.5.1 WTP and uptake probability comparison of currently offered ECS

At the time of examining the results, ECS is offered the following locations in the Netherlands: the University Medical Center (UMC) Groningen, Amsterdam University Medical Center (AUMC) location AMC in Amsterdam and a commercial company. These offered screenings all have their own characteristics. Table 9 shows the characteristics of these tests, and estimated mean utility, uptake and WTP according to the mixed logit model without interaction terms.

**Table 8-** Willingness to pay and uptake probabilities across currently available expanded carrier screenings

| | Test attributes and levels | | | | | Utility score | | Uptake Probability | WTP (CI =95%) | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| ECS | Diseases tested | Provider | Cost | Information provision | Accuracy | Mean | SD | Mean | Mean | Lower CI | Upper CI |
| AUMC | Package 1 | Specialist | €650 | Counselling | 99% | -0.152 | 2.572 | 27.8 % | €1132.46 | €1000.77 | €1264.22 |
| UMC | Package 1 | GP | €475 | Counselling | 99% | 0.494 | 2.186 | 53.2 % | €1165.20 | €1037.90 | €1292.51 |
| Commercial | Package 1 | Commercial | €169 | Website | 91% | -0.665 | 0.481 | 12.8 % | €401.73 | €277.37 | €526.08 |
| Opt-out | - | - | - | - | - | -1.655 | 2.714 | 6.2 % | €0 | - | - |

The numbers in this Table assume that an individual is fully informed about all the possible screenings in the Netherlands and their characteristics. These numbers are derived from mixed logit without interactions. For the meaning of all the levels and Attributes, please refer to the method section.

The uptake probability displays what the probabilities are for the mean respondent within the sample to undergo one of the screenings. The UMC Groningen test is the most desirable screening in the Netherlands, with a mean WTP of €1165.20 and a probability uptake of 53.2% compared to all the other offered screenings. The second most preferred screening is the screen test offered by the AMC with a mean WTP of €1132.46 and a probability uptake of 27.8%.

The commercial company offers the least preferred screen test with a WTP of €401.73 . Even though this screening has the lowest WTP, the uptake probability is still 12.8% due to the lower price this screening is offered for.

At last, the desirability of an opt-out (not undergoing ECS) is also taken into account in this comparison and has an uptake probability of 6%.

### 4.5.2 WTP and uptake probability comparisons of possible screen offers

**Table 9**- Willingness to pay and uptake probabilities across possible expanded carrier screenings

| | *Comparison (1 vs 2)* | Test attributes and levels | | | | | Uptake Probability | WTP (CI =95%) | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Diseases tested | Provider | Cost | Information provision | Accuracy | Mean | Mean | Lower CI | Upper CI |
| 1 | 1. UMC Groningen | Package 1 | GP | €475 | Counselling | 99% | 65.6% | €1165.20 | €1037.90 | €1292.51 |
| | 2. AMC Amsterdam | Package 1 | Specialist | €650 | Counselling | 99% | 34.4% | €1132.46 | €1000.77 | €1264.22 |
| 2 | 1. UMC Groningen | Package 1 | GP | €475 | Counselling | 99% | 89.6% | €1165.20 | €1037.90 | €1292.51 |
| | 2. Opt-out | - | - | - | - | - | 10.4% | €0 | - | - |
| 3 | 1. AMC Amsterdam | Package 1 | Specialist | €650 | Counselling | 99% | 81.8% | €1132.46 | €1000.77 | €1264.22 |
| | 2. Opt-out | - | - | - | - | - | 18.2% | €0 | - | - |
| 4 | 1. UMC Groningen | Package 1 | GP | €475 | Counselling | 99% | 80.6% | €1165.20 | €1037.90 | €1292.51 |
| | 2. Commercial | Package 1 | Commercial | €169 | Website | 91% | 19.4% | €401.73 | €277.37 | €526.08 |
| 5 | 1. AMC Amsterdam | Package 1 | Specialist | €650 | Counselling | 99% | 68.5% | €1132.46 | €1000.77 | €1264.22 |
| | 2. Commercial | Package 1 | Commercial | €169 | Website | 91% | 31.5% | €401.73 | €277.37 | €526.08 |
| 6 | 1. UMC Groningen | Package 1 | GP | €475 | Counselling | 99% | 14.1% | €1165.20 | €1037.90 | €1292.51 |
| | 2. Perfect ECS (€0) | Package 3 | GP | €0 | Counselling | 99% | 85.9% | €1269.74 | €1106.08 | €1433.40 |
| 7 | 1. Perfect ECS | Package 3 | GP | €200 | Counselling | 99% | 99.4% | €1269.74 | €1106.08 | €1433.40 |
| | 2. Worst ECS | Package 1 | Commercial | €1000 | Website | 91% | 0.6% | €401.73 | €277.37 | €526.08 |
| 8 | 1. Perfect ECS | Package 3 | GP | €200 | Counselling | 99% | 96.6% | €1269.74 | €1106.08 | €1433.40 |
| | 2. Opt-out | - | - | - | - | - | 3.4% | €0 | - | - |
| 9 | 1. Commercial (99%) | Package 1 | Commercial | €169 | Website | 99% | 53.2% | €900.66 | €738.69 | €1062.63 |
| | 2. UMC Groningen | Package 1 | GP | €475 | Counselling | 99% | 46.8% | €1165.20 | €1037.90 | €1292.51 |
| 10 | 1. Commercial (99%, €200) | Package 1 | Commercial | €200 | Website | 99% | 50.8% | €900.66 | €738.69 | €1062.63 |
| | 2. UMC Groningen | Package 1 | GP | €475 | Counselling | 99% | 49.2% | €1165.20 | €1037.90 | €1292.51 |
| 11 | 1. Commercial | Package 1 | Commercial | €169 | Website | 91% | 6.9% | €401.73 | €277.37 | €526.08 |
| | 2. Perfect ECS (€200) | Package 3 | GP | €200 | Counselling | 99% | 93.1% | €1269.74 | €1106.08 | €1433.40 |
| 12 | 1. Commercial (€200, 99%, Package 2) | Package 2 | Commercial | €200 | Website | 99% | 54.8% | €952.49 | €778.03 | €1126.95 |
| | 2. UMC Groningen | Package 1 | GP | €475 | Counselling | 99% | 45.2% | €1165.20 | €1037.90 | €1292.51 |

The numbers in this Table assume that an individual is fully informed about all the possible screenings in the Netherlands and their characteristics. These numbers are derived from mixed logit without interactions. For the meaning of all the levels and Attributes, please refer to the method section.

In Table 10, twelve comparisons were made between currently offered screenings and possible screenings that might be offered in the future, using the mean utility scores of the sample. Table 5 already showed, that the screen offer from UMC Groningen was the most desirable of all available offers. However, more desirable tests can be offered in the future

when more diseases are tested and when the costs of a screening are lower. If the perfect ECS was offered in the Netherlands for €0 and compared to the currently most desirable screening in the Netherlands (offered by UMC Groningen), the mean uptake probability would be 85.9% for the perfect ECS with a WTP of €1165.20 (see comparison 6).

The currently offered commercial ECS has lower uptake probabilities than the currently offered non-commercial screenings. However, if screenings would be commercially offered with higher accuracy rates at a cost of €200, the uptake probability of this test would be close to the screening offered at the UMC in Groningen (see comparison 10).

### 4.5.3 WTP across different respondent groups

**Table 10**- Willingness to pay and uptake probabilities of currently available ECS across different respondent characteristics

| ECS / Characteristic | Willingness to pay | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | AMC Amsterdam | | UMC Groningen | | Commercial | | Base case ECS | |
| | Mean WTP | Δ base case | Mean WTP | Δ base case | Mean WTP | Δ base case | Mean WTP | Δ base case |
| Base case* | €991.38 | 0 | €1039.61 | 0 | -€239.73 | 0 | €100.07 | 0 |
| High education | €698.97 | *-€292.4* | €723.86 | *-€315.75* | €1.09 | *+€240.82* | €51.63 | *-€48.44* |
| Prior knowledge ECS | €3162.17 | *+€2170.79* | €3268.90 | *+€2229.29* | €437.73 | *+€677.46* | €1189.70 | *+€1089.63* |
| Child within 1 year | €741.29 | *-€250.09* | €1039.61 | *+€0* | -€239.73 | *+€0* | €100.07 | *+€0* |
| 1 child | €725.63 | *-€265.75* | €773.86 | *-€265.75* | -€505.48 | *-€265.75* | -€265.75 | *-€365.82* |
| Has partner | €1712.17 | *+€720.79* | €1760.40 | *+€720.79* | €481.06 | *+€720.79* | €620.71 | *€520.64* |

*Base case= Lower education, no prior knowledge ECS, Child later than 1 year, no children.
Screening characteristics AMC: package 1, provider: specialist, price: €650, information provision: counselling, accuracy: 99%. Screening characteristics UMC: package 1, provider: GP, price: €475, information provision: counselling, accuracy: 99%. Screening characteristics Commercial: diseases tested: package 1, provider: commercial, price: €169, information provision: website, accuracy: 91%. Screening characteristics Base case ECS: diseases tested: package 1, provider: commercial, price: €200, information provision: counselling, accuracy: 91%. These numbers are derived from mixed logit with interactions. For the meaning of all the levels and Attributes, please refer to the method section.

Table 11 shows the comparisons made regarding the WTP between the base case sample and multiple respondent characteristics across the current screening offers, according to the mixed logit model with interaction effects.

Having prior knowledge of ECS is the characteristic with the biggest WTP gain overall. For instance, respondents with prior knowledge of ECS within the research sample would be willing to pay €2229.29 more on average for the ECS offered at the UMC Groningen, compared to the base case group. This effect is due to the lower utility decrease for every €

spent on ECS for this subgroup and the lower preferability of an opt-out in the mixed logit model with interaction effects.

Another characteristic with an overall positive effect on the mean WTP, was having a partner. Having a partner would increase the mean WTP by €720.79 on all currently offered screenings (compared to the base case sample). This is due to similar effects this characteristic has on the opt-out as the characteristic consisting of respondents who had prior knowledge of ECS.

The characteristic that had the largest negative effect on the mean WTP for non-commercial ECS was having a degree in higher education (-€315.75). This negative effect occurred because this subgroup had a greater utility decrease for every € spent on ECS compared to the base case group and a lower utility decrease for the opt-out option (see Table 8).

The same subgroup (with a higher educational level) would be willing to pay €240.82 more for a commercially offered test compared to the base case group. This is due to ECS information provided using a website being more preferred by this subgroup. However, this is still lower than the mean estimated WTP from Table 9, the mean WTP for a commercially offered screening was €401.73 .

### 4.6 Extra choice task

**Table 11**- Extra choice task

| Attribute | **Screening option 1** | **Screening option 2** | **Option 3 (Opt-out)** |
|---|---|---|---|
| *Costs* | €1000 | €100 | Opt-out |
| *Accuracy* | 99 out of 100 tests have a correct result | 50 out of 100 tests have a correct result | |
| *n chosen (%)* | 261 (54.3%) | 35 (7.3%) | 185 (38.5%) |

This choice task was only answered by respondents who were found to be qualified, just like with the other choice tasks. For the meaning of all the levels and Attributes, please refer to the method section.

Table 12 displays the results of an extra more simplified choice-task that was added to the DCE, but was not included in the mixed logit estimations. Screening option 2 was much less preferred than option 1 (7.3% vs 54.3%), even though the costs were substantially lower. The second most popular option in this choice task was the opt-out, which was chosen by 38.5% of the respondents.

### 4.7 Ranking exercise

**Figure 3-** Ranking score of the attributes according to contingent valuation method

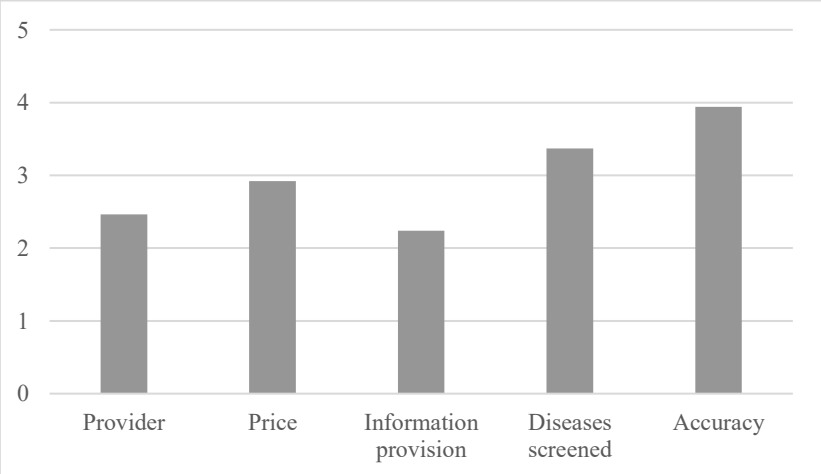



Figure 3 displays the results from the contingent valuation question, where respondents had to rank the attributes according to their importance. As can be perceived from figure 3, respondents ranked the attributes from most important to least important: accuracy, diseases screened, price, provider, information provision.

# 5. Discussion

## 5.1 Objective

The main goal of this study was to gain more insight in how Dutch individuals from the general population who have a child wish and are open towards expanded carrier screening value expanded carrier screening (ECS) and its (possible) characteristics in terms of monetary units/willingness to pay (WTP). Additionally, this study aimed to estimate how certain respondent characteristics were related to fluctuations in the WTP estimate and WTP of the different screening characteristics. At last, these WTP estimations were further compared to currently available screen offers to observe how these offerings related to the preferences of the sample.

The characteristic that has the most sizable effect on the overall utility of an ECS in the discrete choice experiment (DCE), is the price, followed by ECS test the accuracy, information provision, provider and number/type of diseases tested respectively. Consequently, the accuracy is the attribute with the largest effect on the WTP. The most favourable ECS levels are €200, 99% accuracy, information provided during the counselling prior to the ECS, the general practitioner/specialist or midwife as the provider and package 3 of the possible diseases tested. The least favourable ECS levels are a price of €1000, 91% accuracy, information provided using a website or brochure, commercial company as the provider and package 1 of the possible diseases tested. The most and least favourable levels mentioned are limited to the levels used in the DCE given to the respondent sample.

The estimated best currently offered non-commercial ECS in the Netherlands has a mean WTP of €1165.20, whereas the commercially offered ECS has a mean WTP of €401.73 . The true costs of the noncommercially and commercially offered ECS are €475 and €169 respectively. Even though the costs of the commercially offered ECS is lower than the non-commercial one, the latter had a higher uptake probability (51.2% vs 16.0%) when comparing all possible choices a Dutch individual has.

The WTP of the currently available ECS offers in the Netherlands are estimated to be well above the actual costs of them (Table 9). Respondent characteristics that have a positive influence on the WTP are having a partner and having knowledge of ECS prior to the survey.

However, the results also revealed that the groups consisting of respondents with a degree in higher education or who have children are willing to pay substantially less than the mean. Having children might have a negative effect on WTP as these individuals/parents are more experienced in pregnancy and childbirth and thereby were more aware of their needs when having children.

## 5.2 Interpretation

### 5.2.1 Comparing results with prior research

At the moment of completing this thesis, there are no studies available regarding WTP discrete choice experiments for ECS yet. A comparison with DCE studies regarding prenatal screening techniques is suboptimal, as the perceived most important characteristics consist of the risk of miscarriage[42,43,46]. In ECS, safety is not an issue as the test is carried out before conceiving and involves a non-invasive genetic test[27].

Preferences of ECS have been studied before. Plantinga et al. made use of a more simplified method, i.e. psychological surveys, to gain information about the preferences regarding ECS in the Netherlands. Plantinga et al. concluded that the General Practitioner (GP) was the most favourable provider of an ECS (44%), followed by having no preference for provider at all (18%). The midwife was preferred by 7% of the sample. The current study found very similar findings, considering the GP has the highest utility gain compared to a commercial provider. While this outcome is not found significantly different than the utility estimations made for midwife or specialist, this indifference is also on par with the fact that many respondents had no preference at all towards the provider of the test in Plantinga et al[17]. The possibility of a commercial provider was not taken into account in Plantinga et al[17].

Furthermore, similar findings are found regarding the way of information provision by Plantinga et al. In both this and the Plantinga et al. study, a face-to-face consult with the provider is the most preferred (37%). This preference was followed by having information provided by brochure (21%), having no preference at all (15%) and a website (13%). The latter results slightly differ with the results of the current study since the levels ‘Website’ and ‘Brochure’ have similar utility losses[17].

Other results of Plantinga et al. did have different outcomes than the current study. The results regarding testing for genetic predispositions in an ECS showed that many respondents (64%) would not be interested in such a test in Plantinga et al. This outcome is different from the current study as adding genetic dispositions to an ECS shows a slight utility gain (versus testing only for serious diseases), although these levels are the least statistically significant. In addition, the median WTP was reported to be €75 with a range of €5 and €5000 and no further information given, whereas the mean estimated WTP in this study is €1165.20 for an ECS comparable to the one offered in Plantinga et al[17]. This considerable difference might be due to the use of a contingent valuation method in Plantinga et al. and the fact that the samples differ. In in this study only individuals were included that were open towards ECS.

### 5.2.2 Preferability of commercial offers

Although commercial offers regarding ECS prove to be less preferrable than non-commercial offers, there might still be situations where the commercial alternative is chosen as the costs are lower[13]. How preferable a commercial offer is also depends on what assumption is made by the individual regarding the accuracy, considering no or very limited information is given about this characteristic by commercial providers. The minimum standards of commercial genetic test providers (direct-to-customer) in what DNA sequencing technologies have to be utilized are far more lenient than the minimum standards for non-commercial tests[13]. If the accuracy is assumed to be as high as the non-commercial offers by certain individuals, the commercial screenings might prove to be more preferable for these individuals.

The lowest accuracy level included in the DCE was 91%. This level was used to describe the accuracy of the commercial provider and accordingly estimate the WTP and uptake probability. No firm statements can be made on whether this level matches the actual accuracy, as commercial companies do not distribute this information. However, to discern the preferability of screenings with lower accuracy, an additional choice task was included in the DCE that was not taken into account in the regression models. This choice task is displayed in Table 12 (page 49). Of the qualified sample, 54.3% chose option 1, 7.3% option 2 and 38.5% the opt-out. Individuals who did not prefer spending €1000 but also did not want to have a screening with 50% accuracy are believed to have chosen for the opt-out option. These results confirm that individuals have a risk averse attitude regarding lower ECS

accuracies, which is a characteristic of commercial tests. This was also confirmed by the Bijsterbosch study, where interviewed respondents reported similar statements[18].

### 5.3 Strengths and limitations

One strength of this study was the quality of the survey with the accompanying DCE used to gain information from the respondents. This survey was the result of extensive planning, piloting and multiple feedback and its results are believed to give broad insight into the preferences of the sample.

In terms of limitations, one limitation of a DCE is that a limited number of attributes can be included, as too many attributes causes fatigue for the respondents and ultimately decreases the reliability and validity of the results[49]. During the WTP and uptake-probability estimations of the current offers regarding ECS, only the test characteristics according to the DCE attributes are taken into account. These characteristics are not the only facets of decision making regarding participation in ECS for an individual. Other factors that also come into play are how information is provided about the outcome of the test, whether the screening focusses on individual or couple results and the travel-time to the screening. The latter characteristic is especially relevant for the comparisons made between screenings offered by university hospitals or commercial providers. It can be argued that if travel-time was added, the preferability of a commercial provider would increase, as those screenings are ordered online and executed at home.

Another limitation that is shared by DCEs and other WTP methods, is that the WTP derived from such methods is known to be overestimated due to hypothetical bias[60]. This hypothetical bias can be perceived as an double bias, as hypothetical choices are presented in a DCE and individuals pay in reality less than they state in a WTP study[60]. Even though the estimated WTP is higher than the actual cost of ECS currently in the Netherlands, it is known that not too many individuals or couples actually undertake the screening in the Netherlands. However, there are multiple reasons why the uptake of the ECS screen offers in the Netherlands is modest yet. This could also be because not all individuals are informed about the existence of ECS (awareness) or due to characteristics not taken into account in this study.

Furthermore, the standard deviation of the opt-out level is estimated to be high, meaning that there was a big variation in the utility loss of an opt-out and therefore for not having an ECS test at all. This variation is partly due to a part of the sample that chose for the opt-out option in all choice tasks (n=42). Of these respondents, 31 (73.8%) state that they only chose for the opt-out option because they think the lowest included price level (€200) is more than they would be willing to spent and 3 (7.1%) stated that 99% accuracy is not enough for them to accept the screening. These statements indicate that for some the characteristics regarding accuracy and price should improve for them to consider ECS. If higher accuracy levels and lower cost levels were included in the DCE, information would have been gained regarding the preferences of this group. These respondents were still included in the qualified sample, because they were open towards ECS.

At last, in the current study it is thought that a lot students have participated. However, no questions were added in the survey to determine whether a respondent was a student. This may be seen as a limitation, as characteristics that are shared by both students and non-students could have very different effects on the preferences and WTP depending on which group the respondent belongs to. It is thought that the noticeable negative effects of having a higher educational level on the WTP might also be due to a part of the students belonging to this group. Students generally have less income than (full-time) working individuals, meaning they are not able to spend as much for ECS, while having a higher educational level.

## 5.4 Aspects of validity and reliability

### 5.4.1 Selection bias

It is thought that no major bias was caused due to the two ways of recruiting respondents. Even though a part of the participants were gathered from the social circles of the researcher, the larger part of the participants were gathered using the services of a market research firm that provides qualified survey respondents. The overview of the respondent characteristics suggests that all characteristics are well represented and in a balanced fashion (Table 4 and 5).

However, some differences were found between the sample consisting of respondents gathered by Dynata and the sample that was gathered by the researchers (Table 6, page 38). These differences are not thought to have caused complications in terms of the selection, as the services from Dynata were partly utilized because the sample gathered by the researchers was not thought to be balanced. Due to the sample of Dynata more balance was introduced regarding the male-female composition, the age groups, the income groups and the education groups.

The 215 respondents who dropped out of the study because they did not complete the survey had characteristics comparable to the included sample, with a mean age of 27.3 years, mean income of €2667 and 50.3% having prior knowledge of ECS. However, the 67 respondents that were excluded due to repetitive choices, going through the survey too fast or due to failing the dominant strategy, had characteristics that were fairly different from the included group. The mean income per month of this group was €4451, 77.6% had prior knowledge of ECS and 63.4% answered to have a congenital genetic disorder themselves. Nonetheless, these characteristics can be somewhat discredited as the reasons this group was excluded might indicate that the answers were not serious.

### 5.4.2 Information bias

In terms of information bias, the survey and DCE design were finalized with a lot of feedback that was obtained during the pilot survey, where respondents were able to note what parts were not clear and where they had difficulties. Extra information was given when respondents seemed not to fully understand a certain part and levels were simplified when respondents did not fully grasp them. In addition, the pilot survey gave the researchers the

opportunity to add questions in situations where more information was needed, for instance when respondents chose for the opt-out options many times.

To make sure that respondents understood what was asked from them, a dominant strategy was added to the survey in the form of a choice task. If respondents failed to select the dominant strategy, they were given a second chance by asking whether they were certain of their choice. If they were neither able to select the dominant strategy in the second chance, they were excluded before the analysis of the results.

At last, it is thought that the mixed logit models which were used to analyse the data from the DCE, were the right statistical models to execute. In the mixed logit model the assumption is made that each individual has its own preferences. Even if certain levels are not described by individual preferences, this is shown during the formation of the model, where levels can be imported as fixed variables instead of random when the SDs are insignificant.

### 5.4.3 Generalizability

This study was done to gain information on the preferences regarding ECS of the Dutch population. These results are not fully generalizable to other countries or health systems, as the Netherlands has specific heath care characteristics that are not shared with (many) other countries. The GP is known to be the gatekeeper of hospital- and specialist care in the Netherlands and is a familiar face for its patients and is someone a lot of health-related matters can be asked from[61]. In countries where the GP does not fulfil this role, the GP might not seem as preferable as an provider as it seems in this study. Similar differences might be seen in the preferability of the midwife as the provider of an ECS, as community midwifery is typical for the Dutch healthcare system.

In regards to the characteristics of the included sample, it was shown (Table 4 and 5) that there was an imbalance in the male-female ratio and that this sample included more individuals with a higher educational level than the national mean. These imbalances are something to be considered when valuing the generalizability of this study. Even though no differences were shown in the utilities and WTP according to the gender of a respondent, respondents with a degree in higher education were shown to have negative impact on the

mean WTP and a positive impact on the utility of the accuracy and information provision levels (when compared to the base case ECS).

### 5.4.4 Reliability

Within the survey several components were added to measure the reliability of the answers and to get more insight in how the methods used in the survey might differentiate the answers compared to other methods.

First, a contingent valuation ranking exercise was added to the survey, where the respondents ranked the attributes in terms of importance after the DCE. The mean ranking scores of the different attributes are displayed in figure 3 (4.6, page 49). As can be perceived, respondents ranked the attributes from most important to least important: accuracy, diseases screened, price, provider, information provision. This is different from when discerning the attribute importance using the utility coefficients from the mixed logit, where price is the most important attribute followed by accuracy and the diseases tested being the least important attribute. For the diseases screened attribute this difference may be due to how the levels were organized, with respondents not seeing much difference between the three packages. For accuracy and price these differences were due to the different techniques used, where respondents ranked the attributes directly in the ranking exercise and indirectly in DCE. However, the attribute importance deducted from the DCE would might have been different if lower price or higher accuracy levels were used.

Furthermore, to access information on whether respondents might alternate their preferences during the DCE, a duplicate choice-task was added. Of the final research sample, 21.6% chose a different option in the second duplicate choice-task. This percentage may indicate that some respondents were still forming their preferences while doing the experiment. This can also provide insight into the test-retest reliability, even though not many of the respondents did not have the same answer in the duplicate question. For DCEs in general, it is believed that the test-retest variations are low and do not affect the outcomes of a DCE study[62].

Moreover, feedback was acquired from the respondents in terms of how understandable and feasible they thought the survey was. Of the qualified respondents, 438 thought the survey

and DCE was very well understandable (91.4%) and 40 respondents (8.4%) said the survey was “rather understandable”, In terms of feasibility, 66% of the respondents agreed or strongly agreed that the survey was workable for them, 24.6% was neutral and 9.4% disagreed or strongly disagreed. The feedback regarding the feasibility were somewhat expected, as DCEs require more focus from the participant than regular surveys.

At last, the sample size is believed to be sufficient, meaning that the sample size cannot be an aspect that causes unreliability of the results. This risk is also minimized by the execution of a pilot survey, of which the results were used to create a d-efficient DCE design in the final survey[63]. The sample size being sufficient can also be deducted from the results, where most coefficients are significant within a *p*-value of 0.001.

### 5.5 Discrepancy Proposal-Thesis

Internally, there were some alterations made from what was strategized in the proposal. Many of the changes were made regarding the attributes and levels. It was stated in the proposal that the DCE would make use of six attributes. The attribute that was not used in the pilot and final DCE was the attribute ‘Individual or couple result’. This change was made as the researchers felt the need to lower the amount of attributes to make the DCE more feasible and because individuals do not have much choice within this attribute in real life[33].

Furthermore, the price, accuracy and diseases tested attribute had one level removed. For price the €50 level was removed, as it was unrealistically low and to bring the price more in agreement with the possible future pricing of ECS. It was not thought that the ECS would get priced (much) lower than €200 because the non-invasive prenatal test (NIPT) was already priced at €175[64]. Next, the highest accuracy level was made 99% instead of 98%, because many of the respondents of the pilot survey thought that 98% was already too low. At last, the “diseases screened” variable was simplified for the respondents, as it was seen in the results from the pilot survey that many respondents did not take the attribute into account because of its complexity.

### 5.6 Recommendations

It is thought that this study has brought many meaningful results that could be used in future policy making regarding ECS and give current providers guidance in the composition of their screening. Currently available offerings of ECS are seen to fit well within the needs of the Dutch population, but improvements could still be made. Even though the WTP was seen to be well above the current pricing of ECS, it is still thought revisions could be made as even within the current sample there were respondents who were open towards ECS but either could not or would not afford such screening. As this type of screening is a very useful tool for informed-decision making regarding conceiving (pre-pregnancy), it is important for it to be accessible for the whole Dutch population[6,7,8].

Making ECS more accessible for the Dutch population is also something policy makers could help with. At the moment, non-commercial ECS is only available in two places in the Netherlands and has to be paid out-of-pocket. Additionally, it was seen that respondents who were informed about ECS prior to the survey had a higher WTP, implying that they desire this screening more. Many individuals in the sample yet did not know about the possibility of ECS. It is thought that there are a lot of individuals in the Netherlands that would be interested in ECS if they knew about its existence. Informing the Dutch population of the existence of ECS, making ECS more widely available and battling the high out-of-pocket costs could all be realized if ECS was fully integrated in the Dutch health-system and health insurance.

Furthermore, there was an interest in ECS from a commercial party, even though these providers have no minimum standards in the techniques utilized and no information given about the accuracy. Problems could arise if individuals assume a commercial screening is as reliable as a non-commercial screening. More research should be done in the assumptions individuals make about these screenings to evaluate whether (extra) measures should be taken in terms of the transparency and techniques applied by commercial providers.

At last, more research is needed in ECS preferences by non-Dutch individuals to be able to make claims regarding ECS for health-systems that are differently arranged from the Netherlands.

# 6. Conclusion

In conclusion, the price and the accuracy of a screening were seen to be the most important aspects in the preferability of an expanded carrier screening (ECS). An ECS with 99% accuracy was shown to have a mean WTP of €498.93 higher than a screening with 91% accuracy within the study sample.

Additionally, the overall WTP was seen to be well above the pricing of currently available screenings. The screening that had the best fit with the preferences of the sample had a mean WTP of €1165.20 while being priced for €475. Additionally, while a screening from a commercial providers was shown to be less preferable, there would still be a demand for it in the current market due to the low costs and some individuals preferring information provision through a website.

At last, it was seen that the WTP for an ECS depended a lot on the characteristics of the respondent. Interestingly enough, individuals with a degree in higher education and/or were shown to be willing to pay the least for a ECS while individuals with a partner and/or prior knowledge of ECS were willing to pay the most.

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# Appendix I – Mixed logit

### Final mixed logit (10000 repetitions)

Mixed logit model — Number of obs = 18,759; LR chi2(7) = 3770.57; Prob > chi2 = 0.0000; Log likelihood = -4666.4225

| Y | Coefficient | Std. err. | z | P>\|z\| | [95% conf. | interval] |
|---|---|---|---|---|---|---|
| **Mean** | | | | | | |
| provider_midwife | .4469064 | .0886672 | 5.04 | 0.000 | .273122 | .6206908 |
| information_website | -.4037592 | .0738556 | -5.47 | 0.000 | -.5485135 | -.2590049 |
| accuracy95 | .5431141 | .0848299 | 6.40 | 0.000 | .3768504 | .7093777 |
| information_brochure | -.2995082 | .0735674 | -4.07 | 0.000 | -.4436976 | -.1553188 |
| opt_out | -1.640526 | .1921545 | -8.54 | 0.000 | -2.017142 | -1.26391 |
| genes2 | .1453315 | .0750531 | 1.94 | 0.053 | -.0017697 | .2924328 |
| genes3 | .2759988 | .1120658 | 2.46 | 0.014 | .0563539 | .4956436 |
| provider_specialist | .3658927 | .0998647 | 3.66 | 0.000 | .1701614 | .561624 |
| provider_GP | .4519284 | .1120179 | 4.03 | 0.000 | .2323773 | .6714795 |
| price | -.0030607 | .0002211 | -13.84 | 0.000 | -.0034941 | -.0026273 |
| accuracy99 | 1.579369 | .1257748 | 12.56 | 0.000 | 1.332855 | 1.825883 |
| **SD** | | | | | | |
| opt_out | 3.169736 | .2057149 | 15.41 | 0.000 | 2.766542 | 3.57293 |
| genes2 | .6738178 | .1051586 | 6.41 | 0.000 | .4677107 | .8799248 |
| genes3 | 1.637709 | .1144192 | 14.31 | 0.000 | 1.413451 | 1.861966 |
| provider_specialist | -.8668347 | .1142816 | -7.59 | 0.000 | -1.090823 | -.6428468 |
| provider_GP | -.678351 | .1253453 | -5.41 | 0.000 | -.9240233 | -.4326787 |
| price | -.0036171 | .000247 | -14.64 | 0.000 | -.0041012 | -.003133 |
| accuracy99 | 1.683789 | .1174768 | 14.33 | 0.000 | 1.453539 | 1.914039 |

The sign of the estimated standard deviations is irrelevant: interpret them as being positive

### Linearity price and accuracy

```
.
. //Linear effect?
. *Price 200 - 500 - 1000
. * + 300 + 800
. test price500 = 0.375*price1000

 ( 1)  [Mean]price500 - .375*[Mean]price1000 = 0

           chi2(  1) =    0.00
         Prob > chi2 =    0.9458

. *OF
. test price500/300 = price1000/800

 ( 1)  .0033333*[Mean]price500 - .00125*[Mean]price1000 = 0

           chi2(  1) =    0.00
         Prob > chi2 =    0.9458

.
. *Accuracy 91-95-99
. * + 4 + 8
. test accuracy95 = 0.5*accuracy99

 ( 1)  [Mean]accuracy95 - .5*[Mean]accuracy99 = 0

           chi2(  1) =    8.94
         Prob > chi2 =    0.0028

. *OF
. test accuracy95/4 = accuracy99/8

 ( 1)  .25*[Mean]accuracy95 - .125*[Mean]accuracy99 = 0

           chi2(  1) =    8.94
         Prob > chi2 =    0.0028

.
```

# Appendix II – Mixed logit with interaction effects

**Accuracy**

Generalized multinomial logit model — Number of obs = 18,759
Log likelihood = -4861.9046 — Wald chi2(32) = 523.56
Prob > chi2 = 0.0000

| Y | Coefficient | Std. err. | z | P>\|z\| | [95% conf. | interval] |
|---|---|---|---|---|---|---|
| **Mean** | | | | | | |
| opt_out | -.8027135 | .1675208 | -4.79 | 0.000 | -1.131048 | -.4743788 |
| genes2 | .2104414 | .0562989 | 3.74 | 0.000 | .1000976 | .3207853 |
| genes3 | .0830096 | .0879446 | 0.94 | 0.345 | -.0893586 | .2553779 |
| provider_midwife | .556531 | .0810504 | 6.87 | 0.000 | .3976751 | .7153869 |
| provider_specialist | .4977862 | .084243 | 5.91 | 0.000 | .332673 | .6628993 |
| provider_GP | .7150937 | .0944478 | 7.57 | 0.000 | .5299794 | .900208 |
| information_brochure | -.3491214 | .0650876 | -5.36 | 0.000 | -.4766907 | -.221552 |
| information_website | -.4120519 | .0677593 | -6.08 | 0.000 | -.5448577 | -.279246 |
| price500 | -.7280957 | .0684201 | -10.64 | 0.000 | -.8621967 | -.5939948 |
| price1000 | -1.832729 | .103364 | -17.73 | 0.000 | -2.035319 | -1.630139 |
| accuracy95 | .0394221 | .6927359 | 0.06 | 0.955 | -1.318315 | 1.39716 |
| accuracy99 | .825263 | .9054217 | 0.91 | 0.362 | -.949331 | 2.599857 |
| kindbinnen1jaarXaccuracy95 | -.0821098 | .1571765 | -0.52 | 0.601 | -.3901701 | .2259504 |
| kindbinnen1jaarXaccuracy99 | .0786506 | .206339 | 0.38 | 0.703 | -.3257665 | .4830676 |
| kennenecsXaccuracy99 | .2276358 | .1606737 | 1.42 | 0.157 | -.0872788 | .5425505 |
| kennenecsXaccuracy95 | .1351064 | .1324527 | 1.02 | 0.308 | -.1244962 | .3947089 |
| kennenaandoeningXaccuracy99 | -.0083386 | .1671968 | -0.05 | 0.960 | -.3360382 | .319361 |
| kennenaandoeningXaccuracy95 | .014264 | .1291652 | 0.11 | 0.912 | -.238895 | .2674231 |
| leeftijdXaccuracy99 | -.043958 | .0153443 | -2.86 | 0.004 | -.0740322 | -.0138837 |
| leeftijdXaccuracy95 | -.0095028 | .0121315 | -0.78 | 0.433 | -.0332802 | .0142745 |
| buitenlandgeborenXaccuracy99 | -.0697678 | .3041768 | -0.23 | 0.819 | -.6659433 | .5264077 |
| buitenlandgeborenXaccuracy95 | .1707538 | .2940918 | 0.58 | 0.562 | -.4056555 | .7471632 |
| heeftpartnerXaccuracy99 | -.3038296 | .1901983 | -1.60 | 0.110 | -.6766115 | .0689522 |
| heeftpartnerXaccuracy95 | -.2454821 | .1654311 | -1.48 | 0.138 | -.569721 | .0787569 |
| aantalkinderenXaccuracy99 | .1018355 | .0921705 | 1.10 | 0.269 | -.0788155 | .2824864 |
| aantalkinderenXaccuracy95 | .0023793 | .0741638 | 0.03 | 0.974 | -.142979 | .1477376 |
| opleiding_hoogXaccuracy99 | .4817732 | .1547696 | 3.11 | 0.002 | .1784303 | .7851161 |
| opleiding_hoogXaccuracy95 | .4648891 | .1294321 | 3.59 | 0.000 | .2112068 | .7185714 |
| gemsalarislogXaccuracy99 | .2337144 | .1285582 | 1.82 | 0.069 | -.018255 | .4856838 |
| gemsalarislogXaccuracy95 | .0925998 | .0941191 | 0.98 | 0.325 | -.0918702 | .2770698 |
| religiejaXaccuracy95 | -.1750242 | .1455547 | -1.20 | 0.229 | -.4603062 | .1102577 |
| religiejaXaccuracy99 | -.0476477 | .180801 | -0.26 | 0.792 | -.4020111 | .3067158 |
| **SD** | | | | | | |
| opt_out | 3.11585 | .1529639 | 20.37 | 0.000 | 2.816046 | 3.415653 |
| genes2 | -.0116505 | .10919 | -0.11 | 0.915 | -.2256589 | .2023579 |
| genes3 | 1.200393 | .0885374 | 13.56 | 0.000 | 1.026863 | 1.373923 |
| provider_midwife | .0426764 | .0976408 | 0.44 | 0.662 | -.148696 | .2340488 |
| provider_specialist | .2746711 | .149756 | 1.83 | 0.067 | -.0188452 | .5681875 |
| provider_GP | -.1190815 | .1424048 | -0.84 | 0.403 | -.3981898 | .1600268 |
| information_brochure | .0489887 | .0948676 | 0.52 | 0.606 | -.1369483 | .2349256 |
| information_website | .0049012 | .0927114 | 0.05 | 0.958 | -.1768099 | .1866122 |
| price500 | .8603809 | .0853148 | 10.08 | 0.000 | .6931669 | 1.027595 |
| price1000 | 1.529124 | .0990787 | 15.43 | 0.000 | 1.334933 | 1.723315 |
| accuracy95 | .154776 | .0786336 | 1.97 | 0.049 | .0006569 | .308895 |
| accuracy99 | .3031238 | .1223572 | 2.48 | 0.013 | .0633081 | .5429395 |
| kindbinnen1jaarXaccuracy95 | .0648558 | .1529632 | 0.42 | 0.672 | -.2349465 | .3646582 |
| kindbinnen1jaarXaccuracy99 | .1263103 | .1736373 | 0.73 | 0.467 | -.2140125 | .4666331 |
| kennenecsXaccuracy99 | .3219397 | .1941735 | 1.66 | 0.097 | -.0586334 | .7025129 |
| kennenecsXaccuracy95 | -.1605431 | .1306799 | -1.23 | 0.219 | -.4166709 | .0955847 |
| kennenaandoeningXaccuracy99 | .8208991 | .2799138 | 2.93 | 0.003 | .2722781 | 1.36952 |
| kennenaandoeningXaccuracy95 | -.0689587 | .1289769 | -0.53 | 0.593 | -.3217488 | .1838315 |
| leeftijdXaccuracy99 | .0006438 | .0045224 | 0.14 | 0.887 | -.0082198 | .0095075 |
| leeftijdXaccuracy95 | -.0027849 | .0027975 | -1.00 | 0.319 | -.008268 | .0026981 |
| buitenlandgeborenXaccuracy99 | -.0512678 | .4428055 | -0.12 | 0.908 | -.9191506 | .816615 |
| buitenlandgeborenXaccuracy95 | -.6097016 | .2322742 | -2.62 | 0.009 | -1.064951 | -.1544525 |
| heeftpartnerXaccuracy99 | .6679188 | .1483393 | 4.50 | 0.000 | .3771791 | .9586585 |
| heeftpartnerXaccuracy95 | -.0181982 | .1012427 | -0.18 | 0.857 | -.2166304 | .1802339 |
| aantalkinderenXaccuracy99 | .4819102 | .1243717 | 3.87 | 0.000 | .2381462 | .7256742 |
| aantalkinderenXaccuracy95 | -.1267045 | .082808 | -1.53 | 0.126 | -.2890052 | .0355963 |
| opleiding_hoogXaccuracy99 | 1.31795 | .152178 | 8.66 | 0.000 | 1.019686 | 1.616213 |
| opleiding_hoogXaccuracy95 | -.1108854 | .1036944 | -1.07 | 0.285 | -.3141227 | .092352 |
| gemsalarislogXaccuracy99 | .0210761 | .0207056 | 1.02 | 0.309 | -.0195062 | .0616584 |
| gemsalarislogXaccuracy95 | .0037729 | .0122382 | 0.31 | 0.758 | -.0202136 | .0277594 |
| religiejaXaccuracy95 | -.0407579 | .187179 | -0.22 | 0.828 | -.407622 | .3261061 |
| religiejaXaccuracy99 | .571677 | .2396919 | 2.39 | 0.017 | .1018894 | 1.041465 |

The sign of the estimated standard deviations is irrelevant: interpret them as being positive

**Diseases tested (genes= diseases tested)**

Generalized multinomial logit model — Number of obs = 18,759
Log likelihood = -4847.634 — Wald chi2(32) = 609.57
Prob > chi2 = 0.0000

| Y | Coefficient | Std. err. | z | P>\|z\| | [95% conf. | interval] |
|---|---|---|---|---|---|---|
| **Mean** | | | | | | |
| opt_out | -.9717925 | .1449655 | -6.70 | 0.000 | -1.25592 | -.6876653 |
| genes2 | .8780692 | .6489973 | 1.35 | 0.176 | -.3939421 | 2.150081 |
| genes3 | 1.52753 | .8977252 | 1.70 | 0.089 | -.2319787 | 3.287039 |
| provider_midwife | .530858 | .0807069 | 6.58 | 0.000 | .3726753 | .6890407 |
| provider_specialist | .4711634 | .0845484 | 5.57 | 0.000 | .3054515 | .6368753 |
| provider_GP | .7027366 | .0956326 | 7.35 | 0.000 | .5153001 | .890173 |
| information_brochure | -.3828651 | .0659988 | -5.80 | 0.000 | -.5122203 | -.2535099 |
| information_website | -.4367041 | .0695434 | -6.28 | 0.000 | -.5730067 | -.3004015 |
| price500 | -.7100729 | .0713894 | -9.95 | 0.000 | -.8499936 | -.5701522 |
| price1000 | -1.963261 | .1005096 | -19.53 | 0.000 | -2.160257 | -1.766266 |
| accuracy95 | .6002435 | .0750786 | 7.99 | 0.000 | .4530921 | .7473949 |
| accuracy99 | 1.530131 | .096295 | 15.89 | 0.000 | 1.341396 | 1.718866 |
| kindbinnen1jaarXgenes3 | .213014 | .1994433 | 1.07 | 0.286 | -.1778877 | .6039156 |
| kindbinnen1jaarXgenes2 | -.2207861 | .1439311 | -1.53 | 0.125 | -.5028859 | .0613138 |
| kennenecsXgenes2 | .0650617 | .1209841 | 0.54 | 0.591 | -.1720628 | .3021861 |
| kennenecsXgenes3 | .0369886 | .1651838 | 0.22 | 0.823 | -.2867657 | .3607428 |
| kennenaandoeningXgenes2 | .0017514 | .122169 | 0.01 | 0.989 | -.2376954 | .2411982 |
| kennenaandoeningXgenes3 | -.0045297 | .1617263 | -0.03 | 0.978 | -.3215075 | .3124481 |
| jongereXgenes2 | -.0558161 | .1454005 | -0.38 | 0.701 | -.3407959 | .2291637 |
| jongereXgenes3 | .4059498 | .2146539 | 1.89 | 0.059 | -.0147641 | .8266636 |
| buitenlandgebborenXgenes2 | .1744971 | .263013 | 0.66 | 0.507 | -.340999 | .6899931 |
| buitenlandgebborenXgenes3 | 1.195681 | .2982403 | 4.01 | 0.000 | .6111403 | 1.780221 |
| heeftpartnerXgenes2 | .1599551 | .1453131 | 1.10 | 0.271 | -.1248535 | .4447636 |
| heeftpartnerXgenes3 | .1742208 | .2018169 | 0.86 | 0.388 | -.2213332 | .5697747 |
| aantalkinderenXgenes2 | -.1417242 | .0672002 | -2.11 | 0.035 | -.2734341 | -.0100143 |
| aantalkinderenXgenes3 | .0144534 | .0776997 | 0.19 | 0.852 | -.1378351 | .166742 |
| opleiding_hoogXgenes2 | .1291262 | .1223711 | 1.06 | 0.291 | -.1107168 | .3689692 |
| opleiding_hoogXgenes3 | -.2799729 | .1748606 | -1.60 | 0.109 | -.6226934 | .0627476 |
| gemsalarislogXgenes2 | -.0972172 | .0864943 | -1.12 | 0.261 | -.2667429 | .0723084 |
| gemsalarislogXgenes3 | -.2009181 | .1185698 | -1.69 | 0.090 | -.4333107 | .0314744 |
| religiejaXgenes3 | -.2538152 | .1782444 | -1.42 | 0.154 | -.6031679 | .0955374 |
| religiejaXgenes2 | -.0463188 | .1404296 | -0.33 | 0.742 | -.3215558 | .2289181 |
| **SD** | | | | | | |
| opt_out | 3.231272 | .1403668 | 23.02 | 0.000 | 2.956158 | 3.506385 |
| genes2 | -.2110371 | .0814169 | -2.59 | 0.010 | -.3706113 | -.0514629 |
| genes3 | 1.031147 | .1172058 | 8.80 | 0.000 | .8014279 | 1.260866 |
| provider_midwife | -.0304762 | .0982903 | -0.31 | 0.757 | -.2231217 | .1621694 |
| provider_specialist | .3165844 | .1346647 | 2.35 | 0.019 | .0526464 | .5805224 |
| provider_GP | -.2726477 | .1144703 | -2.38 | 0.017 | -.4970054 | -.0482899 |
| information_brochure | -.0125572 | .1120152 | -0.11 | 0.911 | -.232103 | .2069886 |
| information_website | .0020103 | .1060491 | 0.02 | 0.985 | -.2058422 | .2098628 |
| price500 | .9004159 | .0815645 | 11.04 | 0.000 | .7405523 | 1.060279 |
| price1000 | 1.628565 | .0962754 | 16.92 | 0.000 | 1.439869 | 1.817261 |
| accuracy95 | -.0384572 | .0940279 | -0.41 | 0.683 | -.2227486 | .1458342 |
| accuracy99 | 1.303537 | .0831114 | 15.68 | 0.000 | 1.140642 | 1.466433 |
| kindbinnen1jaarXgenes3 | -.6391276 | .1966927 | -3.25 | 0.001 | -1.024638 | -.253617 |
| kindbinnen1jaarXgenes2 | .1839619 | .163937 | 1.12 | 0.262 | -.1373487 | .5052724 |
| kennenecsXgenes2 | -.0114237 | .1070817 | -0.11 | 0.915 | -.2212999 | .1984525 |
| kennenecsXgenes3 | .3858005 | .1839431 | 2.10 | 0.036 | .0252785 | .7463224 |
| kennenaandoeningXgenes2 | -.3479386 | .1047645 | -3.32 | 0.001 | -.5532733 | -.1426039 |
| kennenaandoeningXgenes3 | -.0970036 | .1654787 | -0.59 | 0.558 | -.4213358 | .2273287 |
| jongereXgenes2 | .4719196 | .1469149 | 3.21 | 0.001 | .1839717 | .7598675 |
| jongereXgenes3 | -.8604911 | .3809595 | -2.26 | 0.024 | -1.607158 | -.1138243 |
| buitenlandgebborenXgenes2 | .715639 | .2241034 | 3.19 | 0.001 | .2764044 | 1.154874 |
| buitenlandgebborenXgenes3 | -.0855343 | .3574214 | -0.24 | 0.811 | -.7860673 | .6149987 |
| heeftpartnerXgenes2 | -.0035807 | .1316514 | -0.03 | 0.978 | -.2616128 | .2544514 |
| heeftpartnerXgenes3 | .0410622 | .1916908 | 0.21 | 0.830 | -.3346449 | .4167692 |
| aantalkinderenXgenes2 | -.1260158 | .0702727 | -1.79 | 0.073 | -.2637477 | .0117161 |
| aantalkinderenXgenes3 | -.0795481 | .1090168 | -0.73 | 0.466 | -.293217 | .1341209 |
| opleiding_hoogXgenes2 | .1142232 | .2100307 | 0.54 | 0.587 | -.2974295 | .5258758 |
| opleiding_hoogXgenes3 | -.9415304 | .2225791 | -4.23 | 0.000 | -1.377777 | -.5052834 |
| gemsalarislogXgenes2 | .0331278 | .0108135 | 3.06 | 0.002 | .0119338 | .0543218 |
| gemsalarislogXgenes3 | .0004596 | .0227964 | 0.02 | 0.984 | -.0442204 | .0451397 |
| religiejaXgenes3 | .0068646 | .285884 | 0.02 | 0.981 | -.5534577 | .5671868 |
| religiejaXgenes2 | .2298668 | .1661018 | 1.38 | 0.166 | -.0956868 | .5554204 |

The sign of the estimated standard deviations is irrelevant: interpret them as being positive

## Provider

Generalized multinomial logit model — Number of obs = 18,759; Wald chi2(42) = 533.35; Log likelihood = -4845.2375; Prob > chi2 = 0.0000

| Y | Coefficient | Std. err. | z | P>\|z\| | [95% conf. | interval] |
|---|---|---|---|---|---|---|
| **Mean** | | | | | | |
| opt_out | -.1471415 | .1618727 | -0.91 | 0.363 | -.4644061 | .1701231 |
| genes2 | .2438296 | .0570066 | 4.28 | 0.000 | .1320989 | .3555604 |
| genes3 | .1454683 | .0811424 | 1.79 | 0.073 | -.0135679 | .3045044 |
| provider_midwife | 1.894706 | .8292034 | 2.28 | 0.022 | .2694973 | 3.519915 |
| provider_specialist | 1.29227 | .8703024 | 1.48 | 0.138 | -.4134918 | 2.998031 |
| provider_GP | 1.741452 | .8239947 | 2.11 | 0.035 | .1264519 | 3.356452 |
| information_brochure | -.3472621 | .0657899 | -5.28 | 0.000 | -.4762078 | -.2183163 |
| information_website | -.4185476 | .0676981 | -6.18 | 0.000 | -.5512334 | -.2858618 |
| price500 | -.7074409 | .0672243 | -10.52 | 0.000 | -.8391981 | -.5756837 |
| price1000 | -1.82073 | .0953785 | -19.09 | 0.000 | -2.007668 | -1.633792 |
| accuracy95 | .6211402 | .0767068 | 8.10 | 0.000 | .4707975 | .7714828 |
| accuracy99 | 1.446107 | .0979692 | 14.76 | 0.000 | 1.254091 | 1.638123 |
| kindbinnen1jaarXmidwife | -.084199 | .1831251 | -0.46 | 0.646 | -.4431177 | .2747196 |
| kindbinnen1jaarXspecialist | -.5534061 | .1924452 | -2.88 | 0.004 | -.9305918 | -.1762204 |
| kennenecsXspecialist | .1749482 | .158606 | 1.10 | 0.270 | -.1359139 | .4858103 |
| kennenecsXmidwife | .3485225 | .1513313 | 2.30 | 0.021 | .0519185 | .6451265 |
| kennenaandoeningXspecialist | .0534449 | .1586858 | 0.34 | 0.736 | -.2575735 | .3644634 |
| kennenaandoeningXmidwife | -.1228548 | .1464243 | -0.84 | 0.401 | -.4098412 | .1641316 |
| jongereXspecialist | .0170553 | .1975049 | 0.09 | 0.931 | -.3700473 | .4041578 |
| jongereXmidwife | .0892036 | .1822837 | 0.49 | 0.625 | -.2680659 | .446473 |
| buitenlandgeborenXspecialist | .5850482 | .2859482 | 2.05 | 0.041 | .0246 | 1.145496 |
| buitenlandgeborenXmidwife | .0447093 | .2834453 | 0.16 | 0.875 | -.5108333 | .6002518 |
| heeftpartnerXspecialist | .3821771 | .1875295 | 2.04 | 0.042 | .014626 | .7497282 |
| heeftpartnerXmidwife | .2678526 | .1789357 | 1.50 | 0.134 | -.0828549 | .6185601 |
| aantalkinderenXspecialist | -.2252177 | .0806247 | -2.79 | 0.005 | -.3832393 | -.0671961 |
| aantalkinderenXmidwife | -.2343687 | .0744179 | -3.15 | 0.002 | -.380225 | -.0885123 |
| opleiding_hoogXspecialist | -.3664874 | .1597542 | -2.29 | 0.022 | -.6795998 | -.053375 |
| opleiding_hoogXmidwife | -.2006386 | .1572205 | -1.28 | 0.202 | -.5087851 | .1075079 |
| gemsalarislogXspecialist | -.1028109 | .1148655 | -0.90 | 0.371 | -.3279431 | .1223212 |
| gemsalarislogXmidwife | -.1810915 | .1102434 | -1.64 | 0.100 | -.3971645 | .0349815 |
| religiejaXmidwife | .0429624 | .18044 | 0.24 | 0.812 | -.3106935 | .3966182 |
| religiejaXspecialist | .1924779 | .1976234 | 0.97 | 0.330 | -.1948569 | .5798126 |
| religiejaXGP | .3717913 | .1886616 | 1.97 | 0.049 | .0020214 | .7415612 |
| kindbinnen1jaarXGP | -.0908435 | .1830942 | -0.50 | 0.620 | -.4497016 | .2680145 |
| kennenecsXGP | .0956191 | .1539276 | 0.62 | 0.534 | -.2060735 | .3973116 |
| kennenaandoeningXGP | -.0328982 | .1480685 | -0.22 | 0.824 | -.3231072 | .2573108 |
| jongereXGP | -.2430075 | .1984224 | -1.22 | 0.221 | -.6319083 | .1458933 |
| buitenlandgeborenXGP | .1347652 | .2936903 | 0.46 | 0.646 | -.4408572 | .7103876 |
| heeftpartnerXGP | .3632626 | .1837745 | 1.98 | 0.048 | .0030713 | .723454 |
| aantalkinderenXGP | -.1087853 | .0790267 | -1.38 | 0.169 | -.2636748 | .0461042 |
| opleiding_hoogXGP | -.3085308 | .154018 | -2.00 | 0.045 | -.6104004 | -.0066611 |
| gemsalarislogXGP | -.142672 | .1076003 | -1.33 | 0.185 | -.3535647 | .0682207 |
| **SD** | | | | | | |
| opt_out | 3.100484 | .1916119 | 16.18 | 0.000 | 2.724931 | 3.476036 |
| genes2 | .0567035 | .1069961 | 0.53 | 0.596 | -.1530049 | .266412 |
| genes3 | 1.132987 | .0918655 | 12.33 | 0.000 | .9529338 | 1.31304 |
| provider_midwife | .0521186 | .0855527 | 0.61 | 0.542 | -.1155617 | .2197988 |
| provider_specialist | -.0208998 | .1220527 | -0.17 | 0.864 | -.2601186 | .218319 |
| provider_GP | .3035078 | .116911 | 2.60 | 0.009 | .0743665 | .5326491 |
| information_brochure | .1097554 | .0756476 | 1.45 | 0.147 | -.0385112 | .2580219 |
| information_website | -.133957 | .0694237 | -1.93 | 0.054 | -.270025 | .002111 |
| price500 | .8193287 | .1077734 | 7.60 | 0.000 | .6080966 | 1.030561 |
| price1000 | 1.450837 | .1037123 | 13.99 | 0.000 | 1.247565 | 1.65411 |
| accuracy95 | -.0070305 | .0767968 | -0.09 | 0.927 | -.1575494 | .1434885 |
| accuracy99 | 1.3143 | .0845604 | 15.54 | 0.000 | 1.148565 | 1.480036 |
| kindbinnen1jaarXmidwife | -.1388333 | .1745552 | -0.80 | 0.426 | -.4809552 | .2032885 |
| kindbinnen1jaarXspecialist | -.120694 | .2136585 | -0.56 | 0.572 | -.5394569 | .2980689 |
| kennenecsXspecialist | .1862231 | .1779168 | 1.05 | 0.295 | -.1624874 | .5349336 |
| kennenecsXmidwife | .020257 | .1202777 | 0.17 | 0.866 | -.2154829 | .2559968 |
| kennenaandoeningXspecialist | .0694816 | .2146587 | 0.32 | 0.746 | -.3512417 | .4902049 |
| kennenaandoeningXmidwife | .0268415 | .1274771 | 0.21 | 0.833 | -.223009 | .2766921 |
| jongereXspecialist | .4738278 | .2054613 | 2.31 | 0.021 | .071131 | .8765246 |
| jongereXmidwife | -.0599358 | .1997402 | -0.30 | 0.764 | -.4514193 | .3315477 |
| buitenlandgeborenXspecialist | .1957281 | .3078703 | 0.64 | 0.525 | -.4076866 | .7991429 |
| buitenlandgeborenXmidwife | .3832976 | .2154961 | 1.78 | 0.075 | -.0390671 | .8056623 |
| heeftpartnerXspecialist | .2366787 | .0945321 | 2.50 | 0.012 | .0513992 | .4219583 |
| heeftpartnerXmidwife | -.1558236 | .1214864 | -1.28 | 0.200 | -.3939325 | .0822854 |
| aantalkinderenXspecialist | .061738 | .0784962 | 0.79 | 0.432 | -.0921118 | .2155878 |
| aantalkinderenXmidwife | .0266762 | .0655257 | 0.41 | 0.684 | -.1017518 | .1551042 |
| opleiding_hoogXspecialist | .3047703 | .1480503 | 2.06 | 0.040 | .0145971 | .5949435 |
| opleiding_hoogXmidwife | .1416188 | .1087121 | 1.30 | 0.193 | -.071453 | .3546906 |
| gemsalarislogXspecialist | .007124 | .0138084 | 0.52 | 0.606 | -.01994 | .034188 |
| gemsalarislogXmidwife | .0269861 | .0109594 | 2.46 | 0.014 | .0055061 | .0484661 |
| religiejaXmidwife | .3905977 | .1870988 | 2.09 | 0.037 | .0238907 | .7573047 |
| religiejaXspecialist | -.0366103 | .2172957 | -0.17 | 0.866 | -.462502 | .3892814 |
| religiejaXGP | .4149482 | .177323 | 2.34 | 0.019 | .0674016 | .7624948 |
| kindbinnen1jaarXGP | -.0864972 | .2388025 | -0.36 | 0.717 | -.5545415 | .3815471 |
| kennenecsXGP | -.018031 | .1571061 | -0.11 | 0.909 | -.3259533 | .2898912 |
| kennenaandoeningXGP | .1367776 | .1468269 | 0.93 | 0.352 | -.1509979 | .4245531 |
| jongereXGP | .0364401 | .1949881 | 0.19 | 0.852 | -.3457296 | .4186097 |
| buitenlandgeborenXGP | .5033812 | .3139047 | 1.60 | 0.109 | -.1118608 | 1.118623 |
| heeftpartnerXGP | -.0051258 | .1120238 | -0.05 | 0.964 | -.2246885 | .2144369 |
| aantalkinderenXGP | .0472891 | .107769 | 0.44 | 0.661 | -.1639342 | .2585124 |
| opleiding_hoogXGP | .1594965 | .1418392 | 1.12 | 0.261 | -.1185031 | .4374961 |
| gemsalarislogXGP | -.0084009 | .0130035 | -0.65 | 0.518 | -.0338873 | .0170855 |

The sign of the estimated standard deviations is irrelevant: interpret them as

## Price

Generalized multinomial logit model

Log likelihood = -4805.0191

Number of obs = 18,759
Wald chi2(32) = 619.02
Prob > chi2 = 0.0000

| Y | Coefficient | Std. err. | z | P>\|z\| | [95% conf. | interval] |
|---|---|---|---|---|---|---|
| **Mean** | | | | | | |
| opt_out | -.8747764 | .1383608 | -6.32 | 0.000 | -1.145959 | -.6035942 |
| genes2 | .2240895 | .0567993 | 3.95 | 0.000 | .112765 | .335414 |
| genes3 | .202656 | .0830075 | 2.44 | 0.015 | .0399642 | .3653478 |
| provider_midwife | .5182384 | .0809591 | 6.40 | 0.000 | .3595615 | .6769153 |
| provider_specialist | .4787774 | .0838831 | 5.71 | 0.000 | .3143694 | .6431853 |
| provider_GP | .6813512 | .0957621 | 7.12 | 0.000 | .4936609 | .8690415 |
| information_brochure | -.3276296 | .0659326 | -4.97 | 0.000 | -.4568552 | -.198404 |
| information_website | -.4075846 | .0676745 | -6.02 | 0.000 | -.5402242 | -.274945 |
| price500 | -.4778432 | .7788632 | -0.61 | 0.540 | -2.004387 | 1.048701 |
| price1000 | -4.981343 | .8829813 | -5.64 | 0.000 | -6.711955 | -3.250732 |
| accuracy95 | .5733719 | .0765582 | 7.49 | 0.000 | .4233206 | .7234231 |
| accuracy99 | 1.55176 | .0982693 | 15.79 | 0.000 | 1.359156 | 1.744365 |
| kindbinnen1jaarXprice1000 | -.4264557 | .2311583 | -1.84 | 0.065 | -.8795176 | .0266063 |
| kindbinnen1jaarXprice500 | .0986381 | .1734564 | 0.57 | 0.570 | -.2413302 | .4386065 |
| kennenecsXprice500 | .5140738 | .1405671 | 3.66 | 0.000 | .2385673 | .7895803 |
| kennenecsXprice1000 | .8390987 | .1705131 | 4.92 | 0.000 | .5048991 | 1.173298 |
| kennenaandoeningXprice500 | .2691753 | .1363967 | 1.97 | 0.048 | .0018426 | .536508 |
| kennenaandoeningXprice1000 | .2177108 | .1706385 | 1.28 | 0.202 | -.1167345 | .5521561 |
| jongereXprice500 | -.0743024 | .1736365 | -0.43 | 0.669 | -.4146236 | .2660188 |
| jongereXprice1000 | .4724884 | .2011868 | 2.35 | 0.019 | .0781696 | .8668072 |
| buitenlandgeborenXprice500 | -.3439034 | .2849813 | -1.21 | 0.228 | -.9024566 | .2146497 |
| buitenlandgeborenXprice1000 | .1609881 | .4215963 | 0.38 | 0.703 | -.6653254 | .9873015 |
| heeftpartnerXprice500 | -.286445 | .1853571 | -1.55 | 0.122 | -.6497382 | .0768483 |
| heeftpartnerXprice1000 | -.3938681 | .2138236 | -1.84 | 0.065 | -.8129546 | .0252185 |
| aantalkinderenXprice500 | -.0365956 | .0856013 | -0.43 | 0.669 | -.2043711 | .1311799 |
| aantalkinderenXprice1000 | .0988341 | .1131968 | 0.87 | 0.383 | -.1230276 | .3206957 |
| opleiding_hoogXprice500 | -.3222694 | .1437296 | -2.24 | 0.025 | -.6039742 | -.0405645 |
| opleiding_hoogXprice1000 | -.8155427 | .1791163 | -4.55 | 0.000 | -1.166604 | -.4644812 |
| gemsalarislogXprice500 | -.0325641 | .1038942 | -0.31 | 0.754 | -.2361929 | .1710648 |
| gemsalarislogXprice1000 | .4276992 | .1167991 | 3.66 | 0.000 | .1987772 | .6566212 |
| religiejaXprice1000 | .0326784 | .195378 | 0.17 | 0.867 | -.3502553 | .4156122 |
| religiejaXprice500 | .105925 | .1593282 | 0.66 | 0.506 | -.2063526 | .4182026 |
| **SD** | | | | | | |
| opt_out | 3.224504 | .1465141 | 22.01 | 0.000 | 2.937342 | 3.511666 |
| genes2 | -.034454 | .120197 | -0.29 | 0.774 | -.2700358 | .2011279 |
| genes3 | 1.185973 | .0822662 | 14.42 | 0.000 | 1.024735 | 1.347212 |
| provider_midwife | .0330551 | .1043046 | 0.32 | 0.751 | -.1713781 | .2374883 |
| provider_specialist | .3118389 | .1454031 | 2.14 | 0.032 | .026854 | .5968238 |
| provider_GP | -.2489508 | .1041873 | -2.39 | 0.017 | -.4531541 | -.0447474 |
| information_brochure | .1700148 | .0880069 | 1.93 | 0.053 | -.0024755 | .3425052 |
| information_website | -.039704 | .0785565 | -0.51 | 0.613 | -.1936718 | .1142639 |
| price500 | .7727797 | .1196396 | 6.46 | 0.000 | .5382904 | 1.007269 |
| price1000 | -.7758191 | .1259905 | -6.16 | 0.000 | -1.022756 | -.5288822 |
| accuracy95 | .2708085 | .0917595 | 2.95 | 0.003 | .0909631 | .4506538 |
| accuracy99 | 1.285882 | .0854687 | 15.05 | 0.000 | 1.118367 | 1.453398 |
| kindbinnen1jaarXprice1000 | -1.106909 | .2243005 | -4.93 | 0.000 | -1.54653 | -.6672879 |
| kindbinnen1jaarXprice500 | .1408603 | .185446 | 0.76 | 0.448 | -.2226072 | .5043277 |
| kennenecsXprice500 | .1843583 | .1768745 | 1.04 | 0.297 | -.1623094 | .5310259 |
| kennenecsXprice1000 | .2198262 | .1756405 | 1.25 | 0.211 | -.1244228 | .5640752 |
| kennenaandoeningXprice500 | .1417718 | .1306785 | 1.08 | 0.278 | -.1143535 | .397897 |
| kennenaandoeningXprice1000 | -.5367484 | .1262874 | -4.25 | 0.000 | -.7842672 | -.2892296 |
| jongereXprice500 | .0606389 | .2278297 | 0.27 | 0.790 | -.3858991 | .507177 |
| jongereXprice1000 | -.7838997 | .1632398 | -4.80 | 0.000 | -1.103844 | -.4639555 |
| buitenlandgeborenXprice500 | -.7080804 | .3487064 | -2.03 | 0.042 | -1.391532 | -.0246284 |
| buitenlandgeborenXprice1000 | -1.610089 | .3849387 | -4.18 | 0.000 | -2.364555 | -.8556236 |
| heeftpartnerXprice500 | .4690045 | .2162824 | 2.17 | 0.030 | .0450989 | .8929102 |
| heeftpartnerXprice1000 | .8331641 | .112155 | 7.43 | 0.000 | .6133443 | 1.052984 |
| aantalkinderenXprice500 | -.0169669 | .0559909 | -0.30 | 0.762 | -.126707 | .0927732 |
| aantalkinderenXprice1000 | -.0518564 | .0524624 | -0.99 | 0.323 | -.1546808 | .050968 |
| opleiding_hoogXprice500 | .148201 | .177884 | 0.83 | 0.405 | -.2004451 | .4968471 |
| opleiding_hoogXprice1000 | 1.376795 | .1575447 | 8.74 | 0.000 | 1.068013 | 1.685577 |
| gemsalarislogXprice500 | -.0092285 | .0190513 | -0.48 | 0.628 | -.0465685 | .0281114 |
| gemsalarislogXprice1000 | -.0250497 | .0215279 | -1.16 | 0.245 | -.0672436 | .0171441 |
| religiejaXprice1000 | -.0906399 | .2170072 | -0.42 | 0.676 | -.5159663 | .3346865 |
| religiejaXprice500 | -.2906784 | .1712429 | -1.70 | 0.090 | -.6263084 | .0449516 |

The sign of the estimated standard deviations is irrelevant: interpret them as being positive

## Opt-out

Generalized multinomial logit model — Number of obs = 18,759
Wald chi2(22) = 610.07
Log likelihood = -4827.3355 — Prob > chi2 = 0.0000

| Y | Coefficient | Std. err. | z | P>\|z\| | [95% conf. | interval] |
|---|---|---|---|---|---|---|
| **Mean** | | | | | | |
| opt_out | 6.921963 | 1.179603 | 5.87 | 0.000 | 4.609985 | 9.233942 |
| genes2 | .2295839 | .0576369 | 3.98 | 0.000 | .1166176 | .3425502 |
| genes3 | .1115964 | .0800937 | 1.39 | 0.164 | -.0453843 | .2685771 |
| provider_midwife | .5589351 | .0794856 | 7.03 | 0.000 | .4031461 | .714724 |
| provider_specialist | .4841334 | .0846567 | 5.72 | 0.000 | .3182092 | .6500575 |
| provider_GP | .7364533 | .0941967 | 7.82 | 0.000 | .5518311 | .9210754 |
| information_brochure | -.3734375 | .0656388 | -5.69 | 0.000 | -.5020871 | -.2447878 |
| information_website | -.4468651 | .0673653 | -6.63 | 0.000 | -.5788987 | -.3148314 |
| price500 | -.698202 | .0659392 | -10.59 | 0.000 | -.8274405 | -.5689635 |
| price1000 | -1.736981 | .0951935 | -18.25 | 0.000 | -1.923557 | -1.550405 |
| accuracy95 | .5925358 | .0747151 | 7.93 | 0.000 | .4460969 | .7389747 |
| accuracy99 | 1.46813 | .096398 | 15.23 | 0.000 | 1.279193 | 1.657067 |
| kindbinnen1jaarXopt_out | .3529456 | .21888 | 1.61 | 0.107 | -.0760513 | .7819425 |
| kennenecsXopt_out | -.5670948 | .1897043 | -2.99 | 0.003 | -.9389083 | -.1952812 |
| kennenaandoeningXopt_out | -.4544561 | .2206331 | -2.06 | 0.039 | -.8868891 | -.0220231 |
| jongereXopt_out | -1.221899 | .231132 | -5.29 | 0.000 | -1.67491 | -.7688889 |
| buitenlandgeborenXopt_out | -.4377994 | .3323804 | -1.32 | 0.188 | -1.089253 | .2136543 |
| heeftpartnerXopt_out | -1.277575 | .2207657 | -5.79 | 0.000 | -1.710268 | -.8448826 |
| aantalkinderenXopt_out | .490404 | .1115669 | 4.40 | 0.000 | .2717369 | .7090711 |
| opleiding_hoogXopt_out | -.1881591 | .2055285 | -0.92 | 0.360 | -.5909875 | .2146693 |
| gemsalarislogXopt_out | -.8178728 | .1602381 | -5.10 | 0.000 | -1.131934 | -.5038119 |
| religiejaXopt_out | .9354423 | .187669 | 4.98 | 0.000 | .5676178 | 1.303267 |
| **SD** | | | | | | |
| opt_out | 1.905684 | .1123316 | 16.96 | 0.000 | 1.685518 | 2.12585 |
| genes2 | .2904272 | .0983105 | 2.95 | 0.003 | .0977422 | .4831121 |
| genes3 | 1.334199 | .0857727 | 15.56 | 0.000 | 1.166088 | 1.502311 |
| provider_midwife | .1185632 | .0881558 | 1.34 | 0.179 | -.0542191 | .2913455 |
| provider_specialist | -.4204775 | .1037936 | -4.05 | 0.000 | -.6239092 | -.2170458 |
| provider_GP | .2610822 | .1273187 | 2.05 | 0.040 | .0115422 | .5106222 |
| information_brochure | .0657332 | .0829941 | 0.79 | 0.428 | -.0969323 | .2283986 |
| information_website | .0567038 | .0823362 | 0.69 | 0.491 | -.1046723 | .2180799 |
| price500 | .690143 | .1071555 | 6.44 | 0.000 | .4801221 | .900164 |
| price1000 | 1.462674 | .1074437 | 13.61 | 0.000 | 1.252088 | 1.673259 |
| accuracy95 | .0851204 | .0697281 | 1.22 | 0.222 | -.0515442 | .2217849 |
| accuracy99 | 1.271618 | .083324 | 15.26 | 0.000 | 1.108306 | 1.43493 |
| kindbinnen1jaarXopt_out | 2.93608 | .2118322 | 13.86 | 0.000 | 2.520896 | 3.351263 |
| kennenecsXopt_out | .3638207 | .1206776 | 3.01 | 0.003 | .127297 | .6003444 |
| kennenaandoeningXopt_out | 2.381922 | .2542773 | 9.37 | 0.000 | 1.883548 | 2.880296 |
| jongereXopt_out | -.572134 | .1604203 | -3.57 | 0.000 | -.886552 | -.257716 |
| buitenlandgeborenXopt_out | .6287838 | .2954635 | 2.13 | 0.033 | .049686 | 1.207882 |
| heeftpartnerXopt_out | 1.534853 | .1272234 | 12.06 | 0.000 | 1.2855 | 1.784206 |
| aantalkinderenXopt_out | .6792385 | .1026803 | 6.62 | 0.000 | .4779888 | .8804882 |
| opleiding_hoogXopt_out | -.0663388 | .1804026 | -0.37 | 0.713 | -.4199214 | .2872437 |
| gemsalarislogXopt_out | .1456294 | .0174695 | 8.34 | 0.000 | .1113898 | .179869 |
| religiejaXopt_out | 2.693727 | .2626452 | 10.26 | 0.000 | 2.178952 | 3.208502 |

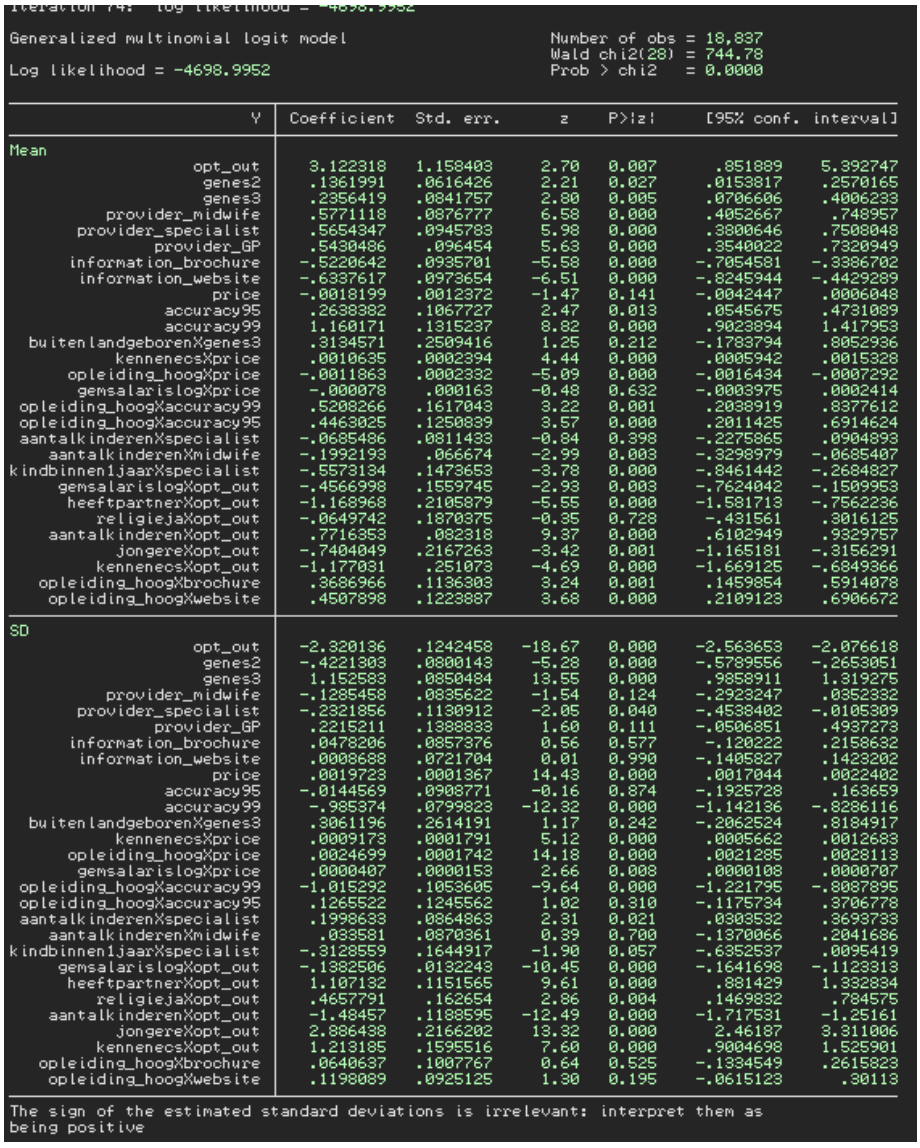
The sign of the estimated standard deviations is irrelevant: interpret them as being positive

## Information provision

Generalized multinomial logit model — Number of obs = 18,759
Wald chi2(32) = 573.83
Log likelihood = -4892.5935 — Prob > chi2 = 0.0000

| Y | Coefficient | Std. err. | z | P>\|z\| | [95% conf. | interval] |
|---|---|---|---|---|---|---|
| **Mean** | | | | | | |
| opt_out | -.7710365 | .1562759 | -4.93 | 0.000 | -1.077332 | -.4647413 |
| genes2 | .2293971 | .0570866 | 4.02 | 0.000 | .1175095 | .3412847 |
| genes3 | .1512434 | .0823979 | 1.84 | 0.066 | -.0102535 | .3127404 |
| provider_midwife | .5327661 | .0805416 | 6.61 | 0.000 | .3749074 | .6906247 |
| provider_specialist | .472203 | .08401 | 5.62 | 0.000 | .3075464 | .6368596 |
| provider_GP | .7103643 | .0969842 | 7.32 | 0.000 | .5202788 | .9004498 |
| information_brochure | -.2336117 | .6731237 | -0.35 | 0.729 | -1.55291 | 1.085686 |
| information_website | -1.550076 | .7544879 | -2.05 | 0.040 | -3.028845 | -.0713066 |
| price500 | -.7044292 | .0707009 | -9.96 | 0.000 | -.8430003 | -.5658581 |
| price1000 | -1.880966 | .1031185 | -18.24 | 0.000 | -2.083075 | -1.678858 |
| accuracy95 | .605929 | .0746049 | 8.12 | 0.000 | .459706 | .752152 |
| accuracy99 | 1.538846 | .0969749 | 15.87 | 0.000 | 1.348779 | 1.728913 |
| kindbinnen1jaarXwebsite | -.0079556 | .1590937 | -0.05 | 0.960 | -.3197736 | .3038624 |
| kindbinnen1jaarXbrochure | .0594507 | .1419324 | 0.42 | 0.675 | -.2187316 | .337633 |
| kennenecsXbrochure | .0981798 | .1282927 | 0.77 | 0.444 | -.1532692 | .3496289 |
| kennenecsXwebsite | .2494952 | .1487853 | 1.68 | 0.094 | -.0421186 | .541109 |
| kennenaandoeningXbrochure | .0001497 | .1264609 | 0.00 | 0.999 | -.2477091 | .2480085 |
| kennenaandoeningXwebsite | .0297647 | .1375412 | 0.22 | 0.829 | -.239811 | .2993404 |
| jongereXbrochure | .1945453 | .144337 | 1.35 | 0.178 | -.0883501 | .4774407 |
| jongereXwebsite | .2345985 | .1597877 | 1.47 | 0.142 | -.0785797 | .5477766 |
| buitenlandgeborenXbrochure | .762558 | .2994327 | 2.55 | 0.011 | .1756807 | 1.349435 |
| buitenlandgeborenXwebsite | .464766 | .296418 | 1.57 | 0.117 | -.1162027 | 1.045735 |
| heeftpartnerXbrochure | .0346525 | .1477934 | 0.23 | 0.815 | -.2550174 | .3243223 |
| heeftpartnerXwebsite | .0394557 | .1717877 | 0.23 | 0.818 | -.297242 | .3761534 |
| aantalkinderenXbrochure | .109282 | .0707938 | 1.54 | 0.123 | -.0294713 | .2480353 |
| aantalkinderenXwebsite | .168487 | .0697246 | 2.42 | 0.016 | .0318293 | .3051448 |
| opleiding_hoogXbrochure | .538981 | .1200394 | 4.49 | 0.000 | .3037081 | .774254 |
| opleiding_hoogXwebsite | .7126273 | .1317022 | 5.41 | 0.000 | .4544957 | .9707588 |
| gemsalarislogXbrochure | -.0929269 | .0884131 | -1.05 | 0.293 | -.2662134 | .0803595 |
| gemsalarislogXwebsite | .0418836 | .0976797 | 0.43 | 0.668 | -.149565 | .2333323 |
| religiejaXwebsite | .0912944 | .1538777 | 0.59 | 0.553 | -.2103003 | .3928891 |
| religiejaXbrochure | .0271381 | .1394407 | 0.19 | 0.846 | -.2461607 | .3004369 |
| **SD** | | | | | | |
| opt_out | 2.993327 | .1490185 | 20.09 | 0.000 | 2.701256 | 3.285398 |
| genes2 | -.1590417 | .0945055 | -1.68 | 0.092 | -.3442691 | .0261857 |
| genes3 | 1.188174 | .1005578 | 11.82 | 0.000 | .9910845 | 1.385264 |
| provider_midwife | -.0655962 | .0978753 | -0.67 | 0.503 | -.2574283 | .1262359 |
| provider_specialist | .3116481 | .1418262 | 2.20 | 0.028 | .033674 | .5896223 |
| provider_GP | -.2801811 | .1291685 | -2.17 | 0.030 | -.5333468 | -.0270154 |
| information_brochure | -.0374416 | .0905066 | -0.41 | 0.679 | -.2148312 | .1399481 |
| information_website | .0514494 | .0962223 | 0.53 | 0.593 | -.1371429 | .2400417 |
| price500 | .8748975 | .0905129 | 9.67 | 0.000 | .6974955 | 1.052299 |
| price1000 | 1.506328 | .1069837 | 14.08 | 0.000 | 1.296644 | 1.716013 |
| accuracy95 | .0409704 | .0837346 | 0.49 | 0.625 | -.1231464 | .2050872 |
| accuracy99 | 1.318965 | .0954656 | 13.82 | 0.000 | 1.131856 | 1.506074 |
| kindbinnen1jaarXwebsite | .1783935 | .1847433 | 0.97 | 0.334 | -.1836968 | .5404838 |
| kindbinnen1jaarXbrochure | .1165848 | .1184591 | 0.98 | 0.325 | -.1155908 | .3487603 |
| kennenecsXbrochure | -.1064602 | .1629795 | -0.65 | 0.514 | -.4258941 | .2129738 |
| kennenecsXwebsite | -.0494953 | .1480476 | -0.33 | 0.738 | -.3396632 | .2406727 |
| kennenaandoeningXbrochure | .0747587 | .1373527 | 0.54 | 0.586 | -.1944476 | .343965 |
| kennenaandoeningXwebsite | .1732091 | .1252115 | 1.38 | 0.167 | -.0722009 | .4186191 |
| jongereXbrochure | -.065835 | .1502984 | -0.44 | 0.661 | -.3604145 | .2287445 |
| jongereXwebsite | -.1200124 | .334174 | -0.36 | 0.719 | -.7749815 | .5349566 |
| buitenlandgeborenXbrochure | .5262328 | .3045965 | 1.73 | 0.084 | -.0707653 | 1.123231 |
| buitenlandgeborenXwebsite | .1945331 | .2679977 | 0.73 | 0.468 | -.3307328 | .7197989 |
| heeftpartnerXbrochure | -.0068358 | .1051997 | -0.06 | 0.948 | -.2130235 | .1993518 |
| heeftpartnerXwebsite | -.04208 | .0879572 | -0.48 | 0.632 | -.2144729 | .1303128 |
| aantalkinderenXbrochure | -.065484 | .0664241 | -0.99 | 0.324 | -.1956729 | .064705 |
| aantalkinderenXwebsite | -.1137316 | .0819542 | -1.39 | 0.165 | -.2743589 | .0468957 |
| opleiding_hoogXbrochure | .0416942 | .1109954 | 0.38 | 0.707 | -.1758527 | .2592412 |
| opleiding_hoogXwebsite | -.2556455 | .1133602 | -2.26 | 0.024 | -.4778274 | -.0334636 |
| gemsalarislogXbrochure | .0023811 | .0107387 | 0.22 | 0.825 | -.0186663 | .0234285 |
| gemsalarislogXwebsite | .0018667 | .012411 | 0.15 | 0.880 | -.0224585 | .0261919 |
| religiejaXwebsite | .072341 | .1870889 | 0.39 | 0.699 | -.2943464 | .4390285 |
| religiejaXbrochure | -.2597408 | .1495928 | -1.74 | 0.083 | -.5529374 | .0334557 |

## Mixed logit model after adding all significant interaction effects



Iteration 74: log likelihood = -4698.9952

Generalized multinomial logit model — Number of obs = 18,837; Wald chi2(28) = 744.78; Log likelihood = -4698.9952; Prob > chi2 = 0.0000

| Y | Coefficient | Std. err. | z | P>\|z\| | [95% conf. | interval] |
|---|---|---|---|---|---|---|
| **Mean** | | | | | | |
| opt_out | 3.122318 | 1.158403 | 2.70 | 0.007 | .851889 | 5.392747 |
| genes2 | .1361991 | .0616426 | 2.21 | 0.027 | .0153817 | .2570165 |
| genes3 | .2356419 | .0841757 | 2.80 | 0.005 | .0706606 | .4006233 |
| provider_midwife | .5771118 | .0876777 | 6.58 | 0.000 | .4052667 | .748957 |
| provider_specialist | .5654347 | .0945783 | 5.98 | 0.000 | .3800646 | .7508048 |
| provider_GP | .5430486 | .096454 | 5.63 | 0.000 | .3540022 | .7320949 |
| information_brochure | -.5220642 | .0935701 | -5.58 | 0.000 | -.7054581 | -.3386702 |
| information_website | -.6337617 | .0973654 | -6.51 | 0.000 | -.8245944 | -.4429289 |
| price | -.0018199 | .0012372 | -1.47 | 0.141 | -.0042447 | .0006048 |
| accuracy95 | .2638382 | .1067727 | 2.47 | 0.013 | .0545675 | .4731089 |
| accuracy99 | 1.160171 | .1315237 | 8.82 | 0.000 | .9023894 | 1.417953 |
| buitenlandgeborenXgenes3 | .3134571 | .2509416 | 1.25 | 0.212 | -.1783794 | .8052936 |
| kennenecsXprice | .0010635 | .0002394 | 4.44 | 0.000 | .0005942 | .0015328 |
| opleiding_hoogXprice | -.0011863 | .0002332 | -5.09 | 0.000 | -.0016434 | -.0007292 |
| gemsalarislogXprice | -.000078 | .000163 | -0.48 | 0.632 | -.0003975 | .0002414 |
| opleiding_hoogXaccuracy99 | .5208266 | .1617043 | 3.22 | 0.001 | .2038919 | .8377612 |
| opleiding_hoogXaccuracy95 | .4463025 | .1250839 | 3.57 | 0.000 | .2011425 | .6914624 |
| aantalkinderenXspecialist | -.0685486 | .0811433 | -0.84 | 0.398 | -.2275865 | .0904893 |
| aantalkinderenXmidwife | -.1992193 | .066674 | -2.99 | 0.003 | -.3298979 | -.0685407 |
| kindbinnen1jaarXspecialist | -.5573134 | .1473653 | -3.78 | 0.000 | -.8461442 | -.2684827 |
| gemsalarislogXopt_out | -.4566998 | .1559745 | -2.93 | 0.003 | -.7624042 | -.1509953 |
| heeftpartnerXopt_out | -1.168968 | .2105879 | -5.55 | 0.000 | -1.581713 | -.7562236 |
| religiejaXopt_out | -.0649742 | .1870375 | -0.35 | 0.728 | -.431561 | .3016125 |
| aantalkinderenXopt_out | .7716353 | .082318 | 9.37 | 0.000 | .6102949 | .9329757 |
| jongereXopt_out | -.7404049 | .2167263 | -3.42 | 0.001 | -1.165181 | -.3156291 |
| kennenecsXopt_out | -1.177031 | .251073 | -4.69 | 0.000 | -1.669125 | -.6849366 |
| opleiding_hoogXbrochure | .3686966 | .1136303 | 3.24 | 0.001 | .1459854 | .5914078 |
| opleiding_hoogXwebsite | .4507898 | .1223887 | 3.68 | 0.000 | .2109123 | .6906672 |
| **SD** | | | | | | |
| opt_out | -2.320136 | .1242458 | -18.67 | 0.000 | -2.563653 | -2.076618 |
| genes2 | -.4221303 | .0800143 | -5.28 | 0.000 | -.5789556 | -.2653051 |
| genes3 | 1.152583 | .0850484 | 13.55 | 0.000 | .9858911 | 1.319275 |
| provider_midwife | -.1285458 | .0835622 | -1.54 | 0.124 | -.2923247 | .0352332 |
| provider_specialist | -.2321856 | .1130912 | -2.05 | 0.040 | -.4538402 | -.0105309 |
| provider_GP | .2215211 | .1388833 | 1.60 | 0.111 | -.0506851 | .4937273 |
| information_brochure | .0478206 | .0857376 | 0.56 | 0.577 | -.120222 | .2158632 |
| information_website | .0008688 | .0721704 | 0.01 | 0.990 | -.1405827 | .1423202 |
| price | .0019723 | .0001367 | 14.43 | 0.000 | .0017044 | .0022402 |
| accuracy95 | -.0144569 | .0908771 | -0.16 | 0.874 | -.1925728 | .163659 |
| accuracy99 | -.985374 | .0799823 | -12.32 | 0.000 | -1.142136 | -.8286116 |
| buitenlandgeborenXgenes3 | .3061196 | .2614191 | 1.17 | 0.242 | -.2062524 | .8184917 |
| kennenecsXprice | .0009173 | .0001791 | 5.12 | 0.000 | .0005662 | .0012683 |
| opleiding_hoogXprice | .0024699 | .0001742 | 14.18 | 0.000 | .0021285 | .0028113 |
| gemsalarislogXprice | .0000407 | .0000153 | 2.66 | 0.008 | .0000108 | .0000707 |
| opleiding_hoogXaccuracy99 | -1.015292 | .1053605 | -9.64 | 0.000 | -1.221795 | -.8087895 |
| opleiding_hoogXaccuracy95 | .1265522 | .1245562 | 1.02 | 0.310 | -.1175734 | .3706778 |
| aantalkinderenXspecialist | .1998633 | .0864863 | 2.31 | 0.021 | .0303532 | .3693733 |
| aantalkinderenXmidwife | .033581 | .0870361 | 0.39 | 0.700 | -.1370066 | .2041686 |
| kindbinnen1jaarXspecialist | -.3128559 | .1644917 | -1.90 | 0.057 | -.6352537 | .0095419 |
| gemsalarislogXopt_out | -.1382506 | .0132243 | -10.45 | 0.000 | -.1641698 | -.1123313 |
| heeftpartnerXopt_out | 1.107132 | .1151565 | 9.61 | 0.000 | .881429 | 1.332834 |
| religiejaXopt_out | .4657791 | .162654 | 2.86 | 0.004 | .1469832 | .784575 |
| aantalkinderenXopt_out | -1.48457 | .1188595 | -12.49 | 0.000 | -1.717531 | -1.25161 |
| jongereXopt_out | 2.886438 | .2166202 | 13.32 | 0.000 | 2.46187 | 3.311006 |
| kennenecsXopt_out | 1.213185 | .1595516 | 7.60 | 0.000 | .9004698 | 1.525901 |
| opleiding_hoogXbrochure | .0640637 | .1007767 | 0.64 | 0.525 | -.1334549 | .2615823 |
| opleiding_hoogXwebsite | .1198089 | .0925125 | 1.30 | 0.195 | -.0615123 | .30113 |

The sign of the estimated standard deviations is irrelevant: interpret them as being positive

**Final mixed logit model with interaction effects**

Generalized multinomial logit model — Number of obs = 18,759
Log likelihood = -4675.4085 — Wald chi2(22) = 507.87
Prob > chi2 = 0.0000

| Y | Coefficient | Std. err. | z | P>\|z\| | [95% conf. | interval] |
|---|---|---|---|---|---|---|
| **Mean** | | | | | | |
| kindbinnen1jaarXspecialist | -.4903021 | .1423205 | -3.45 | 0.001 | -.7692451 | -.2113591 |
| provider_midwife | .6292128 | .0878127 | 7.17 | 0.000 | .4571031 | .8013225 |
| information_brochure | -.6029858 | .0953935 | -6.32 | 0.000 | -.7899536 | -.416018 |
| opleiding_hoogXbrochure | .4433019 | .1187687 | 3.73 | 0.000 | .2105195 | .6760843 |
| information_website | -.6661708 | .0982485 | -6.78 | 0.000 | -.8587344 | -.4736073 |
| price | -.0019605 | .0001748 | -11.22 | 0.000 | -.002303 | -.001618 |
| provider_specialist | .5490226 | .089955 | 6.10 | 0.000 | .372714 | .7253313 |
| provider_GP | .643576 | .0981861 | 6.55 | 0.000 | .4511347 | .8360173 |
| heeftpartnerXopt_out | -1.413101 | .350956 | -4.03 | 0.000 | -2.100963 | -.7252402 |
| opleiding_hoogXaccuracy95 | .506081 | .1266543 | 4.00 | 0.000 | .2578431 | .7543188 |
| kennenecsXprice | .0010746 | .0002043 | 5.26 | 0.000 | .0006743 | .001475 |
| accuracy95 | .2858287 | .1049271 | 2.72 | 0.006 | .0801754 | .491482 |
| opleiding_hoogXwebsite | .4741239 | .1263181 | 3.75 | 0.000 | .2265448 | .7217029 |
| aantalkinderenXmidwife | -.1605652 | .0566555 | -2.83 | 0.005 | -.271608 | -.0495224 |
| kennenecsXopt_out | -.8577569 | .3068344 | -2.80 | 0.005 | -1.459141 | -.2563724 |
| opt_out | -.3083087 | .3294506 | -0.94 | 0.349 | -.95402 | .3374025 |
| genes2 | .2053083 | .0671574 | 3.06 | 0.002 | .0736823 | .3369344 |
| genes3 | .1994093 | .0983551 | 2.03 | 0.043 | .006637 | .3921817 |
| accuracy99 | 1.140901 | .1512653 | 7.54 | 0.000 | .8444267 | 1.437376 |
| opleiding_hoogXprice | -.0018977 | .0002808 | -6.76 | 0.000 | -.002448 | -.0013474 |
| opleiding_hoogXaccuracy99 | .6455876 | .1965154 | 3.29 | 0.001 | .2604245 | 1.030751 |
| aantalkinderenXopt_out | .6748463 | .1605234 | 4.20 | 0.000 | .3602263 | .9894663 |
| **SD** | | | | | | |
| opt_out | 2.727531 | .1623411 | 16.80 | 0.000 | 2.409348 | 3.045714 |
| genes2 | -.6907558 | .086311 | -8.00 | 0.000 | -.8599222 | -.5215893 |
| genes3 | 1.506783 | .1044722 | 14.42 | 0.000 | 1.302021 | 1.711545 |
| accuracy99 | 1.241035 | .1377461 | 9.01 | 0.000 | .9710576 | 1.511012 |
| opleiding_hoogXprice | -.0033175 | .0002374 | -13.98 | 0.000 | -.0037828 | -.0028522 |
| opleiding_hoogXaccuracy99 | -1.075975 | .2414205 | -4.46 | 0.000 | -1.54915 | -.6027995 |
| aantalkinderenXopt_out | 1.880069 | .2231729 | 8.42 | 0.000 | 1.442658 | 2.31748 |

The sign of the estimated standard deviations is irrelevant: interpret them as

# Appendix III – Ranking exercise

1=provider,2=price,3=informationprovision,4=diseases,5=accuracy

```
. ************************ Ranking ****************************************
. //in ranking: 1=provider,2=price,3=informationprovision,4=genes,5=accuracy
. //rankingattribuut_1 rankingattribuut_2 rankingattribuut_3 rankingattribuut_4 rankingattribuut_5 hebben allemaal een nummer gekregen 1-5 -1 is eerste keus, 2 tweede keus etc.
. //Vraag: hoe vaak is attribuutX op 1 etc. gezet
. //....% van de respondenten heeft attribuutX als meest belangrijke gerankt
.
. tabulate rankingattribuut_1
```

| rankingattribuut_1 | Freq. | Percent | Cum. |
|---|---|---|---|
| 1 | 56 | 11.69 | 11.69 |
| 2 | 64 | 13.36 | 25.05 |
| 3 | 77 | 16.08 | 41.13 |
| 4 | 136 | 28.39 | 69.52 |
| 5 | 146 | 30.48 | 100.00 |
| Total | 479 | 100.00 | |

```
. tabulate rankingattribuut_2
```

| rankingattribuut_2 | Freq. | Percent | Cum. |
|---|---|---|---|
| 1 | 94 | 19.62 | 19.62 |
| 2 | 83 | 17.33 | 36.95 |
| 3 | 110 | 22.96 | 59.92 |
| 4 | 81 | 16.91 | 76.83 |
| 5 | 111 | 23.17 | 100.00 |
| Total | 479 | 100.00 | |

```
. tabulate rankingattribuut_3
```

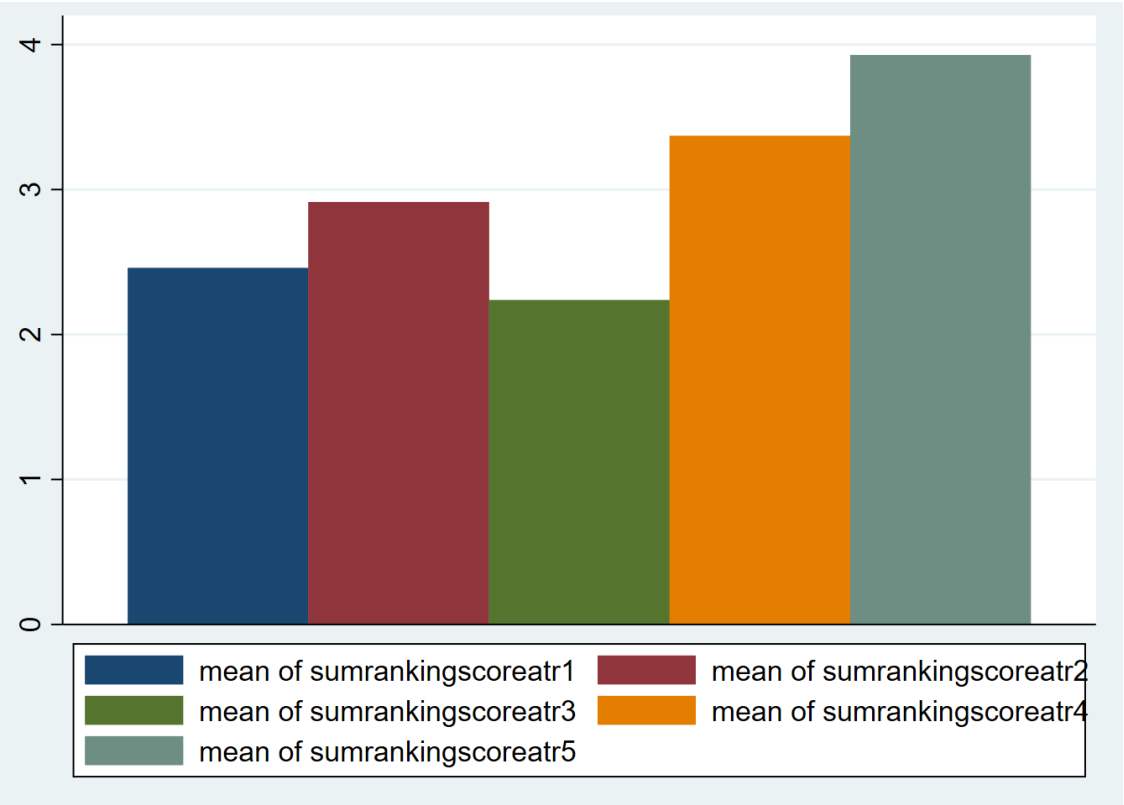
| rankingattribuut_3 | Freq. | Percent | Cum. |
|---|---|---|---|
| 1 | 35 | 7.31 | 7.31 |
| 2 | 48 | 10.02 | 17.33 |
| 3 | 85 | 17.75 | 35.07 |
| 4 | 145 | 30.27 | 65.34 |
| 5 | 166 | 34.66 | 100.00 |
| Total | 479 | 100.00 | |

```
. tabulate rankingattribuut_4
```

| rankingattribuut_4 | Freq. | Percent | Cum. |
|---|---|---|---|
| 1 | 103 | 21.50 | 21.50 |
| 2 | 134 | 27.97 | 49.48 |
| 3 | 123 | 25.68 | 75.16 |
| 4 | 82 | 17.12 | 92.28 |
| 5 | 37 | 7.72 | 100.00 |
| Total | 479 | 100.00 | |

```
. tabulate rankingattribuut_5
```

| rankingattribuut_5 | Freq. | Percent | Cum. |
|---|---|---|---|
| 1 | 191 | 39.87 | 39.87 |
| 2 | 150 | 31.32 | 71.19 |
| 3 | 84 | 17.54 | 88.73 |
| 4 | 35 | 7.31 | 96.03 |
| 5 | 19 | 3.97 | 100.00 |
| Total | 479 | 100.00 | |


0
1
2
3
4
mean of sumrankingscoreatr1
mean of sumrankingscoreatr2
mean of sumrankingscoreatr3
mean of sumrankingscoreatr4
mean of sumrankingscoreatr5

# Appendix IV – Respondent exclusion

**Respondent amount at start**

```
. sum resp_id

    Variable |        Obs        Mean    Std. dev.       Min        Max
-------------+---------------------------------------------------------
     resp_id |      1,611      842.82    473.9771         6       1658
```

**Respondent amount after removal respondents who stopped during first questions**

```
. drop if sys_lastquestion=="Con" | sys_lastquestion=="Start2" | sys_lastquestion=="Start" | sys_lastquestion=="leeftijd" | sys_lastquestion=="start" | sys_lastquesti
> on=="start2" | sys_lastquestion=="hoesnelkinderen" | sys_lastquestion=="kinderwens"
(475 observations deleted)

. sum resp_id

    Variable |        Obs        Mean    Std. dev.       Min        Max
-------------+---------------------------------------------------------
     resp_id |      1,136    778.1831    481.1862         6       1658
```

**Respondent amount after removal respondents without child-wish within 10 years or outside of age range**

```
. gen screenout=1 if (leeftijd < 18 | leeftijd > 40 | kinderwens==2) | hoesnelkinderen_4_other == "15" | hoesnelkinderen_4_other == "14"  | hoesnelkinderen_4_other ==
>  "20" | hoesnelkinderen_4_other == "25" | hoesnelkinderen_4_other == "14" | hoesnelkinderen_4_other == "Over 12 jaar" | hoesnelkinderen_4_other == "afdfdaf"
(819 missing values generated)

.
. replace screenout=0 if screenout==.
(819 real changes made)

.
. sum resp_id if screenout==1

    Variable |        Obs        Mean    Std. dev.       Min        Max
-------------+---------------------------------------------------------
     resp_id |        317    821.7382    474.2903        11       1658

. sum resp_id if screenout==0

    Variable |        Obs        Mean    Std. dev.       Min        Max
-------------+---------------------------------------------------------
     resp_id |        819    761.3248     483.062         6       1657

.
. di 475+317
792

. //excluded=818 vs 793
.
. drop if screenout==1
(317 observations deleted)
```

**Disqualified respondent amount**

```
. gen notopenecs=1 if openecs==3
(763 missing values generated)

. replace notopenecs=0 if notopenecs==.
(763 real changes made)

.
. sum resp_id if notopenecs==1

    Variable |        Obs        Mean    Std. dev.       Min        Max
-------------+---------------------------------------------------------
     resp_id |         56    943.1071    406.2101        46       1647

.
```

**Respondent amount after removal respondents who did not finish DCE**

```
. gen complete=1 if (sys_lastquestion=="Einde" | sys_lastquestion=="Einde2" | sys_lastquestion=="Einde1" | sys_lastquestion=="evaluatieeind_r1" | sys_lastquestion=="e
> valuatieeind_r2" | sys_lastquestion=="evaluatieeind_r3" | sys_lastquestion=="evaluatieeind_r4" | sys_lastquestion=="evaluatieeind_r5" | sys_lastquestion=="karakteri
> stieken" | sys_lastquestion=="karakteristieken" | sys_lastquestion=="karakteristiekenopen" | sys_lastquestion=="duidelijk" | sys_lastquestion=="watnietduidelijk" |
> sys_lastquestion=="veelskip_3_other" | sys_lastquestion=="openeva" | sys_lastquestion=="watnietduidelijk1" | sys_lastquestion=="veelskip" | sys_lastquestion=="ranki
> ngattribuut_1" | sys_lastquestion=="rankingattribuut_2" | sys_lastquestion=="rankingattribuut_3" | sys_lastquestion=="rankingattribuut_5" | sys_lastquestion=="ranki
> ngattribuut_4" | sys_lastquestion=="rankingattribuut" | sys_lastquestion=="evaluatieeind") & resp_id < 245
(725 missing values generated)

.
. replace complete=1 if (sys_lastquestion=="Einde2" | sys_lastquestion=="evaluatieeind_r1" | sys_lastquestion=="evaluatieeind_r2" | sys_lastquestion=="evaluatieeind_r
> 3" | sys_lastquestion=="evaluatieeind_r4" | sys_lastquestion=="evaluatieeind_r5" | sys_lastquestion=="karakteristieken" | sys_lastquestion=="karakteristieken" | sys
> _lastquestion=="karakteristiekenopen" | sys_lastquestion=="duidelijk" | sys_lastquestion=="watnietduidelijk" | sys_lastquestion=="veelskip_3_other" | sys_lastquesti
> on=="openeva" | sys_lastquestion=="watnietduidelijk1" | sys_lastquestion=="veelskip" | sys_lastquestion=="rankingattribuut_1" | sys_lastquestion=="rankingattribuut_
> 2" | sys_lastquestion=="rankingattribuut_3" | sys_lastquestion=="rankingattribuut_5" | sys_lastquestion=="rankingattribuut_4" | sys_lastquestion=="rankingattribuut"
>  | sys_lastquestion=="evaluatieeind") & resp_id >= 245
(454 real changes made)

.
end of do-file

. do "C:\Users\95dav\AppData\Local\Temp\STD9f20_000000.tmp"

. replace complete=0 if complete==.
(271 real changes made)

.
end of do-file

. do "C:\Users\95dav\AppData\Local\Temp\STD9f20_000000.tmp"

. drop if complete==0 & notopenecs==0
(215 observations deleted)

.
end of do-file

. do "C:\Users\95dav\AppData\Local\Temp\STD9f20_000000.tmp"

. sum resp_id if notopenecs==0

    Variable |        Obs        Mean    Std. dev.       Min        Max
-------------+---------------------------------------------------------
     resp_id |        548    634.9726    373.2281          6       1341
```

**Respondent amount after removal respondents who failed second chance of dominant question**

```
. drop if dominantfout==1 & complete==1 & notopenecs==0
(38 observations deleted)

.
end of do-file

. do "C:\Users\95dav\AppData\Local\Temp\STD9f20_000000.tmp"

. sum resp_id if notopenecs==0

    Variable |        Obs        Mean    Std. dev.       Min        Max
-------------+---------------------------------------------------------
     resp_id |        510    619.1941    373.3007         6       1341

.
```

**Respondent amount after removal respondents who finished survey within 4 minutes**

```
. gen minutesspent= (int(sys_sumpagetimes)/60)

.
end of do-file

. do "C:\Users\95dav\AppData\Local\Temp\STD9f20_000000.tmp"

. sum minutesspent if minutesspent < 4 & complete==1 & notopenecs==0

    Variable |        Obs        Mean    Std. dev.       Min        Max
-------------+---------------------------------------------------------
minutesspent |         26    3.438462    .4769526       1.95       3.95

.
end of do-file

. do "C:\Users\95dav\AppData\Local\Temp\STD9f20_000000.tmp"

. drop if minutesspent < 4 & complete==1 & notopenecs==0
(26 observations deleted)

.
end of do-file

. do "C:\Users\95dav\AppData\Local\Temp\STD9f20_000000.tmp"

. sum resp_id if notopenecs==0

    Variable |        Obs        Mean    Std. dev.       Min        Max
-------------+---------------------------------------------------------
     resp_id |        484    608.7211    372.0438         6       1341

.
```

```
. summarize minutesspent, d

                        minutesspent
-------------------------------------------------------------
      Percentiles      Smallest
 1%     1.216667       1.016667
 5%     2.333333       1.033333
10%          3.6       1.083333       Obs                 566
25%         5.55            1.1       Sum of wgt.         566

50%     9.008333                      Mean              18.871
                        Largest       Std. dev.       54.03465
75%     14.08333       341.5833
90%     26.41667       536.7667       Variance        2919.743
95%     48.41667       666.8666       Skewness        9.183432
99%     282.3167         694.55       Kurtosis         100.326

.
```

**Respondent amount after removal respondents who always chose for the first or second option in the DCE**

```
. gen same_choice_in_all_optie1=0

. replace same_choice_in_all_optie1=1 if cbc_question1==1 & cbc_question2==1 & cbc_question3==1 & cbc_question4==1 & cbc_question5==1 & cbc_question6==1 & cbc_question7==1 & cbc_question8==1 &
>  cbc_question9==1 & cbc_question10==1 & cbc_question11==1 & cbc_question12==1 & cbc_question13==1
(1 real change made)

. replace same_choice_in_all_optie1=1 if cbc_question14==1 & cbc_question15==1 & cbc_question16==1 & cbc_question17==1 & cbc_question18==1 & cbc_question19==1 & cbc_question20==1 & cbc_questio
> n21==1 & cbc_question22==1 & cbc_question23==1 & cbc_question24==1 & cbc_question25==1 & cbc_question26==1
(2 real changes made)


. //Optie 2
. gen same_choice_in_all_optie2=0

. replace same_choice_in_all_optie2=1 if cbc_question1==2 & cbc_question2==2 & cbc_question3==2 & cbc_question4==2 & cbc_question5==2 & cbc_question6==2 & cbc_question7==2 & cbc_question8==2 &
>  cbc_question9==2 & cbc_question10==2 & cbc_question11==2 & cbc_question12==2 & cbc_question13==2
(0 real changes made)

. replace same_choice_in_all_optie2=1 if cbc_question14==2 & cbc_question15==2 & cbc_question16==2 & cbc_question17==2 & cbc_question18==2 & cbc_question19==2 & cbc_question20==2 & cbc_questio
> n21==2 & cbc_question22==2 & cbc_question23==2 & cbc_question24==2 & cbc_question25==2 & cbc_question26==2
(0 real changes made)

. sum resp_id if same_choice_in_all_optie1==1 | same_choice_in_all_optie2==1

    Variable |        Obs        Mean    Std. dev.       Min        Max
-------------+---------------------------------------------------------
     resp_id |          3    587.3333     294.731         255        817

. di 484-3
481

. di 1071+3
1074

. drop if  same_choice_in_all_optie1==1 | same_choice_in_all_optie2==1
(3 observations deleted)
```

| disqualified | Freq. | Percent | Cum. |
|---|---|---|---|
| 0 | 481 | 89.57 | 89.57 |
| 1 | 56 | 10.43 | 100.00 |
| Total | 537 | 100.00 | |

# Appendix V- Priors used for pilot survey

| Attribute | Levels | Ngene utility range |
|---|---|---|
| **Accuracy*** | - 90 uit 100 tests correct result<br>- 95 in 100 tests correct result<br>- 99 in 100 tests correct result | Base case<br>0.1-0.2<br>0.2-0.3 |
| **Price (per person)*** | - €50<br>- €200<br>- €500<br>- €1000 | Base case<br>0.000001 - -0.08<br>-0.08 - -0.14<br>-0.14 - -0.2 |
| **Type of diseases tested on** | - Base level: early onset very serious<br>- Second level: Base level + late onset serious diseases<br>- Third level: Second level + milder diseases<br>- Fourth level: third level + Non-health related genes | base case<br>-0.1,0.1<br>-0.1,0.1<br>-0.15 - -0.25 |
| **Type of counseling (before testing)** | - Counseling<br>- Brochure<br>- Website | Base case<br>-0.05 - -0.15<br>-0.05 - -0.15 |
| **Provider** | - Commercial company<br>- Midwife<br>- Medical specialist<br>- General practitioner | Base case<br>- 0.1 - 0.1<br>0.1 - 0.175<br>0.175 - 0.25 |

# Appendix VI- Priors gained from pilot survey

**B-coefficients and SD pilot survey (conditional logit)**

| Attribute | Levels | Ngene utility range |
|---|---|---|
| **Accuracy*** | - 90 uit 100 tests correct result<br>- 95 in 100 tests correct result<br>- 99 in 100 tests correct result | Base case<br>1.156325 (.2570058)<br>1.765769 (.2550984) |
| **Price (per person)*** | - €50<br>- €200<br>- €500<br>- €1000 | Base case<br>-.2768765 (.2228818)<br>-.8496314 ( .2508106)<br>-1.327891 (.3382636) |
| **Type of diseases tested on** | - Base level: early onset very serious<br>- Second level: Base level + late onset serious diseases<br>- Third level: Second level + milder diseases<br>- Fourth level: third level + Non-health related genes | base case<br>.3699 (.2579/1.96=0.1316)<br>.3322 (.2265/1.96=0.1156)<br>-.3635 (.3873/1.96=0.1976) |
| **Type of counseling (before testing)** | - Counseling<br>- Brochure<br>- Website | Base case<br>-.6177964 (.2502328)<br>-.6233324 ( .2412099) |
| **Provider** | - Commercial company<br>- Midwife<br>- Medical specialist<br>- General practitioner | Base case<br>1.114211 (.2692908)<br>.9903513 ( .2816647 )<br>1.524527 (.3322003) |

## Priors used in final survey

OPTIE 1 (91-95-99)

| Attribute | Levels | Ngene utility range |
|---|---|---|
| **Accuracy*** | - 91 uit 100 tests correct result<br>- 95 in 100 tests correct result<br>- 99 in 100 tests correct result | Base case<br>1.167522 (.2424307)<br>1.755121 ( .247608) |
| **Price (per person)*** | - €200<br>- €500<br>- €1000 | Base case<br>-.6825074 (.1803627)<br>-1.130126 (.2676978) |
| **Type of diseases tested on** | - Base level: Serious<br>- Second level: Serious + mild<br>- Third level: Serious + mild + Non-health related genes | Base case<br>.1574703(.21628/1.96=0.1103)<br>-.5503995 ( .3292974) |
| **Type of counseling (before testing)** | - Counseling<br>- Brochure<br>- Website | Base case<br>-.6221769 (.2372494)<br>-.6460257 ( .2314101) |
| **Provider** | - Commercial company<br>- Midwife<br>- Medical specialist<br>- General practitioner | Base case<br>1.08059 (.2708738)<br>1.052785 ( .2816165)<br>1.549676 ( .3346958) |

**Ngene script**

```
Design
;alts   = altA, altB, altC
;eff    = (mnl,d,mean)
;bdraws = halton(300)
;rows   = 24
;block = 2

;model:
U(AltA)  = b1.dummy [(n,1.167522,0.2424307)|(n,1.755121,0.247608)] * accuracy [0.95, 0.99, 0.91]
        + b2.dummy [(n,-0.6825074,0.1803627)|(n,-1.130126,0.2677)] * price [500, 1000, 200]
        + b3.dummy [(u,0.1,0.4)|(n,-0.5503995,0.3293)] * diseases [1, 2, 0]
        + b4.dummy [(n,-0.6221769,0.2372494)|(n,-0.6460257 ,0.2314)] * counseling  [1, 2, 0]
        + b5.dummy [(n,1.08059,0.270874)|(n,1.0528,.28162)|(n,1.54968,0.3347)] * provider [1, 2, 3, 0]

/
U(AltB)  = b1.dummy * accuracy
        + b2.dummy * price
        + b3.dummy * diseases
        + b4.dummy * counseling
        + b5.dummy * provider

/
U(AltC)  = b0
$
```

# Appendix VII- Final survey

Start

**Introductie vragenlijst**

Beste deelnemer,

Alvast ontzettend bedankt voor uw interesse en deelname aan deze enquête. Het doel van deze enquête is om een beter beeld te krijgen van de voorkeuren van mogelijke gebruikers van de dragerschapstest. Op deze manier kunnen deze voorkeuren worden meegenomen bij het maken van keuzes voor de invoering van de test.

De dragerschapstest is een test die door koppels met een kinderwens kan worden gedaan voorafgaand aan de zwangerschap. Hiermee kan worden vastgesteld of zij allebei drager zijn van een dezelfde genetische aandoening, en daardoor een verhoogde kans hebben op een kindje met een genetische aandoening. Verderop in de vragenlijst zult u uitgebreide informatie krijgen over deze test.

Dit onderzoek wordt uitgevoerd door twee studenten Health Economics (Policy and Law) van de Erasmus Universiteit Rotterdam. Het invullen van deze enquête kost ongeveer 15 minuten en is volledig anoniem.

Mocht u vragen of opmerkingen hebben over deze vragenlijst, dan kunt u contact met ons opnemen via **dragerschapsonderzoek@gmail.com**

ERASMUS UNIVERSITEIT ROTTERDAM

Volgende

Con

Ik begrijp dat ...

...deelname aan dit onderzoek vrijwillig is.

...mijn antwoorden anoniem zullen worden behandeld voor een onderzoeksrapportage.

...individuele antwoorden niet benoemd worden in het onderzoeksrapport.

...deze vragenlijst gericht is op individuen tussen de 18 en 40 die denken of wensen binnen 10 jaar (meer) kinderen te krijgen.

...door deel te nemen aan het onderzoek, ik een belangrijke bijdrage lever aan de wetenschap.

Con = 1 Dit begrijp ik en ik ga akkoord met de deelname.

Ter Volgende

leeftijd

Wat is uw leeftijd?

kinderwens

Wenst of denkt u binnen 10 jaar (meer) kinderen te krijgen?

kinderwens = 1
Ja

kinderwens = 2
Nee

Ter Volgende

hoesnelkinderen

Hoe snel denkt u kinderen te willen

hoesnelkinderen = 1
Binnen 1 jaar

hoesnelkinderen = 2
Binnen 5 jaar

hoesnelkinderen = 3
Binnen 10 jaar

hoesnelkinderen_4_other
hoesnelkinderen = 4
Anders, binnen zoveel jaar:

Ter Volgende

geslacht

Wat is uw geslacht?

geslacht = 1 Man

geslacht = 2 Vrouw

geslacht = 3 Anders

Provincie

In welke provincie woont u?

Provincie=1 Drenthe

Provincie=2 Flevoland

Provincie=3 Friesland

Provincie=4 Gelderland

Provincie=5 Groningen

Provincie=6 Limburg

Provincie=7 Noord-Brabant

Provincie=8 Noord-Holland

Provincie=9 Overijssel

Provincie=10 Utrecht

Provincie=11 Zeeland

Provincie=12 Zuid-Holland

scholing

Wat is uw hoogst behaalde opleidingsniveau / op welk niveau ben je op dit moment student?

scholing=1 Basisschool

scholing=2 Voorbereidend middelbaar beroepsonderwijs (vmbo)

scholing=3 Hoger algemeen voortgezet onderwijs (havo)

scholing=4 Voorbereidend wetenschappelijk onderwijs (vwo)

scholing=5 Middelbaar beroepsonderwijs (mbo)

scholing=6 Hoger beroepsonderwijs (hbo)

scholing=7 Wetenschappelijk onderwijs (wo)

Salaris

Wat is uw netto inkomen per maand?

Salaris=1 0 t/m 1000 euro

Salaris=2 1001 t/m 2000 euro

Salaris=3 2001 t/m 3000 euro

Salaris=4 3001 t/m 4000 euro

Salaris=5 4001 t/m 5000 euro

Salaris=6 5001 t/m 7500 euro

Salaris=7 7501 t/m 10.000 euro

Salaris=8 Meer dan 10.000 euro

religie

Bent u gelovig?

religie=1 religie_1_other Ja, ik geloof in/volgens de volgende religie:

religie=2 Nee

religie=3 Hier wil ik geen antwoord op geven

Partner

Heeft u op dit moment een partner?

Partner = 1
Ja

Partner = 2
Nee

Ter Volgende

Hoelangpartner

Hoe lang heeft u een relatie met uw huidige partner (in jaren)?

Ter Volgende

Geenpartner

U heeft op dit moment geen partner. Stel uzelf bij het invullen van deze vragenlijst voor dat u op een moment in uw leven bent waarop u een partner heeft waarmee u kinderen zou willen.

Teru Volgende

zelfgeboren

Bent u in Nederland geboren?

zelfgeboren = 1
Ja

zelfgeboren_2_other
zelfgeboren = 2
Nee, ik ben geboren in:

aantalkinderen

Hoeveel kinderen heeft u op dit moment?

Moedergeboren

Is uw moeder in Nederland geboren?

Moedergeboren = 1
Ja

Moedergeboren_2_other
Moedergeboren = 2
Nee, mijn moeder is geboren in:

Vadergeboren

Is uw vader in Nederland geboren?

Vadergeboren = 1
Ja

Vadergeboren_2_other
Vadergeboren = 2
Nee, mijn vader is geboren in:

Prenataalediagnostiek

Bij prenatale diagnostiek wordt er voor de geboorte van een kindje gecontroleerd of het kindje bepaalde aandoeningen heeft. Dit kan bijvoorbeeld door bloed van de moeder te testen of het vruchtwater, of door een uitgebreide echo te doen.

Heeft u tijdens mogelijke voorgaande zwangerschappen gebruik gemaakt van prenatale diagnostiek / Zou u in de toekomst het gebruik van prenatale diagnostiek overwegen tijdens een mogelijke zwangerschap?

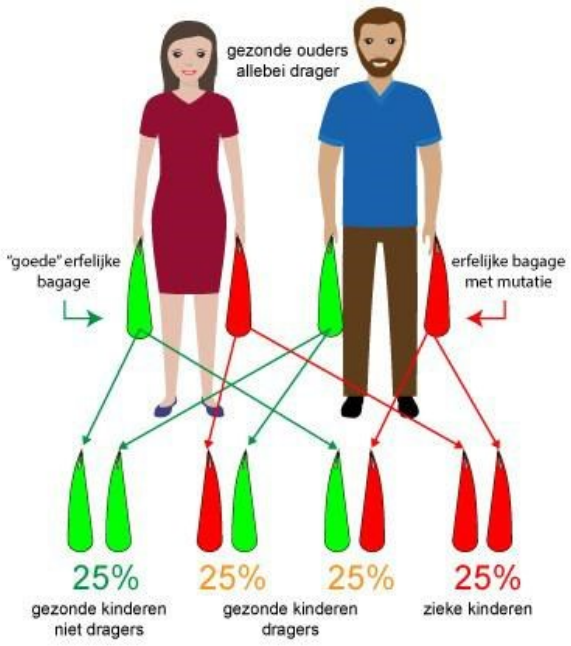
Prenataalediagnostiek = 1
Ja

Prenataalediagnostiek = 2

Nee

Ter Volgende

## De dragerschapstest en doel van het huidige onderzoek




De meeste kinderen in Nederland zijn gelukkig gezond. Er worden echter ook zieke kinderen geboren of kinderen die later in hun leven ziek worden, bijvoorbeeld doordat zij een erfelijke aandoening hebben. Ook als u zelf gezond bent, kunt u een kindje krijgen met een erfelijke aandoening. Binnen uw genen zit informatie opgeslagen waar uw erfelijke eigenschappen in zijn vastgelegd. Deze informatie bepaalt voor een groot deel hoe u eruit ziet en zorgt ervoor dat uw lichaam goed werkt. Van ieder gen (bijvoorbeeld het gen dat uw oogkleur bepaalt), bestaan meerdere variaties. Voor ieder kenmerk heeft een persoon twee variaties, die het kenmerk bepalen.

Soms is één van de twee genen die een bepaald kenmerk bepalen van een persoon anders dan normaal. Zo'n afwijking heet een mutatie. Dragers van een genetische ziekte hebben een fout in één van de twee dezelfde genen. Daarom hebben zij geen gezondheidsklachten, omdat zij naast het ‘foute’ gen nog een ‘goed’ gen hebben. Maar als de partner van een drager ook drager is van hetzelfde 'foute' gen, is er een kans van 1 op 4 dat uw toekomstig kindje wel met twee mutaties geboren wordt en dus een genetische aandoening heeft. Met een preconceptie dragerschapstest kunt u vaststellen of u drager bent van een dergelijke recessieve erfelijke ziekte **voordat er sprake is van een zwangerschap** . Voor het onderzoek hoeft enkel bloed afgenomen te worden bij beide partners.

Het doel van een dragerschapstest is om aan toekomstige ouders informatie te geven over gezondheidsrisico's van hun toekomstig kind en hen te helpen bij de keuzes bij het krijgen van kinderen. Wanneer toekomstge ouders weten dat er een kans bestaat op een kind met een recessieve erfelijke aandoening, zijn er verschillende keuzes die het paar kan maken. Ten eerste kan het paar zich voorbereiden op de mogelijke komst van een kind met een ernstige aandoening. Ten tweede kunnen zij ervoor kiezen om IVF* te ondergaan en tijdens dit traject een embryo zonder genetische afwijking te laten selecteren. Ook kunnen paren kiezen voor het adopteren van een kind, een zaad- of eiceldonor of zij kunnen ervoor kiezen om geen kinderen te krijgen (met de huidige partner). Voorafgaand aan de zwangerschap heeft een paar de meeste keuzemogelijkheden.

* IVF staat voor in vitro fertilisatie. Bij deze techniek worden eicellen in het lab bevrucht met zaadcellen. Dit vormt samen een embryo en zal vervolgens bij de

vrouw in de baarmoeder geplaatst worden.

Bekijk de onderstaande video om meer te weten te komen over de dragerschapstest:

Wanneer er met de preconceptie dragerschapstest getest wordt op 50 ernstige ziekten die vroeg in het leven ontstaan, zal ongeveer 1 uit 150 koppels een positieve test hebben. Omdat er vervolgens een 25% kans op een ziek kind is, betekent dit dat in ongeveer 1 op 600 zwangerschappen in Nederland sprake is van één van die 50 geteste genetische ziekten.

Het doel van de vragenlijst is om erachter te komen wat personen met een kinderwens die openstaan voor een dragerschapstest belangrijke kenmerken vinden van de test. Op basis van de voorkeuren van de mogelijke gebruiker kan de preconceptie dragerschapstest worden ingericht op een manier die zo veel mogelijk aansluit bij de wensen van de gebruiker. Hierbij wordt gekeken naar de kosten van de test, de aanbieder, de betrouwbaarheid, manier van informatievoorziening en op welke ziekten er getest wordt.

voorkennisecs

**Heeft u voorafgaand aan deze vragenlijst al eens gehoord van de dragerschapstest voor koppels met een kinderwens?**

voorkennisecs = 1
Ja

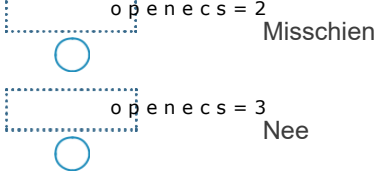
voorkennisecs = 2
Nee

openecs

**Stelt u zich voor: er wordt u een gratis, volledig betrouwbare dragerschapstest aangeboden, waarbij u de keuze heeft op welke erfelijke ziekten er wordt getest, zou u dit dan overwegen?**

openecs = 1


Ja







Teru Volgende

## Genetische aandoeningen

Er bestaan veel verschillende soorten autosomaal recessieve genetische aandoeningen, die verschillen in leeftijd waarop zij tot uiting komen, ernst, en of er behandeling mogelijk is of niet. Er kan onderscheid gemaakt worden tussen ziekten die de meeste mensen als ernstig beschouwen en ziekten die de meeste mensen als mild beschouwen.

### Ernstige ziekten

De meeste mensen beschouwen een ziekte als een ernstige genetische aandoening als deze onbehandelbaar is en gepaard gaat met veel pijn en/of een ernstige lichamelijke handicap en/of een ernstige verstandelijke handicap en/of vroegtijdig overlijden. In deze definitie speelt het geen rol of de ziekte vroeg of later in het leven tot uiting komt.

Voorbeelden van ernstige aandoeningen:

- *Pontocerebellaire hypoplasie*: door de genetische afwijking ontwikkelen bepaalde delen van de hersenen zich niet goed. Hierdoor kunnen kinderen met deze ziekte meestal niet praten, lopen, zitten en hebben zij moeite met eten en drinken. De meeste kinderen met deze aandoening overlijden op jonge leeftijd.

- *Ziekte van Parkinson:* Afwijkingen in bepaalde genen kunnen leiden tot het ontwikkelen tot een erfelijke vorm van de ziekte van Parkinson. De ziekte van Parkinson ontwikkelt zich meestal op latere leeftijd, wanneer mensen tussen de 40 en 60 jaar oud zijn. Bij de ziekte van Parkinson kunnen veel verschillende soorten klachten optreden. Zo kan er sprake zijn van depressiviteit, dementie, trillende ledematen, problemen met het starten en uitvoeren van bewegingen en stijve spieren. Vaak is er uiteindelijke en opname in een verpleeghuis noodzakelijk en overlijden mensen met de ziekte van Parkinson vroegtijdig.

**Milde ziekten**

De meeste mensen beschouwen een ziekte als een milde genetische

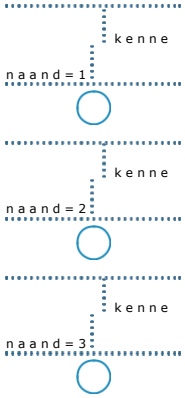
aandoening als deze gepaard gaan met milde lichamelijke handicap of verstandelijke handicap of behandelbaar is.

Voorbeelden van milde ziekten zijn:

- *Doofheid:* bepaalde vormen van doofheid worden veroorzaakt door een autosomaal overervende ziekte.

- *Miyoshi spierdystrofie*: door een afwijking in bepaalde specifieke genen ontstaan er klachten van de spieren. Dit begint meestal op jongvolwassen leeftijd met zwakte van de kuitspieren waardoor er problemen kunnen ontstaan met traplopen, rennen en springen. Over de jaren heen kan de ziekte zich uitbreiden naar de rest van de benen en de bovenarmen. In sommige gevallen is uiteindelijk een rolstoel nodig.


**Bent/kent/kende u iemand met een aangeboren genetische aandoening?**




Ja

Nee

Weet ik niet

familieaand

Is er binnen uw famillie iemand met een aangeboren genetische aandoening?

familieaand=1 Ja

familieaand=2 Nee

familieaand=3 Weet ik niet

zelfaand

Heeft u zelf een aangeboren genetische aandoening?

zelfaand=1 Ja

zelfaand=2 Nee

zelfaand=3 Zeg ik liever niet

IntroducerenDCE

## Introductie keuzetaken

Hopelijk heeft u nu een goed beeld van wat de preconceptie dragerschapstest is en waarvoor deze gebruikt kan worden. De dragerschapstest heeft verschillende kenmerken, die kunnen variëren. In het volgende deel van de vragenlijst zullen we u stap voor stap kennis laten maken met de verschillende kenmerken. Ook zullen we u vragen om steeds een keuze te maken tussen drie denkbeeldige opties. Twee van deze opties variëren van elkaar op basis van een aantal kenmerken. De derde optie houdt in dat u geen dragerschapstest zou laten uitvoeren.

Teru Volgende

Intro1aanbieder0prijs_Fixed1

**Aanbieder en prijs**

Het eerste kenmerk van de dragerschapstest waarbinnen variaties mogelijk zijn, is door wie de test wordt aangeboden. De test zou kunnen worden aangeboden door de **huisarts, verloskundige, medisch specialist** in het ziekenhuis of door een **commercieel bedrijf**. Bij een medisch specialist zou u bijvoorbeeld kunnen denken aan de gynaecoloog of de klinisch geneticus (erfelijkheidsarts).

In het geval van een huisarts, medisch specialist of verloskundige wordt de daadwerkelijke genetische test uitgevoerd binnen een laboratorium van een academisch ziekenhuis. Bij een commercieel bedrijf wordt dit gedaan in het lab van de commerciële instantie. De test wordt in alle gevallen uitgevoerd door hiervoor opgeleid laboratoriumpersoneel.

De taken van de aanbieder zijn om het bloed af te nemen, dit op te sturen voor onderzoek en om de uitslag van de test met u te delen. Alle aanbieders die als optie worden gegeven, hebben de juiste kennis en vaardigheden om deze taken uit te voeren. Wanneer uit de uitslag blijkt dat er sprake is van een verhoogd risico op een kind met een erfelijke aandoening, zal u worden doorverwezen naar de specialist op dit gebied die u verder zal begeleiden.

Het tweede kenmerk van de dragerschapstest waarbinnen variaties mogelijk zijn, is hoeveel u **zelf** voor de test zou moeten betalen. De test zou kunnen worden aangeboden voor **200, 500 of 1000 euro** per paar. Dit zou dus het bedrag zijn dat **niet** door de zorgverzekering wordt gedekt.

€200 €500 €1000

**Voorbeeldvraag**:

Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

U heeft ook de optie om **geen test** te kiezen. U kiest geen van beide tests, omdat u ook in de realiteit helemaal **geen test zou laten uitvoeren**, als de twee gegeven opties de enige beschikbare opties zouden zijn.

(1 of 1)

| Test 1 | Test 2 |
| --- | --- |
| | |

| | | |
|---|---|---|
| **Aanbieder** | Medisch specialist | Commercieel bedrijf |

koppel

hapstest

Prijs

dragersc

€1000

€200

Intro1aanbieder0prijs_Fix
ed1 Select

Intro1aanbieder0prijs_Fixed1 Select

Intro1aanbieder0prijs_Fi

Geen test

Ik zou geen van beide tests ondergaan

Intro1aanbieder0prijs_Fixed1
Select

Teru

Volgende

**Informatievoorziening**

Het derde kenmerk van de dragerschapstest waarbinnen variaties mogelijk zijn, is de **informatievoorziening voorafgaand aan de test**. Er zijn drie mogelijke manieren waarop u de informatie zou kunnen ontvangen:

**- Middels het krijgen van een brochure.**

Deze brochure kan digitaal worden gedownload, of op papier worden thuisbezorgd. In de brochure is alle belangrijke informatie over de dragerschapstest te lezen. Ook is er een ervaringsverhaal te lezen van mensen die een dragerschapstest hebben gedaan en wat de gevolgen voor hen waren.

**- Middels het bezoeken van een website.**

Op deze website is dezelfde informatie te vinden als in de brochure, aangevuld met filmpjes die lastige begrippen verder uitleggen.

**- Middels het hebben van een persoonlijk gesprek met de zorgverlener van de test.**

In dit gesprek wordt alle belangrijke informatie over de dragerschapstest besproken, u kunt vragen stellen en overleggen met de aanbieder over de gevolgen die de test zou kunnen hebben.


Mocht er sprake zijn van een positieve uitslag (u en uw partner zijn beide drager van dezelfde ziekte/aandoening) dan zult u verwezen worden naar de erfelijkheidsarts en door hem/haar verder begeleid worden.

**Voorbeeldvraag**:

Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

(1 of 1)

| | Test 1 | Test 2 | |
|---|---|---|---|
| **Aanbieder** | | Medisch specialist | Verloskundige |
| **Prijs koppel** | | €1000 | €200 |

**dragerschapstest**

**Informatievoorziening**Website

intro2informatiemanier_Fixed 1Select

B
rochure

intro2informatiemanier_Fixed 1Select

Geen test

Ik zou geen van beide tests ondergaan

intro2informatiemanier_Fixed1 Select

Teru

Volgende

intro3ziekte_Fixed1

**Genetische aandoeningen waarop getest wordt**

Zoals eerder uitgelegd zit de informatie over hoe wij eruit zien opgeslagen in onze genen, en kan een afwijking in een gen leiden tot ziekte. Het vierde kenmerk van de dragerschapstest waarbinnen variaties mogelijk zijn, is het aantal en type genen waarop getest wordt.

U kunt een keuze maken uit pakket 1-3, waarbij pakket 1 het minst uitgebreide pakket is, en er bij ieder pakket extra genen bij komen waarop getest wordt. Hieronder worden de paketten uitgebreid toegelicht:

Als u meer informatie zoekt over het de onderstreepte woorden, beweeg dan met uw muis over het woord (mits u deze vragenlijst op een computer invult).

**- Pakket 1**

Met dit genenpakket wordt getest op genen die leiden tot aandoeningen die door de meeste mensen worden gezien als ernstige aandoeningen. Voorbeelden hiervan zijn: Pontocerebellaire hypoplasie en de ziekte van Parkinson.

**- Pakket 2**

Dit genenpakket bestaat uit alle genen die in pakket 1 getest werden (ernstige aandoeningen) in combinatie aandoeningen die door de meeste mensen worden gezien als milde aandoeningen. Voorbeelden hiervan waren: doofheid en Miyoshi spierdystrofie.

**- Pakket 3**

Dit genenpakket bestaat uit alle genen die in pakket 2 (en 1) getest werden (ernstige en milde aandoeningen) in combinatie met genen die niet leiden tot ziekte, maar bijvoorbeeld kijken naar oogkleur, atletisch zijn, haarkleur, muzikaliteit.

Samenvattend:

**- Pakket 1: testen op ernstige aandoeningen**

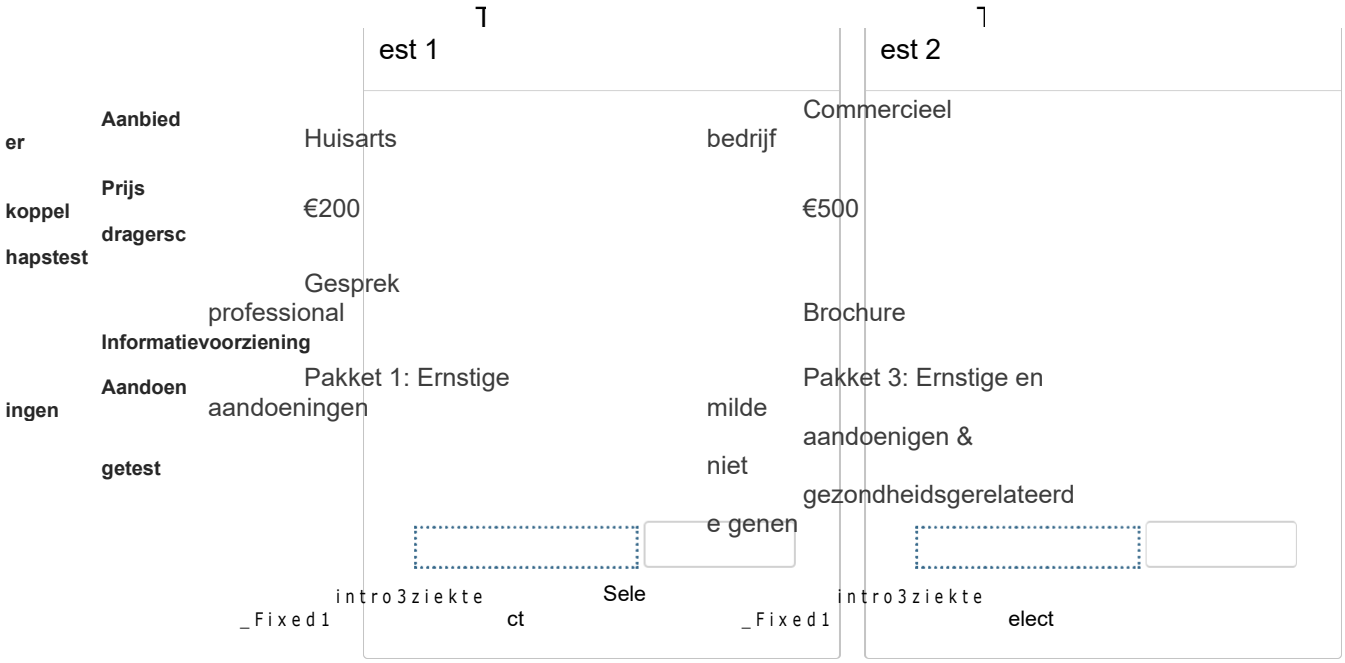
**- Pakket 2: testen op ernstige en milde aandoenigen**
**(Pakket 1 + milde aandoeningen)**

**- Pakket 3: testen op ernstige en milde aandoeningen en niet gezondheidsgeralateerde eigenschappen**
**(Pakket 1 + 2 + niet gezondheidsgeralateerde eigenschappen)**

**Voorbeeldvraag**:

Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

(1 of 1)




Geen test

Ik zou geen van beide tests ondergaan

intro3ziekte_Fixed1

Select

Teru

Volgende

intro4nauwkeurigheid_Fixed1

**Nauwkeurigheid**

Het vijfde kenmerk van de dragerschapstest waarbinnen variaties mogelijk zijn, is de nauwkeurigheid van de test. Door de verschillende technieken die gebruikt kunnen worden voor genetische testen, kan de nauwkeurigheid verschillen. Een foute uitslag kent geen gezondheidsklachten voor het individu maar brengt wel veel onnodige zorgen.

Binnen dit onderzoek wordt de nauwkeurigheid beschreven aan de hand van het aantal testen dat de correcte uitslag geeft. De uitslag van de test kan op twee manieren incorrect zijn:

- Fout-positief: De uitslag van de test is positief (volgens de test zijn beide partners in het stel drager van één of meer dezelfde geteste ziekten), maar de partners zijn in werkelijkheid geen drager van één of meer dezelfde geteste aandoeningen.

- Fout-negatief: De uitslag van de test is negatief (volgens de test zijn beide partners in het stel geen drager van één of meer dezelfde geteste ziekten), maar de partners zijn in werkelijkheid wel drager van één of meer dezelfde geteste aandoeningen.

Een voorbeeld hiervan zou kunnen zijn: 95 van de 100 tests is correct.
Dit zou dus betekenen dat 5 van de 100 tests de incorrecte uitslag geeft, wat gelijk is aan 1 op de 20 tests.

**Voorbeeldvraag**:

Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

(1 of 1)

| | Test 1 | Test 2 |
|---|---|---|
| **Aanbieder koppeldragerschapstest** | Verloskundige | Verloskundige |
| **Prijs** | €200 | €500 |
| **Informatievoorziening** | Gesprek professional | Gesprek professional |
| **Aandoeningen getest** | Pakket 2: Ernstige en milde aandoenigen | Pakket 2: Ernstige en milde aandoenigen |
| **Nauwkeurigheid** | 99 uit 100 tests correcte uitslag | 91 uit 100 tests correcte uitslag |


intro4nauwkeurigheid_Fixed1 Select


intro4nauwkeurigheid_Fixed1 Select

Geen test

Ik zou geen van beide tests ondergaan

intro4nauwkeurigheid_Fixed1

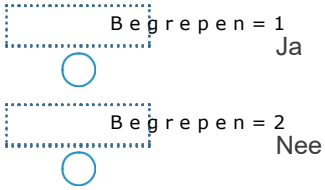
Select

Teru

Volgende

Begrepen

Heeft u de uitleg goed begrepen?




Ter Volgende

Dominant

Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Dominant=1

Test 1

Prijs: €50 euro
Nauwkeurigheid: 99 uit 100 tests correcte uitslag

Dominant=2

Test 2

Prijs: €1000 euro
Nauwkeurigheid: 95 uit 100 tests correcte uitslag

Dominant=3

Geen test

Ter

Volgende

Dominantfout

U heeft gekozen voor een test waarbij u meer betaalt, terwijl de betrouwbaarheid van de test minder hoog is. Zou u daadwerkelijk meer willen betalen voor een minder betrouwbare test?

Dominantfout = 1
Ja

Dominantfout = 2
Nee

Ter

Volgende

Dominantgeenkeuze

U heeft ervoor gekozen geen van beide testen te ondergaan. Weet u zeker dat u geen van beide tests zou willen ondergaan als de ene optie de meest goedkope optie is (€50 euro) met de hoogst mogelijke betrouwbaarheid (100 uit 100 tests correcte uitslag)?

Dominantgeenkeuze = 1
Ja

Dominantgeenkeuze = 2
Nee

Ter

Volgende

Vastekenmerken

U heeft nu ~~kennis~~ gemaakt met alle karakteristieken van de dragerschapstest die kunnen variëren. De belangrijkste kenmerken die **niet variëren** zetten we hier op een rijtje:

- Dragerschapstest wordt voorafgaand aan de zwangerschap uitgevoerd.

- Om de test te kunnen uitvoeren hoeft er enkel bloed te worden afgenomen bij u en uw partner.

- De test geeft u informatie over de genen waar u en uw partner allebei drager van zijn. U mag daarna zelf beslissen wat u met deze informatie wil doen.

- Een positieve test (u en uw partner zijn beiden drager) zal altijd worden opgevolgd door een gesprek met een erfelijkheidsarts.

Startkeuzetaken

Er volgen nu 13 keuzetaken, waarin we u steeds willen vragen om de optie te kiezen die het meest uw voorkeur heeft: test 1, test 2 of geen test.

Teru Volgende

CBCblock1_Fixed1

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken), klik dan op deze link.

(1 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| Aanbieder | Verloskundige | Commercieel bedrijf |
| Prijs | €1000 | €500 |
| Informatievoorziening | Brochure | Website |
| Aandoeningen getest | Pakket 1: Ernstige aandoeningen | Pakket 3: Niet gezondheidsgerelateerde genen en ernstige en milde aandoenigen |
| Nauwkeurigheid uitslag | 91 uit 100 tests correcte uitslag | 95 uit 100 tests correcte uitslag |
| | CBCblock1_Fixed1Selecteer | CBCblock1_Fixed1Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock1_Fixed1 Selecteer |

Teru Volgende

CBCblock1_Fixed2

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken), klik dan op deze link.

(2 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| Aanbieder | Medisch specialist | Verloskundige |
| Prijs | €500 | €1000 |
| Informatievoorziening | Gesprek professional | Brochure |
| Aandoeningen getest | Pakket 3: Niet gezondheidsgerelateerde genen en ernstige en milde aandoenigen | Pakket 2: Ernstige en milde aandoeningen |
| Nauwkeurigheid | 95 uit 100 tests correcte uitslag | 99 uit 100 tests correcte uitslag |
| | CBCblock1_Fixed2Selecteer | CBCblock1_Fixed2Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock1_Fixed2 Selecteer |

Teru Volgende

CBCblock1_Fixed3

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken), klik dan op deze link.

(3 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| Aanbieder | Huisarts | Medisch specialist |
| Prijs | €500 | €200 |
| Informatievoorziening | Gesprek professional | Website |
| Aandoeningen getest | Pakket 3: Niet gezondheidsgerelateerde genen en ernstige en milde aandoenigen | Pakket 1: Ernstige aandoeningen |
| Nauwkeurigheid | 99 uit 100 tests correcte uitslag | 95 uit 100 tests correcte uitslag |
| | CBCblock1_Fixed3Selecteer | CBCblock1_Fixed3Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock1_Fixed3 Selecteer |

Teru Volgende

CBCblock1_Fixed4

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken), klik dan op deze link.

(4 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| **Aanbieder** | Medisch specialist | Huisarts |
| **Prijs** | €1000 | €200 |
| **Informatievoorziening** | Gesprek professional | Brochure |
| **Aandoeningen getest** | Pakket 1: Ernstige aandoeningen | Pakket 2: Ernstige en milde aandoeningen |
| **Nauwkeurigheid** | 99 uit 100 tests correcte uitslag | 91 uit 100 tests correcte uitslag |
| | CBCblock1_Fixed4Selecteer | CBCblock1_Fixed 4Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock1_Fixed4 Selecteer |

Teru Volgende

CBCblock1_Fixed5

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken), klik dan op deze link.

(5 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| **Aanbieder** | Verloskundige | Medisch specialist |
| **Prijs** | €200 | €500 |
| **Informatievoorziening** | Gesprek professional | Website |
| **Aandoeningen getest** | Pakket 2: Ernstige en milde aandoeningen | Pakket 1: Ernstige aandoeningen |
| **Nauwkeurigheid uitslag** | 91 uit 100 tests correcte uitslag | 99 uit 100 tests correcte uitslag |
| | CBCblock1_Fixed5Selecteer | CBCblock1_Fixed 5Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock1_Fixed5 Selecteer |

Teru Volgende

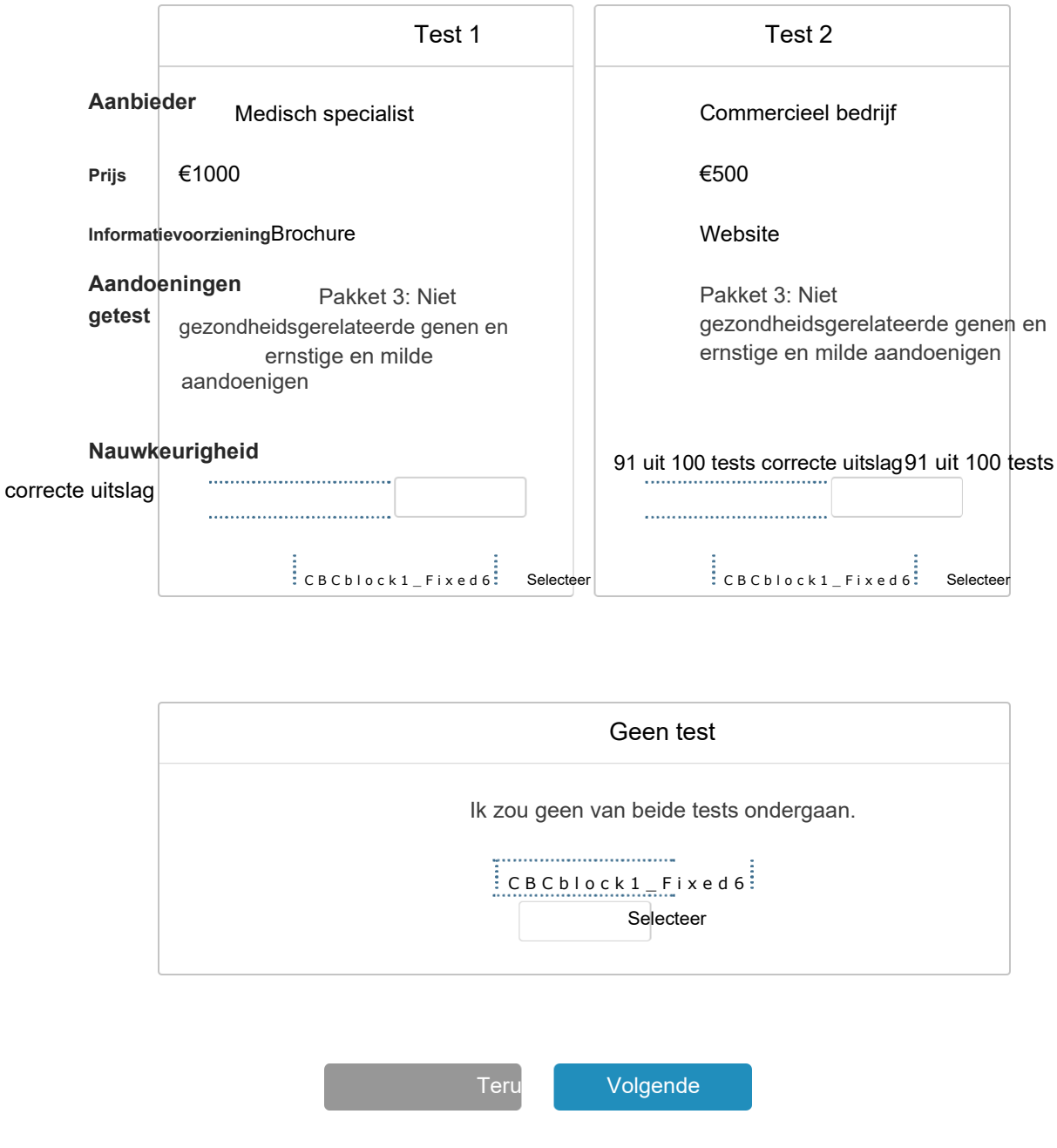
CBCblock1_Fixed6

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken), klik dan op deze link.

(6 of 13)







Teru Volgende

CBCblock1_Fixed7

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken), klik dan op deze link.

(7 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| **Aanbieder** | Commercieel bedrijf | Huisarts |
| **Prijs** | €500 | €200 |
| **Informatievoorziening** | Website | Gesprek professional |
| **Aandoeningen getest** | Pakket 2: Ernstige en milde aandoeningen | Pakket 3: Niet gezondheidsgerelateerde genen en ernstige en milde aandoenigen |
| **Nauwkeurigheid uitslag** | 99 uit 100 tests correcte uitslag | 91 uit 100 tests correcte uitslag |
| | CBCblock1_Fixed7Selecteer | CBCblock1_Fixed7Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock1_Fixed7 Selecteer |

Teru Volgende

tussenvraagblock1

U bent op de helft van de keuzetaken, wat vind u van de vragenlijst tot nu toe? Meerdere antwoorden zijn mogelijk.

tussenvraagblock1_1
- [ ] Informatief

tussenvraagblock1_2
- [ ] Interessant

tussenvraagblock1_3
- [ ] Plezierig

tussenvraagblock1_4
- [ ] Lang

tussenvraagblock1_5
- [ ] Geen van de mogelijke antwoorden

Ter Volgende

CBCblock1_Fixed8

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken), klik dan op deze link.

(8 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| Aanbieder | Commercieel bedrijf | Huisarts |
| Prijs | €200 | €1000 |
| Informatievoorziening | Brochure | Gesprek professional |
| Aandoeningen getest | Pakket 1: Ernstige aandoeningen | Pakket 2: Ernstige en milde aandoeningen |
| Nauwkeurigheid uitslag | 99 uit 100 tests correcte uitslag | 91 uit 100 tests correcte uitslag |
| | CBCblock1_Fixed8Selecteer | CBCblock1_Fixed 8Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock1_Fixed8 Selecteer |

Teru Volgende

CBCblock1_Fixed9

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken), klik dan op deze link.

(9 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| **Aanbieder** | Huisarts | Verloskundige |
| **Prijs** | €1000 | €200 |
| **Informatievoorziening** | Brochure | Website |
| **Aandoeningen getest** | Pakket 3: Niet gezondheidsgerelateerde genen en ernstige en milde aandoenigen | Pakket 1: Ernstige aandoeningen |
| **Nauwkeurigheid** | 95 uit 100 tests correcte uitslag | 91 uit 100 tests correcte uitslag |
| | CBCblock1_Fixed9Selecteer | CBCblock1_Fixed9Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock1_Fixed9 Selecteer |

Teru Volgende

CBCblock1_Fixed10

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken), klik dan op deze link.

(10 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| **Aanbieder** | Medisch specialist | Verloskundige |
| **Prijs** | €200 | €500 |
| **Informatievoorziening** | Brochure | Gesprek professional |
| **Aandoeningen getest** | Pakket 2: Ernstige en milde aandoeningen | Pakket 3: Niet gezondheidsgerelateerde genen en ernstige en milde aandoenigen |
| **Nauwkeurigheid uitslag** | 95 uit 100 tests correcte uitslag | 99 uit 100 tests correcte uitslag |
| | CBCblock1_Fixed10 Selecteer | CBCblock1_Fixed10 Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock1_Fixed10 Selecteer |

Teru Volgende

CBCblock1_Fixed11

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken), klik dan op deze link.

(11 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| **Aanbieder** | Verloskundige | Medisch specialist |
| **Prijs** | €500 | €1000 |
| **Informatievoorziening** | Website | Gesprek professional |
| **Aandoeningen getest** | Pakket 2: Ernstige en milde aandoeningen | Pakket 1: Ernstige aandoeningen |
| **Nauwkeurigheid uitslag** | 95 uit 100 tests correcte uitslag | 99 uit 100 tests correcte uitslag |
| | CBCblock1_Fixed11Selecteer | CBCblock1_Fixed11Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock1_Fixed11 Selecteer |

Teru Volgende

CBCblock1_Fixed12

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken), klik dan op deze link.

(12 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| **Aanbieder** | Verloskundige | Commercieel bedrijf |
| **Prijs** | €200 | €1000 |
| **Informatievoorziening** | Website | Gesprek professional |
| **Aandoeningen getest** | Pakket 1: Ernstige aandoeningen | Pakket 2: Ernstige en milde aandoeningen |
| **Nauwkeurigheid uitslag** | 91 uit 100 tests correcte uitslag | 99 uit 100 tests correcte uitslag |
| | CBCblock1_Fixed12Selecteer | CBCblock1_Fixed12Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock1_Fixed12 Selecteer |

Teru Volgende

CBCblock1_Fixed13

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken), klik dan op deze link.

(13 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| Aanbieder | Verloskundige | Commercieel bedrijf |
| Prijs | €1000 | €500 |
| Informatievoorziening | Brochure | Website |
| Aandoeningen getest | Pakket 1: Ernstige aandoeningen | Pakket 3: Niet gezondheidsgerelateerde genen en ernstige en milde aandoenigen |
| Nauwkeurigheid uitslag | 91 uit 100 tests correcte uitslag | 95 uit 100 tests correcte uitslag |
| | CBCblock1_Fixed13Selecteer | CBCblock1_Fixed13Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock1_Fixed13 Selecteer |

Teru Volgende

CBCblock1Fixed14_Fixed1

Dit is de laatste keuzetaak. De opties zijn iets anders dan de opties bij de eerdere keuzetaken. U hoeft bij deze keuzetaak alleen te letten op de prijs en de nauwkeurigheid van de test (de andere kenmerken zijn gelijk voor beiden tests).

De vraag aan u is echter hetzelfde:

**Welke van de drie opties zou u kiezen?**

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken, klik dan op deze link.

(1 of 1)

| | Test 1 | Test 2 |
|---|---|---|
| **Nauwkeurigheid** | 99 uit 100 tests correcte uitslag | 50 uit 100 tests correcte uitslag |
| **Prijs** | €1000 | €100 |
| | CBCblock1Fixed14_Fixed1 Select | Select CBCblock1Fixed14_Fixed1 |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock1Fixed14_Fixed1 Select |

Teru Volgende

Vastekenmerken1

U heeft nu kennis gemaakt met alle karakteristieken van de dragerschapstest die kunnen variëren. De belangrijkste kenmerken die **niet variëren** zetten we hier op een rijtje:

- Dragerschapstest wordt voorafgaand aan de zwangerschap uitgevoerd

- Om de test te kunnen uitvoeren hoeft er enkel bloed te worden afgenomen bij u en uw partner

- De test geeft u informatie over de genen waar u en uw partner drager van zijn. U mag daarna zelf beslissen wat u met deze informatie wil doen.

- Een positieve test (u en uw partner zijn beiden drager) zal altijd worden opgevolgd door een gesprek met een erfelijkheidsarts.

infodceblock2

Er volgen nu 13 keuzetaken, waarin we u steeds willen vragen om de optie te kiezen die het meest uw voorkeur heeft: test 1, test 2 of geen test.

Teru Volgende

CBCblock2_Fixed1

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken, klik dan op deze link.

(1 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| Aanbieder | Commercieel bedrijf | Commercieel bedrijf |
| Prijs | €1000 | €1000 |
| Informatievoorziening | Gesprek professional | Brochure |
| Aandoeningen getest | Pakket 3: Niet gezondheidsgerelateerde genen en ernstige en milde aandoenigen | Pakket 1: Ernstige aandoeningen |
| Nauwkeurigheid | 91 uit 100 tests correcte uitslag | 91 uit 100 tests correcte uitslag |
| | CBCblock2_Fixed1Selecteer | CBCblock2_Fixed1Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock2_Fixed1 Selecteer |

Teru Volgende

CBCblock2_Fixed2

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken, klik dan op deze link.

(2 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| **Aanbieder** | Huisarts | Verloskundige |
| **Prijs** | €1000 | €200 |
| **Informatievoorziening** | Website | Brochure |
| **Aandoeningen getest** | Pakket 2: Ernstige en milde aandoeningen | Pakket 3: Niet gezondheidsgerelateerde genen en ernstige en milde aandoenigen |
| **Nauwkeurigheid uitslag** | 95 uit 100 tests correcte uitslag | 99 uit 100 tests correcte uitslag |
| | CBCblock2_Fixed2Selecteer | CBCblock2_Fixed2Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock2_Fixed2Selecteer |

Teru Volgende

CBCblock2_Fixed3

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken, klik dan op deze link.

(3 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| Aanbieder | Huisarts | Medisch specialist |
| Prijs | €500 | €200 |
| Informatievoorziening | Brochure | Gesprek professional |
| Aandoeningen getest | Pakket 1: Ernstige aandoeningen | Pakket 3: Niet gezondheidsgerelateerde genen en ernstige en milde aandoenigen |
| Nauwkeurigheid uitslag | 99 uit 100 tests correcte uitslag | 95 uit 100 tests correcte uitslag |
| | CBCblock2_Fixed3Selecteer | CBCblock2_Fixed3Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock2_Fixed3 Selecteer |

Teru Volgende

CBCblock2_Fixed4

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken, klik dan op deze link.

(4 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| **Aanbieder** | Verloskundige | Huisarts |
| **Prijs** | €500 | €200 |
| **Informatievoorziening** | Gesprek professional | Website |
| **Aandoeningen getest** | Pakket 2: Ernstige en milde aandoeningen | Pakket 3: Niet gezondheidsgerelateerde genen en ernstige en milde aandoenigen |
| **Nauwkeurigheid uitslag** | 95 uit 100 tests correcte uitslag | 99 uit 100 tests correcte uitslag |
| | CBCblock2_Fixed4Selecteer | CBCblock2_Fixed4Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock2_Fixed4 Selecteer |

Teru Volgende

CBCblock2_Fixed5

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken, klik dan op deze link.

(5 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| Aanbieder | Verloskundige | Medisch specialist |
| Prijs | €200 | €500 |
| Informatievoorziening | Website | Gesprek professional |
| Aandoeningen getest | Pakket 3: Niet gezondheidsgerelateerde genen en ernstige en milde aandoenigen | Pakket 2: Ernstige en milde aandoeningen |
| Nauwkeurigheid | 95 uit 100 tests correcte uitslag | 91 uit 100 tests correcte uitslag |
| | CBCblock2_Fixed5Selecteer | CBCblock2_Fixed5Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock2_Fixed5 Selecteer |

Teru Volgende

CBCblock2_Fixed6

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken, klik dan op deze link.

(6 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| Aanbieder | Huisarts | Verloskundige |
| Prijs | €200 | €1000 |
| Informatievoorziening | Brochure | Website |
| Aandoeningen getest | Pakket 1: Ernstige aandoeningen | Pakket 2: Ernstige en milde aandoeningen |
| Nauwkeurigheid uitslag | 91 uit 100 tests correcte uitslag | 99 uit 100 tests correcte uitslag |
| | CBCblock2_Fixed6Selecteer | CBCblock2_Fixed 6Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock2_Fixed6 Selecteer |

Teru Volgende

CBCblock2_Fixed7

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken, klik dan op deze link.

(7 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| Aanbieder | Commercieel bedrijf | Medisch specialist |
| Prijs | €1000 | €500 |
| Informatievoorziening | Gesprek professional | Brochure |
| Aandoeningen getest | Pakket 1: Ernstige aandoeningen | Pakket 2: Ernstige en milde aandoeningen |
| Nauwkeurigheid uitslag | 95 uit 100 tests correcte uitslag | 91 uit 100 tests correcte uitslag |
| | CBCblock2_Fixed 7Selecteer | CBCblock2_Fixed 7Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock2_Fixed7 Selecteer |

Teru Volgende

tussenvraagblock2

U bent op de helft van de keuzetaken, wat vind u van de vragenlijst tot nu toe? Meerdere antwoorden zijn mogelijk.

tussenvraagblock2_1
- [ ] Informatief

tussenvraagblock2_2
- [ ] Interessant

tussenvraagblock2_3
- [ ] Plezierig

tussenvraagblock2_4
- [ ] Lang

tussenvraagblock2_5
- [ ] Geen van de mogelijke antwoorden

Ter Volgende

CBCblock2_Fixed8

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken, klik dan op deze link.

(8 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| **Aanbieder** | Medisch specialist | Huisarts |
| **Prijs** | €500 | €1000 |
| **Informatievoorziening** | Brochure | Website |
| **Aandoeningen getest** | Pakket 3: Niet gezondheidsgerelateerde genen en ernstige en milde aandoenigen | Pakket 1: Ernstige aandoeningen |
| **Nauwkeurigheid** | 99 uit 100 tests correcte uitslag | 95 uit 100 tests correcte uitslag |
| | CBCblock2_Fixed8Selecteer | CBCblock2_Fixed8Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock2_Fixed8 Selecteer |

Teru Volgende

CBCblock2_Fixed9

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken, klik dan op deze link.

(9 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| Aanbieder | Commercieel bedrijf | Verloskundige |
| Prijs | €200 | €500 |
| Informatievoorziening | Website | Brochure |
| Aandoeningen getest | Pakket 2: Ernstige en milde aandoeningen | Pakket 1: Ernstige aandoeningen |
| Nauwkeurigheid uitslag | 99 uit 100 tests correcte uitslag | 95 uit 100 tests correcte uitslag |
| | CBCblock2_Fixed9Selecteer | CBCblock2_Fixed 9Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock2_Fixed9 Selecteer |

Teru Volgende

CBCblock2_Fixed10

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken, klik dan op deze link.

(10 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| Aanbieder | Medisch specialist | Commercieel bedrijf |
| Prijs | €1000 | €500 |
| Informatievoorziening | Website | Gesprek professional |
| Aandoeningen getest | Pakket 3: Niet gezondheidsgerelateerde genen en ernstige en milde aandoenigen | Pakket 1: Ernstige aandoeningen |
| Nauwkeurigheid | 99 uit 100 tests correcte uitslag | 95 uit 100 tests correcte uitslag |
| | CBCblock2_Fixed10Selecteer | CBCblock2_Fixed10Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock2_Fixed10 Selecteer |

Teru Volgende

CBCblock2_Fixed11

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken, klik dan op deze link.

(11 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| **Aanbieder** | Commercieel bedrijf | Huisarts |
| **Prijs** | €200 | €1000 |
| **Informatievoorziening** | Gesprek professional | Brochure |
| **Aandoeningen getest** | Pakket 2: Ernstige en milde aandoeningen | Pakket 3: Niet gezondheidsgerelateerde genen en ernstige en milde aandoenigen |
| **Nauwkeurigheid uitslag** | 91 uit 100 tests correcte | 95 uit 100 tests correcte |
| | CBCblock2_Fixed11 Selecteer | CBCblock2_Fixed11 Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock2_Fixed11 Selecteer |

Teru Volgende

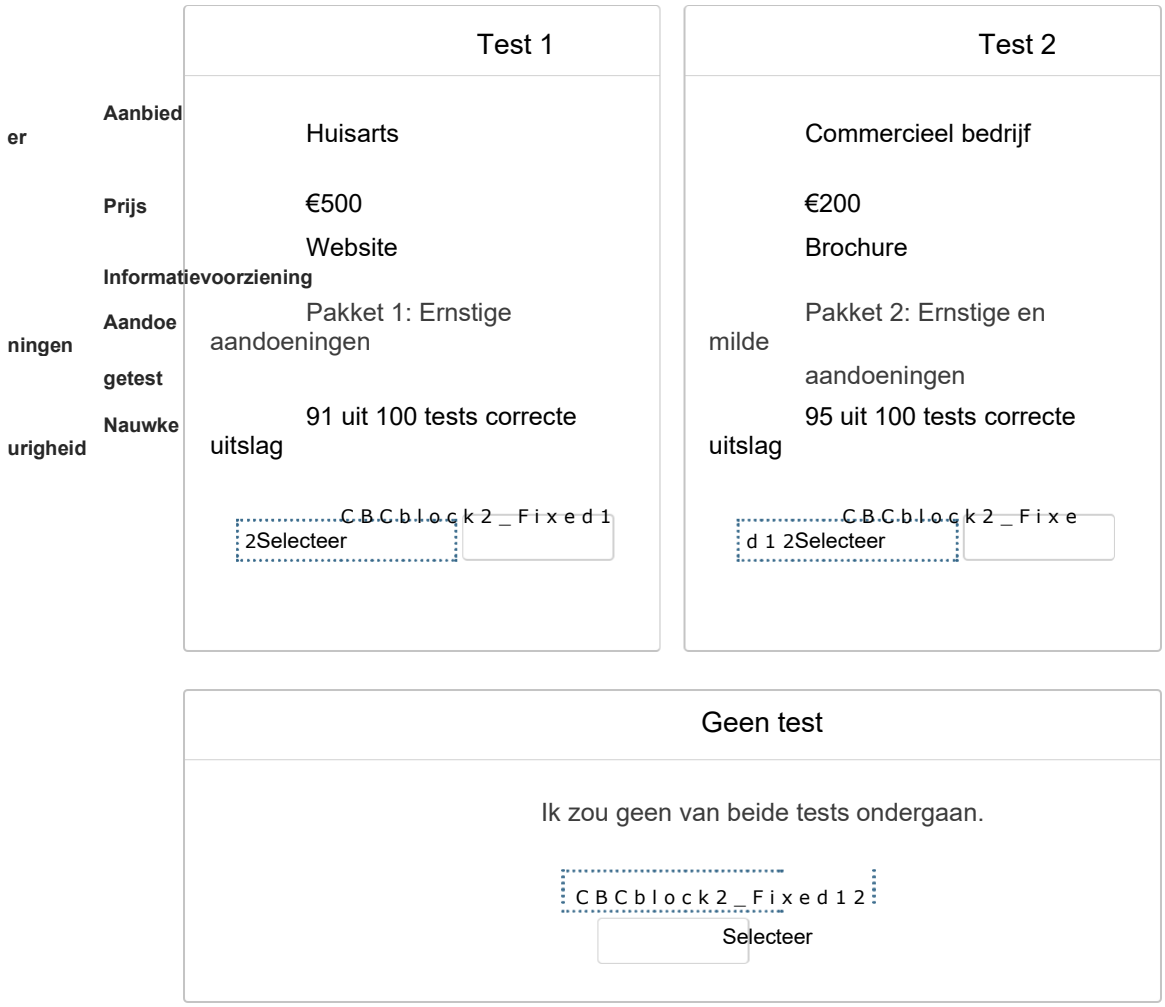
CBCblock2_Fixed12

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken, klik dan op deze link.

(12 of 13)




Teru Volgende

CBCblock2_Fixed13

## Wij zijn benieuwd naar uw voorkeur: welke van de drie opties zou u kiezen?

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken, klik dan op deze link.

(13 of 13)

| | Test 1 | Test 2 |
|---|---|---|
| Aanbieder | Huisarts | Verloskundige |
| Prijs | €200 | €1000 |
| Informatievoorziening | Brochure | Website |
| Aandoeningen getest | Pakket 1: Ernstige aandoeningen | Pakket 2: Ernstige en milde aandoeningen |
| Nauwkeurigheid uitslag | 91 uit 100 tests correcte uitslag | 99 uit 100 tests correcte uitslag |
| | CBCblock2_Fixed13Selecteer | CBCblock2_Fixed13Selecteer |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock2_Fixed13 Selecteer |

Teru Volgende

CBCblock2fixed14_Fixed1

Dit is de laatste keuzetaak. De opties zijn iets anders dan de opties bij de eerdere keuzetaken. U hoeft bij deze keuzetaak alleen te letten op de prijs en de nauwkeurigheid van de test (de andere kenmerken zijn gelijk voor beiden tests).

De vraag aan u is echter hetzelfde:

**Welke van de drie opties zou u kiezen?**

Als u meer informatie zoekt over het kenmerk, beweeg dan met uw muis over het kenmerk (mits u deze vragenlijst op een computer invult).

Als u (een deel) van de hiervoor gegeven informatie opnieuw informatie wil lezen (over de dragerschapstest of kenmerken, klik dan op deze link.

(1 of 1)

| | Test 1 | Test 2 |
|---|---|---|
| **Nauwkeurigheid** | 99 uit 100 tests correcte uitslag | 50 uit 100 tests correcte uitslag |
| **Prijs** | €1000 | €100 |
| | CBCblock2fixed14_Fixed1 Select | Select CBCblock2fixed14_Fixed1 |

| Geen test |
|---|
| Ik zou geen van beide tests ondergaan. |
| CBCblock2fixed14_Fixed1 Select |

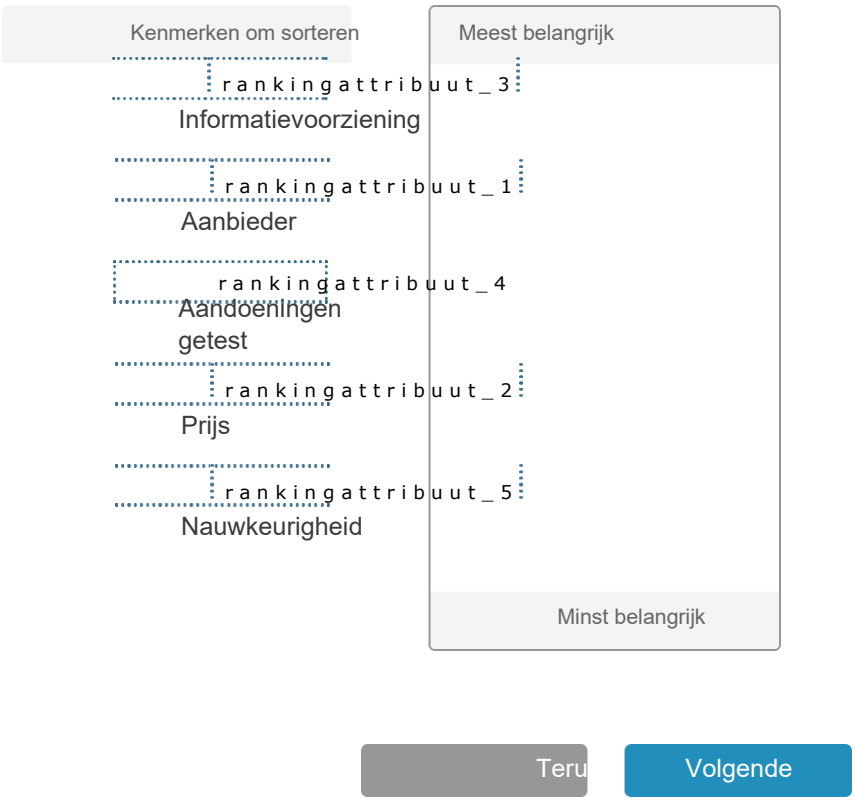
Teru Volgende

rankingattribuut

## Rangschikking kenmerken

Wat zijn voor u de belangrijkste en minst belangrijke kenmerken bij uw keuze voor een bepaalde test?

Sorteer de kenmerken op basis van hoe belangrijk u deze vindt, waarbij u het meest belangrijke kenmerk bovenaan zet, en het minst belangrijke kenmerk onderaan. Om dit te doen, sleep de kenmerken van het linkervak naar het rechtervak en zet ze op de voor u juiste volgorde.




Teru Volgende

veelskip

U heeft in meer dan drie keuzetaken gekozen voor 'Geen test'. Wat was uw reden hiervoor?

veelskip=1 Prijs te hoog in beide opties

veelskip=2 Betrouwbaarheid te laag in beide opties

veelskip=3 veelskip_3_other Anders, namelijk:

Ter Volgende

Eindkeuzetaken

U heeft nu alle keuzetaken afgerond. Hartelijk bedankt hiervoor!

De laatste vragen zullen gaan over wat uw mening is over deze vragenlijst.

Teru | Volgende

Evaluatieeind

**Wat vond u van de vragenlijst?**

| | Helemaal niet mee eens | Niet mee eens | Neutraal | Mee eens | Helemaal mee eens |
|---|---|---|---|---|---|
| Ik kon makkelijk een keuze maken tussen de verschillende opties | Evaluatieeind_r1=1 | Evaluatieeind_r1=2 | Evaluatieeind_r1=3 | Evaluatieeind_r1=4 | Evaluatieeind_r1=5 |
| Ik heb alle karakteristieken van de dragerschapstest meegenomen in de keuzes | Evaluatieeind_r2=1 | Evaluatieeind_r2=2 | Evaluatieeind_r2=3 | Evaluatieeind_r2=4 | Evaluatieeind_r2=5 |
| Ik heb door het invullen van deze vragenlijst een beter inzicht gekregen in mijn voorkeuren voor de kenmerken van de dragerschapstest | Evaluatieeind_r3=1 | Evaluatieeind_r3=2 | Evaluatieeind_r3=3 | Evaluatieeind_r3=4 | Evaluatieeind_r3=5 |
| Ik zou nog een keer deelnemen aan een soortgelijk onderzoek | Evaluatieeind_r4=1 | Evaluatieeind_r4=2 | Evaluatieeind_r4=3 | Evaluatieeind_r4=4 | Evaluatieeind_r4=5 |
| Alle belangrijke karakteristieken van een dragerschapstest worden meegenomen in dit onderzoek | Evaluatieeind_r5=1 | Evaluatieeind_r5=2 | Evaluatieeind_r5=3 | Evaluatieeind_r5=4 | Evaluatieeind_r5=5 |

Karakteristieken

Zijn er nog bepaalde karakteristieken van een dragerschapstest die naar uw mening moeten worden meegenomen in dit onderzoek (en nu nog niet meegenomen zijn)?

Karakteristieken = 1
Ja

Karakteristieken = 2
Nee

Ter Volgende

Karakteristiekenopen

Welke karakteristieken zijn dit?

Teru

Volgende

Duidelijk

Waren de instructies bij de vragenlijst duidelijk?

Duidelijk=1 Ja

Duidelijk=2 Een beetje

Duidelijk=3 Nee

Ter Volgende

watnietduidelijk

Welke dingen waren onduidelijk? Hoe zouden wij dit kunnen verbeteren?

Teru Volgende

watnietduidelijk1

Welke dingen waren onduidelijk? Hoe zouden wij dit kunnen verbeteren?

Teru Volgende

openeva

Heeft u nog opmerkingen over deze vragenlijst?

Teru

Volgende

Einde

Note:

When respondents take the survey in regular mode this page will not be displayed. Respondents will be redirected to the link below:

http://dkr1.ssisurveys.com/projects/end?rst=2&psid=[Script]&pid=[Script]

Einde1

Note:

When respondents take the survey in regular mode this page will not be displayed. Respondents will be redirected to the link below:

https://dkr1.ssisurveys.com/projects/end?rst=1&psid=[Script]&basic=55865&compflag=2

Einde2

Note:

When respondents take the survey in regular mode this page will not be displayed. Respondents will be redirected to the link below:

https://dkr1.ssisurveys.com/projects/end?rst=1&psid=[Script]&basic=55865&compflag=3