

PATIENT PREFERENCES FOR DURATION AND PLANNING OF DIAGNOSIS AND START OF TREATMENT IN CANCER

A quantitative study

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HEALTH SCIENCES

Master thesis

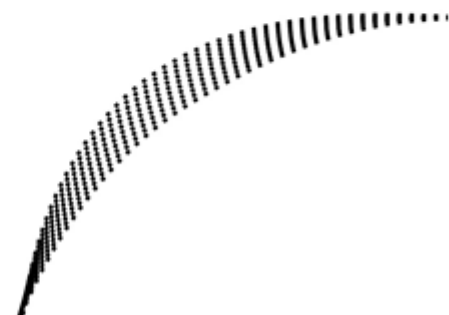
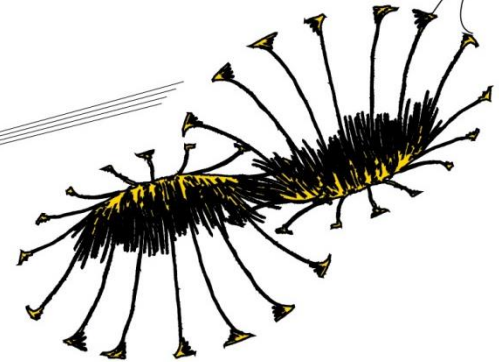
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ABSTRACT

INTRODUCTION. Waiting times in the diagnostic process of cancer can be stressful for patients. Rapid diagnostics is a possible solution for this problem. Several studies investigated the effects of rapid diagnostics on cancer patients, but almost no research is done regarding patients' preferences for rapid diagnostics. Therefore, this study aims to assess patient preferences for duration and planning of diagnosis and start of treatment in cancer.

METHOD. Post-operative breast cancer and colorectal cancer patients from Ziekenhuisgroep Twente and Slingeland Ziekenhuis were invited to fill in a questionnaire. In the questionnaire patients' preferences are asked directly, by means of open and multiple choice questions and indirectly, by means of Best Worst Scaling (BWS) case 2. Logistic regression is used to identify predictors for preferences regarding rapid diagnostics. Conditional logistic regression is used to analyse the BWS data. Distribution of scores is studied by calculating normalized Best-Minus-Worst counts. Subgroup analyses were performed for the variables type of cancer, age and work situation, by comparing attribute importance between subgroups.

RESULTS. 81 patients filled in the questionnaire, whereof 69 patients filled in the questionnaire completely. 91.4% of patients has a preference for rapid diagnostics. Simple logistic regression indicated that willingness to travel longer for a faster diagnosis is predicted by age. Patients who are 64 years or younger are more willing to travel longer than patients who are 65 years or older. Multivariate logistic regression indicated that preference for rapid diagnostics is predicted by cancer type. Breast cancer patients have a stronger preference for rapid diagnostics than colorectal cancer patients. The attribute 'number of hospital visits' is most important for patients and based on the coefficients, patients find it most positive to need one hospital visit for diagnosis. Waiting time between the treatment proposal and start of treatment is the least important attribute for patients. Best-Minus-Worst counts indicated that patients especially disagree about five medical examinations per day (A3_L3), three professionals (A4_L2) and five working days between diagnosis and treatment proposal (A6_L3). Subgroup analyses indicated some notable differences. Patients who are 65 years or older find it more important to have one own professional and 30 minutes travel time to hospital than patients who are 64 years or younger. Patients who do not work find travel time to hospital more important than patients who have a job. Colorectal cancer patients find it more important to have one own professional than breast cancer patients.

CONCLUSION. Taking the limitations of this study into account, it can be concluded that breast and colorectal cancer patients are willing to make concessions in order to get their diagnosis on the same day as when medical examinations take place and to get their treatment proposal as soon as possible. These concessions are traveling longer, having conversations with the professional who is available at that moment and having as much as possible medical examinations on one day. Important differences found between patients groups are that breast cancer patients have a stronger preference for rapid diagnostics than colorectal cancer patients and patients who are 64 years or younger are more willing to travel longer for a faster diagnosis than patients who are 65 or older.

KEY WORDS. Cancer, Waiting time, Rapid diagnostics, Patient preferences, Diagnosis, Start of treatment, Best Worst Scaling

INTRODUCTION

Incidence of cancer

More and more people are diagnosed with cancer in the Netherlands. Incidence of cancer was 104.000 in 2014, which is an increase of 2% compared with 2013. For the coming years an increase in incidence of 3% per year is expected. Amongst others this increase in incidence is due to early detection of cancer and ageing (1). Due to ageing, people live longer, which increases the risk of cancer. Due to early detection of cancer, more people are detected with suspected cancer. Early detection of cancer takes place by means of screening programmes. In the Netherlands, screening programmes are implemented for breast, colorectal and cervical cancer (2). Yearly about 700.000 people with suspected cancer go through the diagnostic process of cancer (3). Because the number of people with suspected cancer increases and the resources for diagnostics do not, there is more demand than available supply for diagnostics in cancer. This causes waiting times in the diagnostic process, which are especially caused by diagnostic imaging (4).

Waiting times

Waiting time is the time that elapses from the time an appointment is made until the real performance of activities in the context of diagnostics and/or treatment (4). A distinction can be made between normative and real waiting times. The normative waiting time is the predetermined maximum time allowed to elapse before an activity or set of activities of diagnostics and/or treatment starts. The real waiting time can be measured afterwards. Except waiting times, there is also time needed for performance of the activities of diagnostics and/or treatment. This time is described as turnaround time (4).

According to normative waiting times for diagnostics in cancer, a patient should be able to turn to a specialist within five working days after referral by the general practitioner (GP). Subsequently within ten working days a treatment has to be proposed to the patient and the chosen treatment has to start within fifteen working days after the moment the treatment is proposed (4). According to real waiting times, only about 40% of cancer patients were able to turn to a specialist within five working days. Slightly more than half of patients got their diagnosis and treatment proposal within ten working days. Other patients had to wait longer in order to turn to a specialist and to get their diagnosis (5). When looking at different types of cancer, it appears that especially colorectal cancer patients experience waiting times. Colorectal cancer patients have to deal with a time interval of approximately 34 days between referral and start of treatment. This delay is caused amongst others by time needed for histological confirmation, completing diagnostics and the discussion of results in a multidisciplinary meeting (6).

Except the existence of waiting times in the diagnostic process, there is also variety in waiting times between hospitals (7). Because of this variety, patients can consider to go to another hospital where are no or shorter waiting times. In order to make a choice for a hospital, patients can compare hospitals based on waiting times. Hospitals are obliged to publish their waiting times for diagnostics and treatments on their website. By 2016 hospitals have to calculate their waiting times all in the same way, in order to make sure that patients can easily compare hospitals based on waiting times (8).

Consequences of waiting times

Waiting times in the diagnostic process can have several consequences. Firstly, waiting times and therefore prolonged uncertainty about a cancer diagnosis can be stressful for patients (4) (9). Until now most research on this topic is done in breast cancer. Breast cancer patients who had a longer diagnostic trajectory have a longer persistence of stressful emotions (10). It also seemed that most breast cancer patients experienced the period before diagnosis as most stressful, compared with the period after diagnosis (10-12).

Diagnosis-related stress levels vary largely per tumour type (13). Potential prostate or testicular cancer patients experience lower levels of stress than potential lung, breast, brain or pancreatic cancer patients (14, 15). Lung cancer patients often have poor prognoses and these patients may feel responsible for their diagnosis through lifestyle behaviours (15). Also brain and pancreatic cancer diagnoses provoke a lot of stress, because of poorer diagnoses due to relative ineffective cancer therapies for those tumour sites (15). Furthermore, colorectal cancer patients might especially experience a lot of stress during the period between diagnosis and start of treatment, because this period often is too long relative to guidelines and also because of the life-threatening character of colorectal cancer (16).

Another possible negative consequence of waiting times in the diagnostic trajectory is a worsened prognosis. If a patient gets a late diagnosis of cancer, this also means a later start of treatment. For many cancer types the chance of cure is greatest if cancer will be detected and treated as early as possible, because of metastasis (4). Just like diagnosis-related stress levels, growth rates of tumours vary per type of cancer and per patient. Another negative consequence concerns a decreased quality of life (17), but this could be associated with high stress levels and a worsened prognosis.

Rapid diagnostics

A possible solution to reduce the waiting times in the diagnostic process is rapid diagnostics. Rapid diagnostics is formalized into the programme 'Sneldiagnostiek' in the Netherlands. With this programme, all patients will get their diagnosis within five working days. 80% of patients will get their diagnosis within 48 hours (7). Rapid diagnostics is already implemented for different types of cancer in several Dutch hospitals. The implementation of rapid diagnostics started with breast cancer at UMC Utrecht in 2011. Barentsz et al. (13) evaluated this first implementation on diagnostic accuracy and patients' anxiety levels and concluded that same-day diagnosis is feasible in the majority of patients. They provided a final diagnosis within one day in almost 80% of patients and it did not have a negative impact on diagnostic accuracy. Furthermore, anxiety rapidly decreased in patients with a benign diagnosis. Anxiety of patients with malignancies did not change over time. Henselmans et al. (10) also did a study about the influence of rapid diagnostics on breast cancer patients in the Netherlands. They concluded that rapid diagnostics shortened a stressful period, especially for women who ultimately do not have breast cancer.

Studies about the effects of rapid diagnostics were also done in other countries. Brocken et al. (17) did a systematic review to study the influence of rapid diagnostic programs and included articles about breast cancer (18-20), melanoma (21), and lung cancer (22). Some studies about breast cancer showed that rapid diagnostics is favourable for women who are diagnosed as not having breast cancer (18, 20, 23). However, rapid diagnostics could be unfavourable for women who ultimately have breast cancer, because these women were found to have increased psychological distress after diagnosis (20, 23). Based on their review, Brocken et al. concluded that the reduction of distress after exclusion of cancer suggests a beneficial effect of rapid diagnostics for those with a

benign diagnosis, irrespective of type of cancer. However, the available evidence was limited and showed some inconsistencies. It was therefore hard to draw a conclusion for patients ultimately diagnosed with cancer.

Problem description and study aim

A lot of research is done regarding the effects of long waiting times and rapid diagnostics on cancer patients. Rapid diagnostics is also already implemented in several Dutch hospitals. However, almost no research is done regarding patients' preferences for diagnosis in cancer. It could be questioned whether longer waiting times only have negative consequences. It might be that some patients need and want time to think and prepare for what is coming (24). Furthermore, it is questionable if rapid diagnostics is suitable for patients with malignancies, since it seemed from several studies that anxiety and distress at breast cancer patients remained the same or increased after diagnosis (10, 13, 20, 23). Therefore, it is important to assess patient preferences regarding rapid diagnostics. Furthermore, it is important to focus not only on diagnosis, but also on start of treatment. When patients are diagnosed rapidly, but treatment does not start earlier, the time period between diagnosis and start of treatment stays long. Especially for colorectal cancer it is important to shorten this time period, because they often experience a lot of stress during this period (16). Besides, rapid treatment also seems important for breast cancer patients, because rapid surgery can reduce a period of bad emotional well-being at breast cancer patients (10). Therefore this study is not focused only on preferences for diagnosis, but also for start of treatment.

There is no clear definition of patient preferences. However, there seems to be convergence in the view that patient preferences are statements made by individuals about their relative desirability of a range of health experiences, treatment options or health states (25). A possible definition used by Wensing et al. (26) is as follows: 'preferences are ideas about what should occur in health care systems'. Since the changing health care system, value is increasingly placed on patients' opinions of health care (25, 27-29). As a result, it is important for health care organizations to involve patients in organizing and improving health care (30, 31). Furthermore, it seems from several studies that cancer patients who are satisfied with their care are more likely to cooperate with their possible treatment, to continue their use of medical services and to maintain a good relationship with their physicians (32-36).

The aim of this study is to assess patient preferences for duration and planning of diagnosis and start of treatment. With the aid of obtained patient preferences, it can be concluded whether cancer patients prefer rapid diagnostics and which aspects they consider as important regarding the diagnostic process and start of treatment. Moreover, there is an aim to analyse differences in patient preferences on the basis of different patient characteristics. The findings of this study will be used as input for an PhD project which aims to develop new planning and control approaches to optimise the organisation of multiple shared resources involved in diagnostics of cancer. The findings could also be used by hospitals that already make use of rapid diagnostics as well as hospitals that have plans to offer rapid diagnostics in the future. These hospitals could use the findings in order to improve the diagnostic process and to respond to the aspects patients consider as most important.

METHOD

Study design

Best Worst Scaling

Patient preferences were assessed by using Best Worst Scaling (BWS). BWS has three different types, also called ‘cases’. Case 2 BWS is chosen for this study. This type of BWS implies that a respondent chooses several times the best and the worst object of a list of attributes with associated levels (a profile). Discussion of different patient preferences methods and argumentation for the choice of case 2 BWS can be found in Appendix 1. The checklist for conjoint analysis of the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) (37) was used in order to set up the BWS. This checklist can be found in Appendix 2.

Attributes and levels

Attributes were identified based on literature research and discussion with professionals who will use the outcomes of this study. After the determination of attributes, levels were identified. Based on recommendations of ISPOR, levels were limited to three per attribute. The chosen attributes and levels are shown in Table 1. Only a subset of attributes will be used per task, which is called a partial profile (37). It is good practice in health care services research to work with full profiles (37), but a full profile with seven attributes is very cognitively demanding for patients, so therefore partial profiles are used.

Table 1. Attributes and levels

Attributes	Levels
1. Travel time to hospital	1. 30 minutes 2. 60 minutes 3. 90 minutes
2. Number of hospital visits for diagnosis	4. 1 5. 3 6. 5
3. Number of medical examinations for diagnosis per day	7. 1 8. 3 9. 5
4. Number of professionals who discuss the results of the medical examinations and the treatment proposal	10. 1 11. 3 12. 5
5. Waiting time between first visit to hospital and the conversation in which the results of the medical examinations will be discussed with the patient	13. 1 working day 14. 2 working days 15. 5 working days
6. Waiting time between the conversation in which the results of the medical examinations will be discussed and the conversation in which the treatment proposal will be discussed with the patient	16. 1 working day 17. 2 working days 18. 5 working days
7. Waiting time between the conversation in which the treatment proposal will be discussed and start of treatment	19. 10 working days 20. 15 working days 21. 20 working days

Experimental design

Subsequently, an experimental design was developed with Sawtooth 6.4.6. This software combined the different attributes and levels in a valid way. As is visible in Table 1, the basis of the case 2 BWS are seven attributes with each three levels. When all these attributes and levels will be combined, 2187 (3^7) tasks are possible. It is impossible to let respondents do 2187 tasks, so therefore a maximum number of tasks had to be determined. It is good practice in health care to use between eight and sixteen tasks in the experimental design (37). With the use of Sawthooth, it is chosen to make use of a design with two versions with each fifteen tasks. The order of attributes is varied, in order to prevent bias (37). The design can be found in Appendix 3.

The goal of an experimental design is to create a set of tasks that will yield as much statistical information as possible for estimating unbiased, precise preference parameters (38). It is desirable that a design is orthogonal (all attribute levels vary independently), balanced (each level of an attribute occurs the same number of times) and efficient (smallest variance matrix) (37). However, using orthogonal designs may be too difficult or confusing for respondents to answer. An increase in cognitive burden of the task can cause losses from increasing measurement error (39). Therefore, a balance must be found between reducing statistical error and making sure that the questionnaire is not too cognitively demanding. Furthermore, it is hard to develop a design with seven attributes which is orthogonal and balanced.

The design used in this study is D-efficient and not orthogonal and balanced. The design is not balanced, because not every attribute-level combination occurred the same number of times. Eighteen attribute-level combinations were used seven times and three attribute-level combinations were used eight times. Because two versions were used, each attribute-level combination is seen at least three times by respondents. The design is not orthogonal, because not all attribute-level combinations vary independently. The design is chosen however, because otherwise the tasks would be too cognitively demanding for patients.

Study population

Inclusion and exclusion criteria

Post-operative breast cancer and colorectal cancer patients were included in this study. The breast cancer patients were operated in Ziekenhuisgroep Twente (ZGT) or Slingeland Ziekenhuis Doetinchem and the colorectal cancer patients were operated at Ziekenhuisgroep Twente.

The patients had to be able to master the Dutch language, because the questionnaire is Dutch. Furthermore, they must be able to fill in a twenty minute questionnaire. Patient preference questions, like best worse scaling questions in this study, can be cognitively demanding, so patients had to be able to fill in these questions.

Sample size

In order to determine a sample size for a BWS study, the following formula is used (40):

300 / minimum frequency of an attribute

With the experimental design described above, the formula has been filled in as follows:

$$300 / (7/2) = 85,7$$

Based on this formula, a sample size of 86 patients is needed for this study.

Data collection

Data for this study is gathered by means of a patient questionnaire. The questionnaire and study design are approved by the Medical Ethics Committee Twente. The questionnaire was as well available online in LimeSurvey as on paper. Patients are asked to fill in this questionnaire during their follow-up period, with a maximum time period of six months after surgery. Together with the participating hospitals it was decided that this is the best moment for patients to fill in a questionnaire, because stress and uncertainty has declined at most patients and patients are also physically better able to fill in a questionnaire. It is decided to include no patients whose surgery took place more than six months ago, because it is possible that these patients do not fully remember their diagnostic trajectory anymore. Data collection took place from 7 October 2015 to 18 December 2015.

Pilot-test

Before the ultimate questionnaire was filled in by patients, firstly pilot-testing of the questionnaire took place with five patients of ZGT (three colorectal and two breast cancer patients). Pilot-testing has several advantages. Firstly, pilot-testing can identify areas of misunderstanding or common errors. Furthermore, pilot-testing can reveal whether respondents understand the instructions and experience the questions as appropriate. Pilot-testing is also useful in order to narrow the list of attributes used in the BWS to make sure that the questionnaire is not too long (37). By using pilot-testing in this study, it became clear that the questionnaire was long and cognitively demanding, especially the BWS questions. Furthermore, it seemed that some questions were unnecessary. Based on the pilot-test, it was decided to remove some unnecessary questions and to change the order of the questions. The BWS questions were divided over two separate parts of the questionnaire and between these parts patients could fill in simple personal characteristics questions. By means of this, patients did not have to fill in all BWS questions one after another, so the questionnaire would be less cognitively demanding.

Questionnaire

The final questionnaire consists of four parts: 1) questions about the diagnostic trajectory of cancer, especially rapid diagnostics, 2) first part of BWS questions, 3) general questions regarding patient characteristics and 4) second part of BWS questions. The first part contains both open questions and multiple choice questions. Using the open questions respondents were asked to describe the advantages and disadvantages of rapid diagnostics. Using the multiple choice questions respondents were asked about different aspects of rapid diagnostics. The second part consists of the explanation of BWS and ten BWS questions. At each question, the respondents got five characteristics of a diagnostic trajectory. These characteristics varied per question. The respondents had to choose the most positive characteristic and the most negative characteristic of this diagnostic trajectory at each question. The third part contains questions about age, gender, work and living situation, etc. Patients were also asked if they were satisfied about their diagnostic trajectory and why (not). It is important to elicit respondent-specific information to allow for testing for systematic differences in preferences based on these characteristics (37). The last part of the questionnaire contains the last five BWS questions. One of the versions of the questionnaire can be found in Appendix 4.

Distribution of the questionnaire

Patients were invited to fill in the questionnaire in two different ways. Breast cancer patients of the Slingeland Ziekenhuis were invited by means of a letter. Thereafter patients who wanted to participate received the questionnaire at home and could fill in the questionnaire on paper or

online. Breast cancer and colorectal cancer patients of ZGT were invited to fill in the questionnaire after they had a follow-up appointment in hospital. Almost all of these patients filled in the questionnaire directly in hospital in the presence of the researcher. However, some patients did not have time to fill in the questionnaire directly after their follow-up appointment and chose to fill in the questionnaire at home. Furthermore, sometimes it was for different reasons not possible to invite some patients in hospital. These patients were invited by phone and filled in the questionnaire at home. At the end of the data collection period some extra colorectal cancer patients of ZGT were invited per letter, in order to include more colorectal cancer patients. Here the same procedure is used as for Slingeland Ziekenhuis.

Statistical analyses

Data from the first and third part of the questionnaire is analysed with IBM SPSS Statistics 22. Patient characteristics and the answers on other multiple choice questions were described with descriptive statistics. Simple and multivariate logistic regression is used to study possible relationships between patient characteristics and preferences regarding rapid diagnostics. Variables and their associated subgroups and the (re)coding of the aspects regarding rapid diagnostics can be found in Appendix 5.

The design for analysis of BWS is made with SPSS and the analysis is done with STATA 14.0, since it is not possible to analyse a case 2 BWS in SPSS. Analysis of BWS in STATA is performed by means of conditional logistic regression, which generated a conditional logit model. First, a general analysis is performed for all respondents. Coefficients were used to interpret the importance of the attribute-level combinations. Coefficients were also used to calculate attribute importance, which indicates how important an attribute is in valuing a diagnostic trajectory. In order to determine attribute importance, first for each attribute the differences in coefficients within that attribute were calculated. Thereafter for all attributes the difference in coefficients within the attribute is divided by the sum of differences of all attributes. Furthermore, coefficients were used to calculate preference percentages for two possible profiles, namely rapid diagnostics and a diagnostic trajectory over several days. For each profile 'e to the power of the sum of coefficients' was calculated. The exponents of both profiles were summed and thereafter for each profile the exponent was divided on the sum of exponents and turned into percentages. With the use of these percentages it can be predicted which diagnostic trajectory will be chosen by patients and with which percentage.

In order to study the distribution of scores, Best-Minus-Worst counts were calculated with STATA. STATA counted how often patients chose an attribute-level combination as best and as worst. Because of the D-efficient BWS design, Best-Minus-Worst counts were normalized. First for each of the two versions of the questionnaire it is calculated how often all attribute-level combinations were seen by the patients and then summed. Thereafter, for each attribute-level combination the number of times that this attribute-level combination was chosen as best is divided by the number of times this attribute-level combination is seen by patients in total. The same procedure is used for worst, however these numbers were turned into negative values.

In order to determine if and how patient preferences vary by respondent characteristics, subgroup analyses are performed for the variables type of cancer, age and work situation. For each subgroup a conditional logistic regression analysis is performed. The obtained coefficients were used to calculate the attribute importance for all attributes per subgroup. These can be compared to each other per subgroup, in order to determine differences in preferences. Coefficients were not directly compared to each other, since this is not allowed.

RESULTS

Patient characteristics

This part is confidential

Descriptive statistics of preferences regarding rapid diagnostics

This part is confidential

Predictors for preferences regarding rapid diagnostics

Several possible relationships between patient characteristics and preferences regarding rapid diagnostics were studied by means of simple logistic regression. The possible relationships studied and their associated p-values are confidential. Simple logistic regression indicated that the willingness to travel longer is predicted by age. Patients who are 64 years or younger are more willing to travel longer for a faster diagnosis than patients who are 65 years or older. Furthermore, simple logistic regression indicated that preference for rapid diagnostics is predicted by type of cancer and by gender. However, multivariate logistic regression of both significant variables indicated that preference for rapid diagnostics was predicted only by type of cancer. This shows that gender is a confounder in the relationship between type of cancer and preference for rapid diagnostics. The coefficient is just slightly changed, so there is no relevant confounding. The coefficient indicates that breast cancer patients have a stronger preference for rapid diagnostics than colorectal cancer patients.

Patients' preferences for diagnosis and start of treatment

By using conditional logistic regression, coefficients of all attribute-level combinations are obtained relative to twenty working days waiting time between treatment proposal and start of treatment (A7_L3). This attribute-level combination is also least preferred by patients, which means that all coefficients are positive. The results of the conditional logistic regression analysis are confidential. 95%-Confidence intervals for the coefficients of Table 4 are visible in Appendix 8. All attribute-level combinations are significant, except five hospital visits for diagnosis.

The coefficients of the attribute-level combinations all have the expected order, except for the attribute 'number of medical examinations', where patients rather have three or five medical examinations per day than one. For the attributes 'travel time to hospital', 'number of professionals' and 'waiting time between treatment proposal and start of treatment' patients only have minor preference for the first levels. This also applies to the attributes 'waiting time between first visit to hospital and diagnosis' and 'between diagnosis and treatment proposal', which both have about the same differences between levels.

At the attribute 'number of hospital visits' there is a difference of 4.36 between level one and three, which is the largest difference between levels of all attributes. This attribute therefore has the highest attribute importance (AI) for patient. Based on the coefficients, patients find it most positive to need one hospital visit for their diagnosis. 'The number of working days between first visit to hospital and diagnosis' is also an important attribute for patients. Patients find it most positive to hear their diagnosis in one working day. 'Waiting time between treatment proposal and start of treatment' is the least important attribute for patients. This attribute has the smallest difference between its levels (0.97).

Table 4. Results of conditional logistic regression analysis and attribute importance (AI)

confidential

Attri- butes	Attribute definition	Coeffi- cients	Std. Err.	z	P > z	AI (%)
A1_L1	30 minutes travel time					
A1_L2	60 minutes travel time					
A1_L3	90 minutes travel time					
A2_L1	1 hospital visit for diagnosis					
A2_L2	3 hospital visits for diagnosis					
A2_L3	5 hospital visits for diagnosis					
A3_L1	1 medical examination per day					
A3_L2	3 medical examinations per day					
A3_L3	5 medical examinations per day					
A4_L1	1 professional					
A4_L2	3 professionals					
A4_L3	5 professionals					
A5_L1	Diagnosis: 1 working day waiting time					
A5_L2	Diagnosis: 2 working days waiting time					
A5_L3	Diagnosis: 5 working days waiting time					
A6_L1	TP: 1 working day waiting time					
A6_L2	TP: 2 working days waiting time					
A6_L3	TP: 5 working days waiting time					
A7_L1	ST: 10 working days waiting time					
A7_L2	ST: 15 working days waiting time					
A7_L3	ST: 20 working days waiting time					

TP: Treatment proposal, ST: Start of treatment

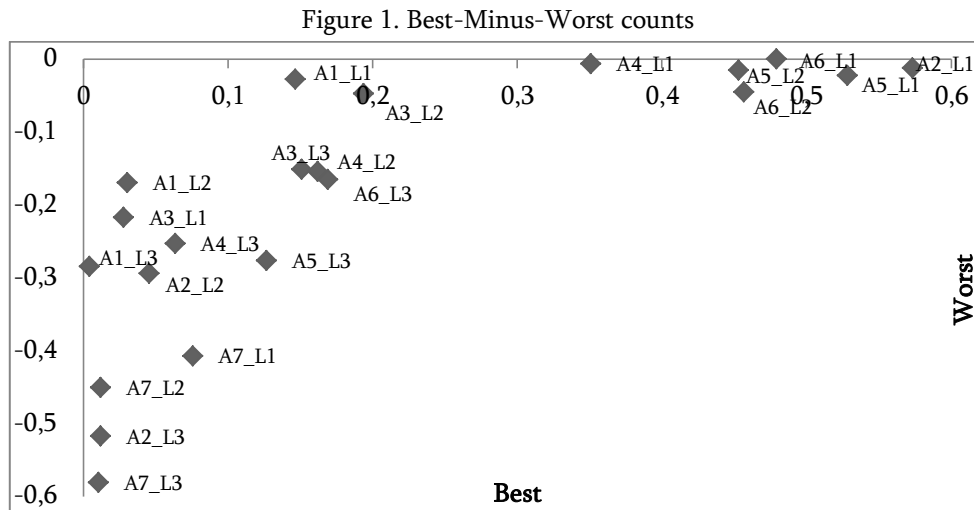
Patient stated preferences

This part is confidential

Distribution of scores

In order to study the distribution of scores, normalized Best-Minus-Worst counts are calculated for all attribute-level combinations, which are shown graphically in Figure 1. Patients especially disagree about five medical examinations per day, three professionals and five working days waiting time between diagnosis and treatment proposal. Furthermore, there is some disagreement amongst the patients about three hospital visits, five professionals, five working days waiting time between first visit to hospital and diagnosis and ten working days waiting time between treatment proposal start of treatment.

Patients agree that thirty minutes travel time, three medical examinations per day, one professional, two working days waiting time between first visit to hospital and diagnosis, two and one working days waiting time between diagnosis and treatment proposal, one working day waiting time between first visit to hospital and diagnosis and one hospital visit are positive attribute-level combinations, in order from least to most positive. They also agree that sixty minutes travel time, one medical examination per day, ninety minutes travel time, fifteen working days waiting time between treatment proposal and start of treatment, five hospital visits and twenty working days waiting time between treatment proposal and start of treatment are negative attributes, in order from least to most negative.



Differences in patients preferences between patient groups

Three subgroup analyses are performed in order to discover differences in preferences between patient groups. The variables and associated subgroups can be found in Appendix 9. The attribute importance for all attributes and subgroups are shown in Figure 2. For type of cancer, the largest difference in attribute importance between the two subgroups is at the attribute ‘number of professionals’. Colorectal cancer patients find it more important to have one own professional than breast cancer patients. As is visible in Appendix 7, not every subgroup of type of cancer consists of at least thirty patients however, so it is questionable if the differences in attribute importance are significant for this variable. For age, the largest difference in attribute importance is at the attribute ‘travel time to hospital’. Patients who are 65 years or older find travel time to hospital more important than patients who are 64 years or younger. Another attribute with a considerable difference in attribute importance for these subgroups is ‘the number of professionals’. Patients who are 65 years or older find it more important to have one own professional than patients who are 64 years or younger. For work situation, there is a big difference in attribute importance for the attribute ‘travel time to hospital’. Patients who do not work find travel time to hospital more important than patients who have a job.

Figure 2. Attribute importance for all attributes and subgroups

This part is confidential

DISCUSSION

Findings and comparison with literature

This study aimed to assess patient preferences for duration and planning of diagnosis and start of treatment in cancer. Almost all patients have a preference for rapid diagnostics, namely 91.4% of patients when asked directly and an average percentage of 90.3% based on patient stated preferences. The number of hospital visits for diagnosis is most important for patients. Within this attribute, patients namely have a strong preference for one hospital visit instead of three or five hospital visits. Patients find it also very positive to hear their diagnosis within one working day and to get their treatment proposal within one working day after diagnosis.

Possible reasons for these preferences are found in a study of Van der Geer et al. (41). This study assessed the feasibility and safety of implementation of the one-stop-shop concept for treatment of patients with basal cell carcinoma. Sixteen patients were included and diagnoses were made within a mean time of hundred minutes. Positive reactions of patients in this study were that it was good to hear the diagnosis immediately, less appointments were needed, accompanying persons needed to schedule only one day and less working days are lost. However, the results of this study cannot be generalized to the current study, as basal cell carcinoma is less life threatening than breast and colorectal cancer and such a fast diagnosis is not possible for these types of cancer. The current study received that the perceived advantages of rapid diagnostics are that you will be less longer in uncertainty and rapid action could be taken. However, an important disadvantage called by some patients is the little time of processing of the information related to the diagnosis. A same type of disadvantage is called by patients in the study of Van der Geer et al. These patients were not previously informed about the possibility of such a fast diagnosis and would have preferred to know about the one-stop-shop concept beforehand, in order to prepare themselves practically and mentally.

The current study indicated that waiting time between getting a treatment proposal and start of treatment is least important for patients. Within this attribute, patients do not have a strong preference for ten working days waiting time instead of fifteen or twenty working days waiting time. This may be due to the fact that the levels of three attributes were expressed in working days. It could be that patients automatically chose the attribute-level combination with the most working days waiting time as most negative, which would be waiting time between treatment proposal and start of treatment in most cases. This attribute namely has the levels ten, fifteen and twenty working days. The other attributes expressed in working days both have the levels one, two and five working days, which sounds faster to patients. The levels of these attributes might be lexicographically preferred to the levels of the attribute 'waiting time between treatment proposal and start of treatment'. The preference of patients for a rapid diagnosis and treatment is in line with results of a systematic literature review of Petersen et al. (42), in which it was concluded that cancer patients find short delay of diagnosis and treatment most important within hospital care.

An interesting finding is that the coefficients of the attribute 'number of medical examinations per day' do not have the expected order. Patients prefer three or five medical examinations per day over one medical examination per day. This is in line with the finding that patients prefer one hospital visit and to get their diagnosis within one working day, which automatically results in more appointments on the day. Most patients (92.6%) feel able to undergo all medical examinations needed for diagnosis on one day.

Another interesting finding is that 79% of patients is willing to have contact with different professionals instead of having one own professional. This is in contrast with results of a study of Bergenmar et al. (43). In this study breast cancer patients were asked how important it is to them to meet the same physician at every appointment. Most of these patients find this very important. Only 3% of these patients think it is not important to meet the same physician. However, in the study of Bergenmar et al. the question is asked in a different way and with a different background. The setting of the study of Bergenmar et al. namely was an outpatient clinic for patients with breast cancer and the study was not focused on rapid diagnostics, but on breast cancer care in general. A possible reason why patients in the current study are willing to have contact with different professionals is that they might expect to get a faster diagnosis by means of this. Another possible reason is that patients see it as a kind of second opinion and feel more confident by getting information from different professionals.

Another aim of this study was to analyse differences in patient preferences on the basis of different patient characteristics. Multivariate logistic regression analysis indicated one predictor for preference for rapid diagnostics, namely type of cancer. Breast cancer patients have a stronger preference for rapid diagnostics than colorectal cancer patients. Other possible predictors, namely gender, age, education, living situation and work situation are also studied, but none of these are statistically significant. With simple logistic regression gender was a predictor for preference for rapid diagnostics, but in the multivariate regression model this relation was not significant and gender acted as a confounder. This may possibly be due to the skewness in the ratio of women and men. More than four times as many women completed the questionnaire than men, which in turn is due to the skewness in ratio of breast cancer and colorectal cancer patients. In a study of Wessels et al. (44), gender had the strongest impact on patient preferences. Gender was a strong predictor for the importance of waiting periods amongst others. Women regarded waiting periods as less desirable than men did. This may suggest that with a larger number of included men the variable gender may become a predictor of preference for rapid diagnostics.

BWS subgroup analyses are performed for three variables with two subgroups each. The largest difference in attribute importance was found at travel time to hospital between patients who work and patients who do not work. Patients who do not work find travel time to hospital considerably more important than patients who work. Remarkably, work situation is not a predictor for the willingness to travel longer for a faster diagnosis. The difference in attribute importance for the variable work situation could be explained by the large number of retirees in the subgroup of patients who do not work. The retirees are almost all 65 years or older. Patients who are 65 years or older find travel time to hospital more important than the younger patients. This is in line with the current study's finding that willingness to travel longer for a faster diagnosis is predicted by age. Simple logistic regression analysis indicated that patients who are 64 years or younger are more willing to travel longer for a faster diagnosis than patients who are 65 years or older. A possible reason for the differences between those subgroups could be that older patients feel less able to have a long journey to a hospital. However, most of the patients who are 64 years or younger have a job and almost half of these younger patients have children at home. It is remarkable that these patients find travel time to hospital less important than the patients who are 65 years or older, since it could be expected that the older patients have more time to travel.

Subgroup analyses are also performed for type of cancer. However, the significance of the differences regarding this variable is questionable, because of the low number of colorectal cancer patients. The largest difference in attribute importance for type of cancer was found for the

attribute 'number of professionals'. Colorectal cancer patients find it more important to have one own professional than breast cancer patients. Remarkably, this difference is not in line with the current study's finding that a higher percentage of colorectal cancer patients is willing to have contact with different professionals, compared to breast cancer patients. Based on these conflicting findings and the questionable significance, no conclusions can be drawn about differences in preference for one own professional between the two types of cancer.

The finding of this study that breast cancer patients prefer rapid diagnostics is not in line with the results of some earlier studies (10, 13, 20, 23), which revealed that rapid diagnostics was possibly not suitable for patients who ultimately had breast cancer. These patients namely had remained or increased anxiety and distress after fast diagnosis. Breast cancer patients in the current study almost all stated that the time until diagnosis is very stressful and they prefer to know their diagnosis as soon as possible, in order to know where they stand and to start their treatment as soon as possible. In another study (24) it was questioned whether breast cancer patients need time to think and prepare for what is coming. In the current study "the little time of processing of the information related to the diagnosis" was called several times as disadvantage of rapid diagnostics. Despite this disadvantage most patients still prefer rapid diagnostics, so this line of thinking is not confirmed in this study.

Strengths and limitations

This study has several strengths and limitations. To our knowledge this is the first study that assessed patient preferences for duration and planning of diagnosis and start of treatment in cancer. Another strength is the quantitative nature of this study, which provides insight into the distribution of preferences and into differences in preferences between certain patient groups.

The most important limitations of this study were regarded to the study population. Despite a data collection period of over two months, the calculated sample-size of 86 patients is not achieved. Therefore, results of this study should be interpreted with caution. This especially applies to the results of subgroup analyses, because on account of the low number of patients it was hard to analyse significant differences between patient groups. It was especially difficult to include colorectal cancer patients, because these patients often still had pain from surgery and therefore were less able to fill in the questionnaire. Because of the relative large number of breast cancer patients and the relative small number of colorectal cancer patients, a lot of women and few men are included in this study. Therefore, it was hard to find significant differences in preferences between women and men. Furthermore, only post-operative patients are included in this study and no patients who had other treatment(s). Moreover, all patients are diagnosed in general hospitals in the east of the Netherlands. It could be that patients who are diagnosed in academic or specialised hospitals in other parts of the country have other preferences than the patients included in the current study. Patients have reasons to choose for an academic or specialised hospital. These hospitals for example also treat rare types of cancer and better meet the volume standards for treatments. Because of these limitations, the study population is not very representative for all breast and colorectal cancer patients.

Some other limitations of this study were regarded to the data collection. Patients were not invited in the same way to complete the questionnaire. Both approaches have their advantages and disadvantages. Some patients completed the questionnaire in hospital after their follow-up appointment and got spoken explanation of the researcher and were able to ask questions to the researcher during completing the questionnaire. The researcher was able to check whether the

questionnaires were filled in correctly. This approach may improve the quality of the data, but is time-consuming for the researcher and causes additional work for the professionals involved. Most patients completed the questionnaire at home and did not get spoken explanation of the researcher. They were able to ask questions to the researcher by mail or phone, but none of these patients made use of this. Furthermore, the researcher was not able to check whether the questionnaires were filled in correctly. Therefore some of the patients did not correctly fill in the BWS questions, which made these answers useless. However, this approach is more practical than completing the questionnaire in hospital, because it takes less time for both the researcher and the professionals involved. Moreover, patients can choose a suitable moment to fill in the questionnaire, which is especially desirable for patients who have other appointments in hospital or still have a lot of pain. Another limitation regarded to the data collection was the influence of accompanying persons. Some patients who completed the questionnaire in hospital were accompanied by their spouse or child(ren) and were sometimes influenced by them during completing the questionnaire. In patients who came alone to hospital this was not the case. Furthermore, it is not known whether patients who completed the questionnaire at home were influenced by their family. The influence of family may have caused bias. Preferences can both be overestimated and underestimated.

A final area of limitation was the BWS design. The design was D-efficient and not orthogonal and balanced. The tasks were divided over two versions, in order to make sure that patients did not have to do thirty tasks, but one version is completed more often than the other. This, together with the unbalanced design, caused that not all attribute-level combinations were seen just as often by all patients. This may have had an effect on the results of the conditional logistic regression analysis. In order to take this problem into account, Best-Minus-Worst counts are normalized, based on the number of times an attribute-level combination is seen by patients. The number of times attribute-level combinations were seen by patients can be found in Appendix 10. Another limitation of the BWS-design was that the levels of three attributes were expressed in working days and some attributes were related to each other. This made some tasks confusing and difficult for a lot of patients.

Future research and recommendations

The findings of this study will be used as input for an PhD project which aims to develop new planning and control approaches to optimise the organisation of multiple shared resources involved in diagnostics of cancer. The findings could also be used by hospitals that already make use of rapid diagnostics as well as hospitals that have plans to offer rapid diagnostics in the future. Although the findings of this study indicate that breast and colorectal cancer patients prefer a fast diagnosis and start of treatment, future research with a larger sample size is needed in order to make more valid conclusions, especially about differences in preferences between patient groups. Therefore, the current study will be continued by bachelor students. Except a larger sample size, it is also recommended to include patients diagnosed in different types of hospitals and with different types of cancer and treatments. According to literature mentioned earlier, breast cancer is a type of cancer from which the diagnostic process entails a lot of stress and colorectal cancer is a life threatening type of cancer from which the period between diagnosis and start of treatment especially entails a lot of stress. It might be that patients with rare or less life threatening and stressful types of cancer have other preferences for diagnosis and start of treatment than the current study population.

Despite the limitations of this study, some findings of the current study can already be useful for the PhD project. It can be taken into account that 98.2% of breast cancer patients and 80.0% of colorectal cancer patients will choose rapid diagnostics over a diagnostic trajectory spread over several days. Furthermore, it can be taken into account that patients prefer to undergo the medical examinations needed as much as possible on one day and prefer to get their diagnosis on the same day. Patients namely prefer to need one hospital visit for their diagnosis. Thereafter, patients prefer to get their treatment proposal as soon as possible. In order to get a fast diagnosis, especially patients who are 64 years or younger are willing to travel longer. Furthermore patients are willing to have contact with the professional who is available at that moment.

The practical implication for hospitals is that offering rapid diagnostics is desirable from the perspective of breast cancer and colorectal cancer patients. Rapid diagnostics is already implemented for breast cancer at Ziekenhuisgroep Twente and Slingeland Ziekenhuis, which seems to be good decisions. Rapid diagnostics is not yet offered to colorectal cancer patients at Ziekenhuisgroep Twente. It is recommended to offer rapid diagnostics also for this type of cancer, in order to enable these patients to undergo the medical examinations needed as much as possible on one day and to provide the diagnosis as soon as possible. It is also recommended to offer these patients a suitable treatment proposal as soon as possible, so that treatment can start as soon as possible. When it is possible to both assign a certain professional to a patient and to offer rapid diagnostics, it is recommended to do this. When this delays the diagnostic process, it is recommended to assign another professional to the patient, in order to offer a fast diagnosis. By offering rapid diagnostics for breast cancer and colorectal cancer, patients from other regions can be attracted to the hospital, since most patients are willing to travel longer for a rapid diagnosis. In attracting patients from other regions, it is recommended to particularly focus on patients younger than 65 years, since these patients are more willing to travel longer for a faster diagnosis.

Conclusion

Taking the limitations of this study into account, it can be concluded that breast and colorectal cancer patients are willing to make concessions in order to get their diagnosis on the same day as when medical examinations take place and to get their treatment proposal as soon as possible. These concessions are traveling longer, having conversations with the professional who is available at that moment and having as much as possible medical examinations needed on one day. Important differences found between patients groups are that breast cancer patients have a stronger preference for rapid diagnostics than colorectal cancer patients and patients who are 64 years or younger are more willing to travel longer for a faster diagnosis than patients who are 65 or older.

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APPENDIX

Appendix 1: Patient preferences methods

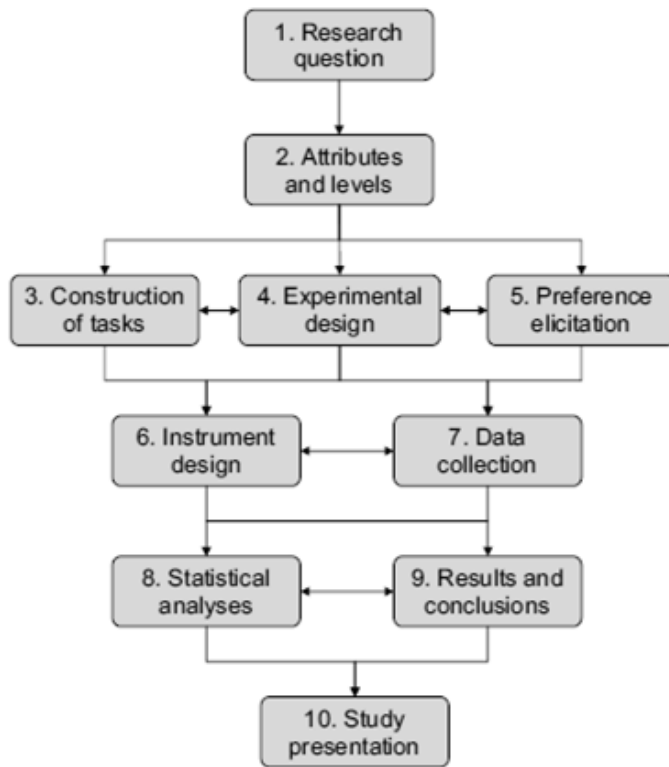
Different methods exist to assess patient preferences. An often used method in health care is the Discrete Choice Experiment (DCE). In a DCE patients are asked to choose between two or more scenarios. The underlying principle of a DCE is that the value of an option is determined by the values of its attributes (45). The extent to which an individual values a good or service depends on the levels of these characteristics (46). However the DCE is used most often in health care compared to other methods such as ranking and rating (46), the DCE has an important disadvantage. A DCE namely can be cognitively demanding for respondents (47), because of the simultaneous assessment of multiple attributes (48). It is not desirable that a questionnaire is cognitively demanding for patients, certainly not for cancer patients who already may be emotional and stressed.

Therefore, another method will be used to elicit patient preferences, namely Best Worst Scaling (BWS). BWS is developed and pioneered by Louviere and has derived from the same random utility framework of DCE and ranking studies. It is generally seen as a good compromise between DCE and ranking methods. More information namely will be obtained with BWS than DCE (49) and less burden is placed on the respondent then whenever a full ranking of all choice options is used (50).

BWS has three different types, also called 'cases'. Case 1 BWS, also called 'object case', is used when the researcher is interested in the relative values associated with each of a list of objects (51). With this type, the respondent selects the best and the worst object of the list. Case 2 BWS, also called 'profile case', is an expansion of case 1 BWS. With case 2 BWS, the respondent also chooses the best and the worst object of the list. However, this method makes use of a structure with attributes and levels, which forms a profile. Case 3 BWS, also called 'multi-profile case', is an expansion of case 2 BWS. It does not consist of one profile like with case 2 BWS, but multiple profiles. These multiple profiles form a choice set. A case 3 BWS requires a respondent to choose the worst profile and the best profile of a choice set (51).

From these three different types of BWS, case 2 BWS is chosen to use for this study. The reason for this choice is that a case 2 BWS is quite similar to a DCE, but it is less cognitively demanding. In a DCE a respondent has to assess multiple attributes simultaneously, in order to choose between two different profiles. With a case 2 BWS on the other hand, the respondent only has to look at one profile and choose the best and the worst attribute of this profile. Case 3 BWS is also quite similar to the DCE, but this method is even more cognitively demanding, because the respondent does not have to make one choice, but two choices and also has to assess multiple attributes of multiple profiles. Therefore case 3 BWS is not chosen for this study. Case 2 BWS was introduced by McIntosh and Louviere (52) and is a popular method in health (51). Furthermore, case 2 BWS is an appropriate method to use when respondents have no experience with choice-making in the area of investigation (53), which may be the case in this research.

Appendix 2: ISPOR checklist for conjoint analysis in health care



(37)

Appendix 3: Best-Worse-Scaling design

This part is confidential

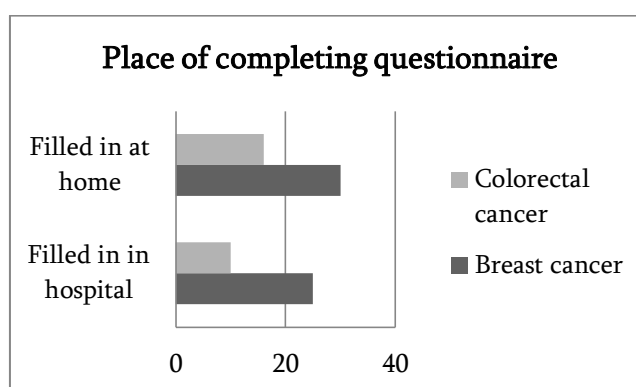
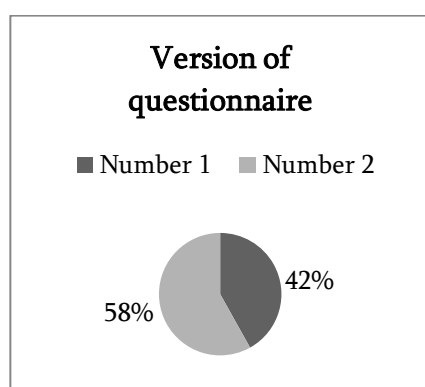
Appendix 4: One of the versions of the questionnaire

This part is confidential

Appendix 5: Variables and associated subgroups and (re)coding of the aspects regarding rapid diagnostics

Variables	Subgroups
Type of cancer	1. Breast cancer 2. Colorectal cancer
Gender	1. Female 2. Male
Age	1. 64 years and younger 2. 65 years and older
Education	1. Low (primary education, lower secondary education, lower vocational education, secondary education) 2. Middle (secondary vocational education, higher secondary education) 3. High (higher professional education, university education)
Living situation	1. Alone 2. Together (with partner and/or children)
Work situation	1. Working (fulltime, parttime) 2. Not working (disabled, retired, housewife)
Aspects	(Re)coding
Preference for rapid diagnostics	1. Yes 2. No
Willingness to travel longer	1. Yes (half an hour, an hour, one and a half hours) 2. No
Handle all medical examinations on one day	1. Yes 2. No
Willingness to have contact with different professionals	1. Yes 2. No

Appendix 6: Data collection figures



Appendix 7: p-values for simple regression analyses

This part is confidential

Appendix 8: 95%-confidence intervals conditional logistic regression analysis

Attributes	[95% Conf. Interval]	
A1_L1	2.34	3.05
A1_L2	1.13	1.81
A1_L3	0.53	1.16
A2_L1	4.17	4.92
A2_L2	0.78	1.43
A2_L3	-0.13	0.50
A3_L1	0.91	1.58
A3_L2	2.24	2.94
A3_L3	1.83	2.53
A4_L1	3.39	4.11
A4_L2	1.86	2.57
A4_L3	0.84	1.51
A5_L1	3.88	4.63
A5_L2	3.24	3.96
A5_L3	1.12	1.80
A6_L1	3.79	4.54
A6_L2	3.18	3.91
A6_L3	1.45	2.08
A7_L1	0.64	1.30
A7_L2	0.12	0.79
A7_L3	omitted	

Appendix 9: Variables and associated subgroups for subgroup analysis

Variable	Subgroups	Number of patients per subgroup
Type of cancer	Breast cancer	49
	Colorectal cancer	25
Age	64 years and younger	39
	65 years and older	34
Work situation	Working	31
	Not working	41

Appendix 10: Overview of the number of times attribute-level combinations were seen by patients

Attribute-level combination	Total number of times seen by patients
A1_L1	253
A1_L2	265
A1_L3	253
A2_L1	253
A2_L2	265
A2_L3	253
A3_L1	253
A3_L2	253
A3_L3	265
A4_L1	308
A4_L2	253
A4_L3	253
A5_L1	265
A5_L2	265
A5_L3	253
A6_L1	265
A6_L2	265
A6_L3	296
A7_L1	265
A7_L2	253
A7_L3	296