

# Lyme patients' preferences in choice of provider for treatment of non-local Lyme borreliosis

A DISCRETE CHOICE EXPERIMENT AMONG LYME PATIENTS



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## Preface

The subject of this thesis is Lyme borreliosis. My interest for this disease arose out of my own experience with Lyme when I was a child. While I did not have problems within the regular healthcare sector, I had heard many stories of patients who felt left alone and desperate. When I found out it was possible to choose my own disease for this thesis, the choice for Lyme borreliosis was easily made.

This research is predominantly meant for both Lyme patients as well as providers of treatment. However, several insights were formed which might also be of use for other researchers interested in preference of patients related to provider characteristics. My wish was to improve the available care for Lyme patients, but there is unfortunately still a long way to go. Nevertheless, I hope to have stirred up the deliberation and awareness concerning the treatment of Lyme borreliosis.

This thesis is the end of my four-year experience with academic research and education. Over the years, I have learnt a lot, of which many was very useful to write this thesis. I have always been a perfectionist and during my master's this has not been any different. As relatives will expect, I have put as much energy and time as possible to finish this thesis. As we would say in Dutch, my "blood, sweat and tears" have lavishly flowed.

The COVID-19 crisis made my master thesis, my whole master studies, different than you would normally imagine. After finishing my bachelor thesis during the lock-down period, I honestly did not expect to graduate during another lockdown again. Surprisingly, I have only been five times on campus to make exams. While in most cases it was only possible to see your fellow students through the laptop screen, I somehow still managed to make some friends. Together, we talked for hours about study as well as other stuff before we even met in real life. They help me a lot with several thesis related questions as well as necessary relaxation.

With finishing this thesis and ending (for now) my years following education, I am looking forward to finally start my career in the healthcare field. The economic and policy aspect from the beginning already attracted my attention. As expected and wished, I will start my career within the same field. I am excited to start and curious about what the coming years will bring.

I would like to thank all my friends, family and boyfriend for the support they gave me during this thesis as well as all the last four years. They eased me when necessary and provided me with useful feedback. Of course, without the participants of this thesis, both the patients and the providers, it would not have been possible to fulfil this research. So, thank you all! A special thank word to my mom, who travelled through half of the country to spread flyers for my questionnaire. Last but not least, I am grateful to be in the position of having two first supervisors, dr. WK. van Deen and prof. dr. EW. de Bekker-Grob who are both experts in the field of discrete choice experiments. I am thankful for the freedom I have gotten to 'go my own way' and further develop the skill to fulfil scientific research independently. Together with the feedback of my second supervisor, prof. dr. M. Varkevisser, they helped me extensively to lift my thesis to a level of which at least I am very proud of.

I hope you all enjoy reading this thesis!

*Vera Niessink*

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## Abstract

Currently, there are many controversies with the treatment of Lyme borreliosis. Two contradicting guidelines and dissatisfaction with the regular healthcare for Lyme borreliosis within the Netherlands pushed patients to alternative care. It was already clear why patients opt for alternative providers, but there was not yet any insight into which characteristics of providers are more and less important and what the uptake rates for different providers are. In addition, there had not been any research related to providers' experiences with Lyme patients' preferences yet. This research aimed to fill these knowledge gaps using a discrete choice experiment (DCE) among patients and interviews among providers.

A DCE is a promising method which makes it possible to analyse patient preferences. A DCE is based on theory which assumes that the characteristics (attributes) of the provider determine the utility a patient receives from the choice. Earlier research showed that examples of characteristics which influence choice of provider are waiting time, travel distance and expertise of provider.

In this DCE the included attributes were the decision maker, costs for treatment, guideline followed, expertise of provider, travel distance to provider and attitude of the provider. Patients chose between provider A and B which differed on these attributes. The questionnaire also included socio-demographic and disease related questions. The questionnaire was tested face-to-face and a pilot DCE was held to update the estimations of the coefficients which increases the statistical efficiency. This research used both the multinomial logit (MNL) model and the latent class model (LCM) to analyse preferences. With the LCM, it is possible to account for preference heterogeneity between different groups (classes) of patients. This research used the socio-demographic and disease related variables to search for variables of class membership. Furthermore, interviews were held with, four general practitioners (GPs) and one specialist from a Dutch Lyme clinic. One GP was more alternative oriented. During these interviews, the experiences of the providers with Lyme patients as well as their expectations about patient preferences and the results of the DCE were discussed.

The DCE results showed that in general, patients prefer a specialised alternative provider that is located within the municipality, that supports the patient and where costs for treatment are low. The LCM was used with two classes in which preferences indeed differed. While class one respondents thought the guideline followed was by far the most important attribute influencing choice, class two respondents place greater importance on travel distance to provider and the attitude of the provider. Patients with a lower health status, with higher costs for treatment and with a provider outside the Netherlands were more likely to belong to class one. An alternative provider was preferred by both groups of patients if the travel distance and the costs were low. Interestingly, the providers expected patients to be more likely to choose a regular specialist. They expected the attitude and expertise of a provider to influence choice the most.

The respondent characteristics reduce the generalizability of the results of the DCE to the whole non-local Lyme patient population. The complementing interviews increase the reliability of the DCE. Moreover, the DCE used an experimental design which made it possible to increase the statistical efficiency. A recommendation for further research is to use of a bigger sample size with more non-chronic patients. It might also be interesting to fulfil a DCE concerning the preferences of treatment characteristics like effectiveness, considering the still great controversies. Concluding, non-local Lyme patients prefer a provider that is located within the municipality, where costs of treatment are low, who is an expert in Lyme disease and who provides treatment according to the ILADS-guideline. However, there is preference heterogeneity in choice of provider.

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## Overview of abbreviations

AMLC	Amsterdams Multidisciplinair Lymeziekte centrum
CAIC	Consistent Akaike Information Criterion
CBO	Dutch quality institute for healthcare
CLD	Chronical Lyme disease
DALY	Disability Life Adjusted Years
DCE	Discrete choice experiment
GP	General practitioner
IDSA	Infectious Disease Society of America
ILADS	International Lyme and Associated Disease Society
LCA	Lyme centrum Apeldoorn
LCM	Latent class model
LLMD	Lyme literate medical doctors
MIXL	Mixed logit
MNL	Multinomial logit
OECD	Organisation for Economic Co-operation and Development
PLDS	Post-Lyme disease syndrome
RUT	Random Utility Theory

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## 1. Introduction

In the Netherlands, Lyme borreliosis is diagnosed in 27.000 cases as a result of a tick-bite each year (1). The annual costs of Lyme borreliosis in the Netherlands are estimated around 20 million euros (2). Between 1994 and 2017, the amount of cases has quadrupled (3), possibly caused by an increase in ticks, awareness (4) and climate change (5). Despite the increasing number of patients however, there are many controversies concerning the treatment of Lyme borreliosis in the Netherlands.

The most common symptom of Lyme disease is a rash, which indicates a local infection (4). Symptoms of non-local infections are in example joint inflammation, fatigue, and fever. Ten to twenty-five percent of patients continue to have symptoms, even years after treatment (6–8). These patients are often diagnosed with post-Lyme disease syndrome (PLDS) or chronic Lyme disease (CLD) (4,7,9–11). In the medical world, there is doubt if CLD is the result of persistence of the bacteria and if the symptoms are caused by the infection or something else (4,12).

Physicians have different opinions about the best suitable treatment as well (4,13,14). Standard treatment for all types is prescribed in the form of antibiotics (4,6,7,9). The specific duration and the kind of antibiotics differs per type of disease and patient (4,7). There are two diverging guidelines concerning Lyme borreliosis, the guidelines of the Infectious Diseases Society of America (IDSA) (15) and of the International Lyme and Associated Disease Society (ILADS) (16). The IDSA-guidelines recommends short-term antibiotic treatment, while the ILADS-guidelines recommends long-term treatment (7,9,13). In addition, more than 30 other types of treatments are provided, including stem cell transplantation (17). Many of these alternative treatments have not been scientifically proven. The association for quackery in the Netherlands stated that providers who follow ILADS-guidelines or offer alternative care, act wrongfully (18,19). Dutch physicians follow guidelines which are based on the IDSA-guidelines (4,20). The Dutch Lyme association (*Lymevereniging*) however, does not support these guidelines (21).

As a result of these contradicting guidelines, some physicians are willing to treat CLD, offer long-term antibiotics and/ or alternative treatment, while others do not (14,22). The Dutch healthcare is rated with only a 2.3 out of 10 by patients with CLD (4). Patients have the perception that regular providers make arbitrary treatment decisions and that these providers deliver inadequate care (23). Patients feel as if regular providers do not take them seriously (23–25). A stable patient-physician relationship is of importance, but is often disturbed because patients feel unhappy about their treatment (4,23,25). Uncertainty about correct treatment negatively affects the relationship as well (23–25). The disturbed relationship stimulates patients to seek care at alternative facilities, even on international level (4,18,19,22–24). Patients seek for ‘Lyme Literate Medical Doctors’ (LLMDs) (13) who claim to be specialised in Lyme disease (26). Research from the *Lymevereniging* showed that only 1 out of 6 patients with CLD is treated in the Netherlands (24). Patients travelling for treatment is not merely a Dutch dilemma and happens for instance in Canada as well (14,27).

Something must be changed to increase patients’ satisfaction with treatment in the Netherlands. The total burden of Lyme disease is 11 Disability Adjusted Live Years (DALY) per 100.000 citizens (28), which is comparable to the DALY of AIDS (71 in ranking) (29). The DALY of Lyme disease is for 86% caused by patients having CLD or PLDS (28). In addition to this high disease burden, uninsured alternative treatment can costs thousands of euros for patients (30). Improvement of patients’ satisfaction might decrease the disease-, financial- and emotional- burden caused by for example high costs and non-suitable treatment.

To increase patients’ satisfaction, it is important to have insight into their preferences. However, there is not yet a quantification of Lyme patients’ preferences available. Scientific research



concerning the choice of provider using either quantitative or qualitative methods is lacking in general. This research therefore aimed to contribute to the ongoing discussion concerning the treatment of Lyme borreliosis by giving insight into patient's preferences and enlarges the available literature concerning choice of provider by patients. To be able to analyse the preferences, the following research question was formulated: ***"What are patients' preferences in the choice of provider for the treatment of non-local Lyme borreliosis"***

It is not yet completely clear which determinants influence the decision of the patients and what patients think is less and more important. Moreover, as mentioned before, there are different types of Lyme disease and not every patient experiences the same symptoms (6,7). Thus, there might be preference differences between different types of patients. Possible choice probabilities can also give insight into preferences of patients. It might be that patients are more likely to opt for an alternative provider, even when, in example, they are expensive. Therefore, the first three sub-questions were formed:

1. *"What determinants are important for Lyme patients in choice of provider for the treatment of non-local Lyme borreliosis, and what trade-offs do they make between them?"*
2. *"Is there preference heterogeneity among Lyme patients in choice of provider for the treatment of non-local Lyme borreliosis?"*
3. *"What are the choice probabilities of Lyme patients for a regular Dutch Lyme specialist and an alternative Lyme specialist?"*

These sub-questions were answered with the use of a discrete choice experiment (DCE) among patients with non-local Lyme borreliosis. Currently it is unknown what physician experiences are with patients' preferences. There is a clash between patients and providers and the outcomes of a treatment are influenced by the satisfaction of patients (31). Better aligning the available providers with the wishes of the patients could improve treatment outcomes. It is therefore important to have insight into the view of providers on patients' preferences. The last sub-question was formed with this in mind:

4. *"What are providers expectations of the preference of Lyme patients in choice of provider?"*

Semi-structured interviews were held with providers from the regular- and alternative healthcare sector to answer the last sub-question in which among other things the results of the DCE were discussed. The following hypotheses were tested for all sub-questions:

1. The travel distance to the provider and the costs of treatment are the most and equally important determinants influencing choice
2. Lyme patients with a self-assessed poor health status have a higher preference for alternative treatment compared to patients with a self-assessed good health status
3. The choice probability for an alternative Lyme specialist is higher for all types of Lyme patients compared to the choice probability for a regular Dutch Lyme specialist
4. The preferences of Lyme patients concerning the choice of provider do not align with the expectations of the preferences by the Dutch providers

This research starts with a discussion of the available research related to the choice of provider, resulting in a conceptual framework. Then, ways to analyse patients' preferences are explored. In chapter 3, the experimental design, the statistical analysis, and the interview guide are extensively discussed. The results of this research are presented in chapter 4. The 5<sup>th</sup> chapter of this research discusses the results and deliberates on limitations and strengths. The conclusion of this research is presented in the last chapter.

## 2. Background

To create a better understanding of the treatment process, the available providers for the treatment of Lyme and the two contradicting guidelines are explained. To gain insight into the preferences of patients, it is important to consider earlier research fulfilled about patient preferences. This section therefore describes research on the choice of provider in general and by Lyme patients as well. In addition, a conceptual framework, based on the model of Kroeger (32), is introduced to map determinants that influence choice of provider by Lyme patients. Lastly, different methods to analyse patients' preferences are described.

### 2.1 Providers of treatment of Lyme borreliosis

In most cases in the Netherlands, the regular treatment pathway of a patient starts by a patient asking advice from a GP. A GP can choose to refer a patient to a hospital Lyme clinic (33). In the Netherlands there are three specialised hospital clinics focussed on Lyme borreliosis. Two of those clinics are academic, namely the *Amsterdams Multidisciplinair Lymeziektecentrum* (AMLC) and the infectious disease centre of Radboudumc (34,35). The other clinic, *Lyme-centrum Apeldoorn* (LCA) is non-academic, but works together with the AMLC and Radboudumc (36). Within the clinics, scientific research about the diagnosis and treatment of Lyme disease is fulfilled (34–36). In addition, they all have multiple kinds of relevant specialist available, such as a neurologist. In general, both the clinics and the GPs offer short-term antibiotics. However, sometimes other treatment is offered, targeted at something else than the *Borrelia* infection.

As mentioned before, there are many types of alternative treatment available. An often mentioned Dutch physician in the discussion about treatment of Lyme is dr. Geert Kingma (37). However, his clinic in the Netherlands has been shut down by the Dutch health care inspection (38). Dr. Kingma currently works in Spain at the Marbella Lyme Clinic (39). This clinic offers in addition to antibiotics also ozone treatment, acupuncture and bio resonance (40). A common known German clinic for Lyme Borreliosis is the BCA Clinic (41–43). Part of their treatment offers are nutritional intravenous therapy, oxygen therapy, photon therapy, magnetic therapy, light therapy, infrared therapy and detox (43). The BCA clinic places special emphasis on personal care and patient satisfaction. MeCebi is a Dutch private clinic that also offers alternative treatment, in the form of bio resonance (44). They also state that they are patient oriented with having years of experience with Lyme disease and claim to have done research as well. Figure 1 represents a schematic overview of the different types of providers and their treatment methods.

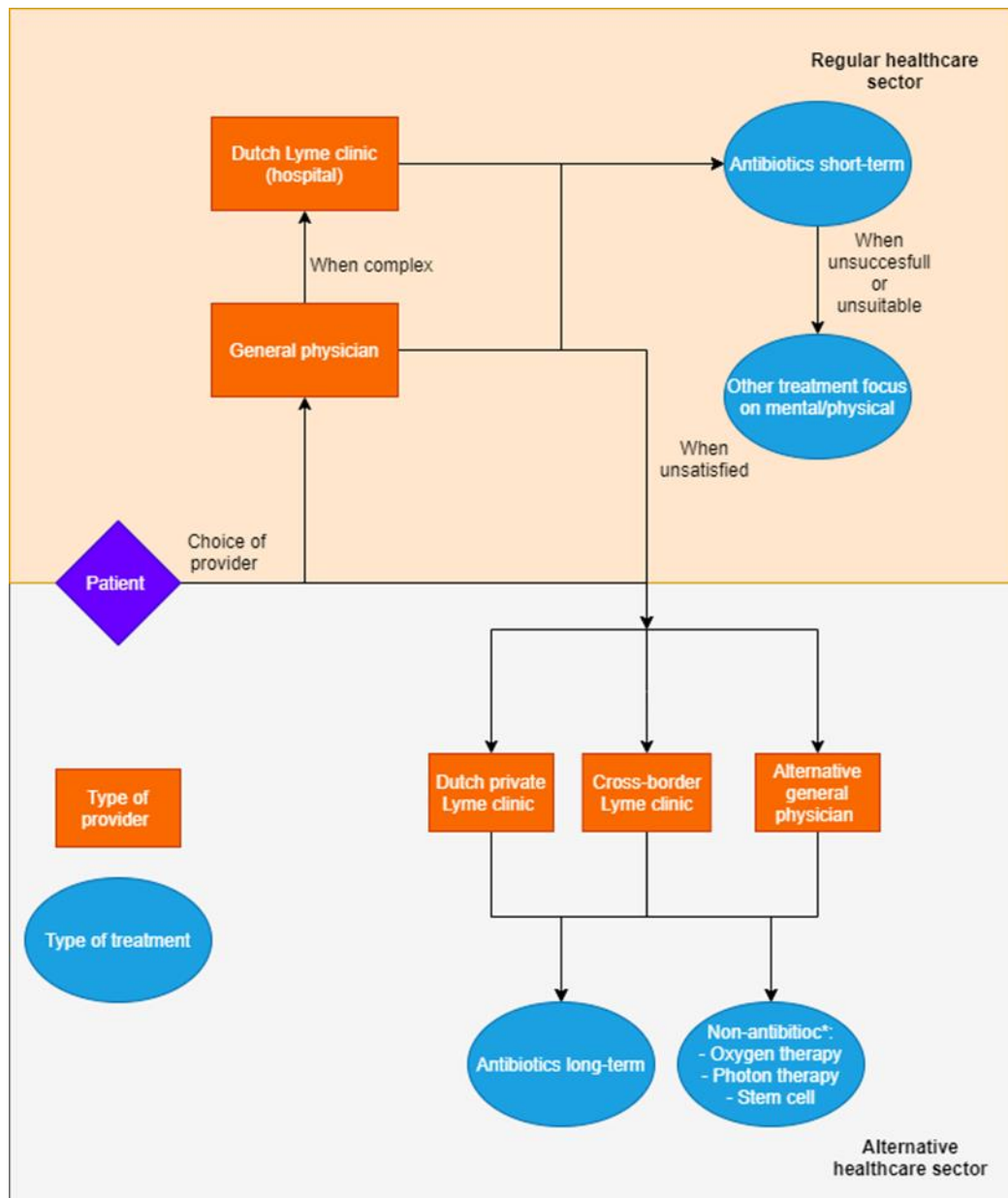


Figure 1: Available providers and their treatment options in both the alternative and regular healthcare sector for Dutch Lyme patients

## 2.2 Treatment according to the CBO- and ILADS-guideline

As mentioned in the introduction, there are in general two diverging guidelines used by providers of treatment for Lyme disease. The recommended treatment for Lyme Borreliosis depends among other things on the guideline followed by the physician. The most common guidelines are those from the ILADS and the IDSA. In the Netherlands, the guidelines of the Dutch Quality Institute for Healthcare (CBO) is followed (4) which are based on the IDSA-guidelines (20). Therefore, this paragraph shortly explains the differences in treatment according to CBO- and ILADS-guidelines.

### 2.2.1 Guidelines of the Dutch Quality Institute for Healthcare

Within the CBO-guideline, the offered treatment depends on the stage of the disease and within that stage, the kind of manifestation (45). Lyme borreliosis is normally treated with antibiotics (4). The CBO-guideline mentions that with persistent symptoms, other types of treatment should be considered, an example of this is cognitive behavioural therapy. With persistent symptoms, there

should be greater emphasis on an integral treatment with more focus on both physical and mental aspects of the health of the patient. The CBO-guideline does not recommend retreatment with antibiotics for these chronic symptoms (45). However, it is mentioned that the authors of the guideline did not reach consensus about the treatment of CLD with antibiotics. Moreover, when the pre-test probability of having Lyme borreliosis is very low, treatment should not be offered, even with a positive serological test (4).

### 2.2.2 Guidelines of the International Lyme and Associated Disease Society

The authors of the ILADS-guideline state that their recommendations are only focusing on treatment for Erythema Migrans and persistent symptoms but are representative for the disseminated and late stage as well (16). It is not stated in the guidelines which treatment should be offered for which manifestation of Lyme borreliosis; this decision is left to the physician. The ILADS-guideline includes the 'role of patient preferences' in their recommendation (16). They for example state a doctor could discuss the risks, benefits and the options for the patient. Shared-decision making, the process where a patient is involved in decision making (46), is mentioned multiple times and is considered of high value (16). The ILADS-guideline places greater emphasises in the avoiding and curing of CLD. As a result of that, if physicians think it is suitable, longer treatment than recommended can be prescribed. It is specifically mentioned that when persisting symptoms occur, retreatment should be considered: *"Clinicians should continue antibiotic therapy for patients who have not fully recovered by the completion of active therapy"* (47).

## 2.3 Available literature on determinants that influence choice of provider

### 2.3.1 General research related to the choice of provider

There have been several studies which map determinants that influence choice of provider by patients, focussing on medical tourism in Europe (48) or Organisation for Economic Co-operation and Development (OECD) countries (49), chronic-ill (50) and patients' choices more generally (51).

A systematic review of multiple studies (51) about patients preferences of providers showed that possible outcomes of treatment seem to be of less importance for patients compared to provider characteristics. A lower waiting time and a higher quality of services are examples of provider characteristics that positively affect patients' preferences for a provider (48–51). A DCE (50) focussed on treatment of chronic-ill patients in primary care showed that the seniority of a practitioner, the distance to the provider but also the costs influence patients' choices. It seems that patients sometimes travel for treatment if treatment in a foreign country is offered at a lower price (49). Patients are less likely to opt for a provider when co-payments are high (51).

In addition, both expertise and attitude of a physician influences choice (51). More specialised providers have a higher chance of being chosen, especially when the provider suits patient's wishes. Patients are more likely to choose for an understanding and friendly acting provider. Shared decision making is appreciated by patients as well.

### 2.3.2 Literature on determinants that influence choice of Lyme patients

In addition to this more general oriented research, a few articles are available that focussed on preferences of patients with Lyme disease. A closely related study from Canada aimed to find out why patients with Lyme disease seek care outside the Canadian healthcare system (14). This research focussed on diagnosis and treatment of Lyme borreliosis and held interviews among 45 patients. It seemed that patients are simultaneously pushed away from regular care and pulled into alternative care. Based on this, the researchers developed a 'push—pull' model with is presented in figure 2.

The start of the model within the 'push' section focusses on experiences with the regular healthcare system. All the patients from the research started within the regular care but have had negative experiences with regular providers. An example of such an experience is misdiagnosis because physicians did not take patients seriously. Patients are often 'being laughed at' by regular physicians, whilst alternative providers showed more respect. A sceptical attitude from a physician negatively affects the patient-provider relationship (22). Patients felt limited in their treatment options because long-term treatment is not available in the regular sector as well (14). These negative experiences created concern among patients about the knowledge of physicians, as described under the 'cognitive reaction' part. Care is therefore often sought at physicians specialised in Lyme disease (LLMDs). All these aspects together resulted in patients seeking care outside the regular system, since their symptoms and quality of life only had become worse.

The second start of the model, within the 'pull' section describes how patients are being attracted to the alternative sector (14). Alternative physicians seem to be more caring and understanding. In addition, patients from support groups often recommend these alternative providers. Lastly, the internet was also a way for patients to gain information about alternative care. Many patients felt accepted by alternative providers, which is part of the 'cognitive and psychological part' and sometimes, patients already preferred alternative medicine. These factors attracted patients to seek care within the alternative system. Nevertheless, there were also disincentives related to both the 'pull' and the 'push' part (14). There are costs related to seeking alternative care, from both an emotional and financial point of view. Moreover, sometimes patients were not certain about their choice to opt for alternative care since this choice is not straightforward.

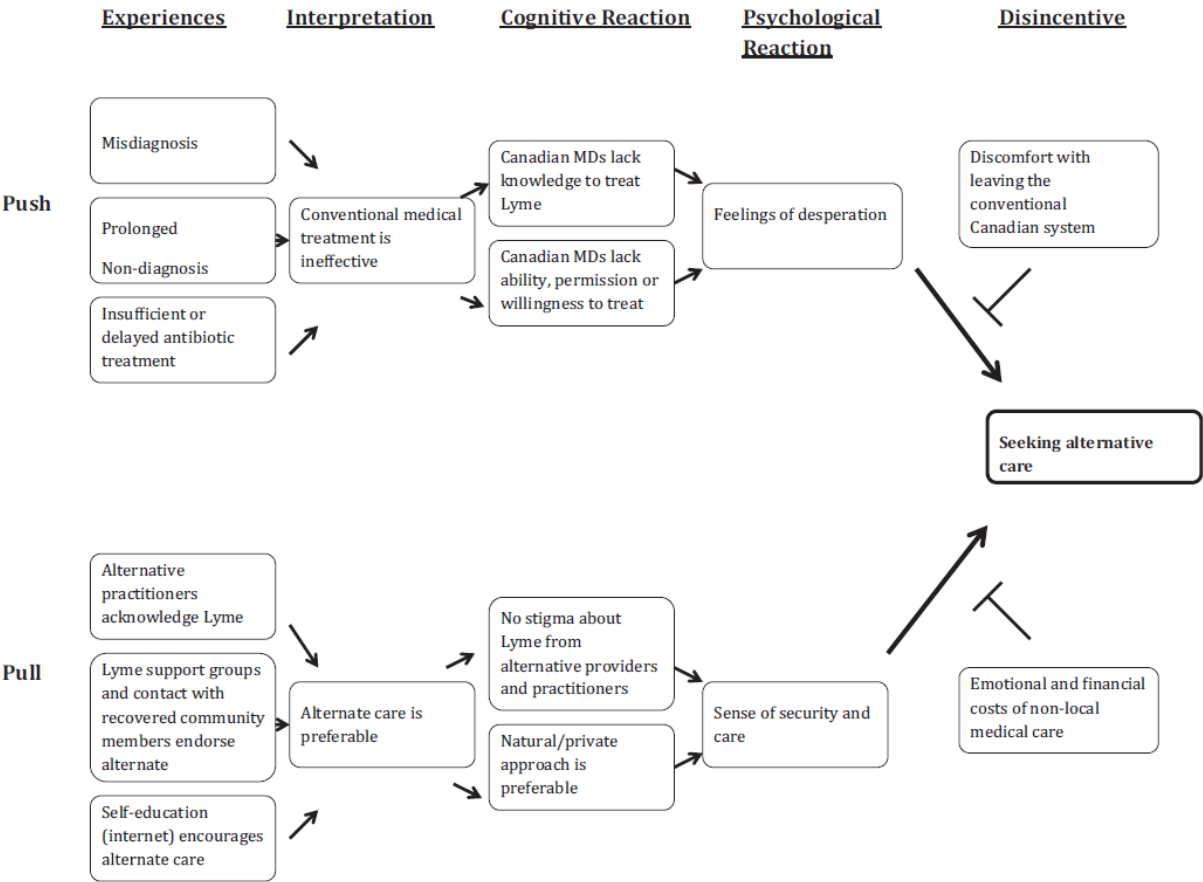


Figure 2: Canadian push-pull model of patients from regular to alternative care as developed by C. Boudreau et al. (14)

A survey from a patients' platform including over 6,000 patients from the United States reported determinants that influence a patient's decision to seek risky (alternative) treatment (52). These factors were, compared to previous mentioned factors, more related to disease outcomes, and included factors as 'severity of illness'. However, the costs of the treatment as well as the availability of alternative treatment were also mentioned. Regular treatment of Lyme disease is reimbursed in the Netherlands, but alternative treatment and cross-border care often not (30,53). This might make alternative providers less attractive (51), since patients are less likely to choose providers with high co-payments.

Research from the *Lymevereniging* among Dutch patients shows that alternative or cross-border care is consumed because patients are stigmatized by regular physicians (24). Dutch patients also feel as if they are not taken seriously within the regular system (23–25). A research from Wageningen University tried to analyse if the Dutch diagnosis and treatment should be improved (25). The research included 32 Dutch general practitioners (GPs) and fulfilled a literature review. According to this research, Dutch GPs seem to lack knowledge of Lyme disease, which is a starting point for issues in the patient-provider relationship. A report from the Dutch Health Council mentions this knowledge gap among both GPs and specialists as well (23). The Health Council published an advice (23) in 2013 towards the House of Representatives covering many aspects, barriers and problems of Lyme disease. The Council accomplished a literature review as well as stakeholder analysis. Within this report, it is also mentioned that Dutch physicians from the regular system often have a negative attitude against Lyme borreliosis. Patients think physicians do not provide adequate treatment and do not recognize the symptoms of Lyme disease.

Lastly, patients seem to have preferences concerning the guideline followed by a physician, since their platforms specifically support ILADS physicians (21,54) and long-term treatment is only prescribed according the ILADS-guideline (16). Moreover, the *Lymevereniging* states that long-term treatment should be reimbursed (24). Short-term treatment often provided by GPs, with currently often a duration even shorter than recommended by CBO-guidelines, is perceived as inadequate by patients (23,24).

## 2.4 The adapted model of Kroeger

Paragraph 2.3 showed that a negative attitude, inadequate treatment and lack of knowledge creates problems in the patient-provider relationship, which stimulates patients to search for alternative providers (14,23–25,52). Thus, a physician's attitude and expertise together with the duration of treatment (related to guideline followed) are factors that influence the choice of a provider. Another important factor are the costs of the treatment (52). Other research also mentioned costs, together with variables as travel distance and waiting times (32,48–51). The latter two factors have not been mentioned in the Lyme specific research but might still influence Lyme patients' choices of provider.

An useful framework to classify all factors is the model of Kroeger, which maps determinants that influence the choice of a healthcare provider (32). Kroeger stated that there are three different types of explanatory variables of choice, which might be interrelated. These types are 'characteristics of the subject', 'characteristics of the disorder' and 'characteristics of the service'. Examples of variables included in the first type are age and income. The second type includes variables like disease severity, but it also considers expected benefits of the treatment. The last type focuses on the service (provider) and includes for instance the costs of the treatment and the accessibility of the provider. The model of Kroeger can be adapted to the specific case of choice of provider for treatment of Lyme borreliosis. The different healthcare providers, in his model called 'healthcare resource', become the GP, the Lyme specialist from a hospital, an alternative provider and no provider. The explanatory

variables included are based on the earlier research mentioned in this chapter. Figure 3 shows the adapted model of Kroeger.

The model has been used to select determinants of focus for this research. Most factors influencing choice of provider, especially by Lyme patients, seem to fit within ‘characteristics of the provider’. Therefore, this study focussed on this type of explanatory variable. Factors that fit within the characteristics of the provider are for example the attitude of a physician and the patient-provider relationship. ‘Characteristics of Lyme borreliosis’ are partially included in the survey as well, with the use of disease-related questions, but are not the focus of this study. Only the *Lymedisease.org* study mentioned that these factors might influence the choice of provider (52). This study included sociodemographic variables to gain insight into the possible influence of ‘characteristics of the patient’.

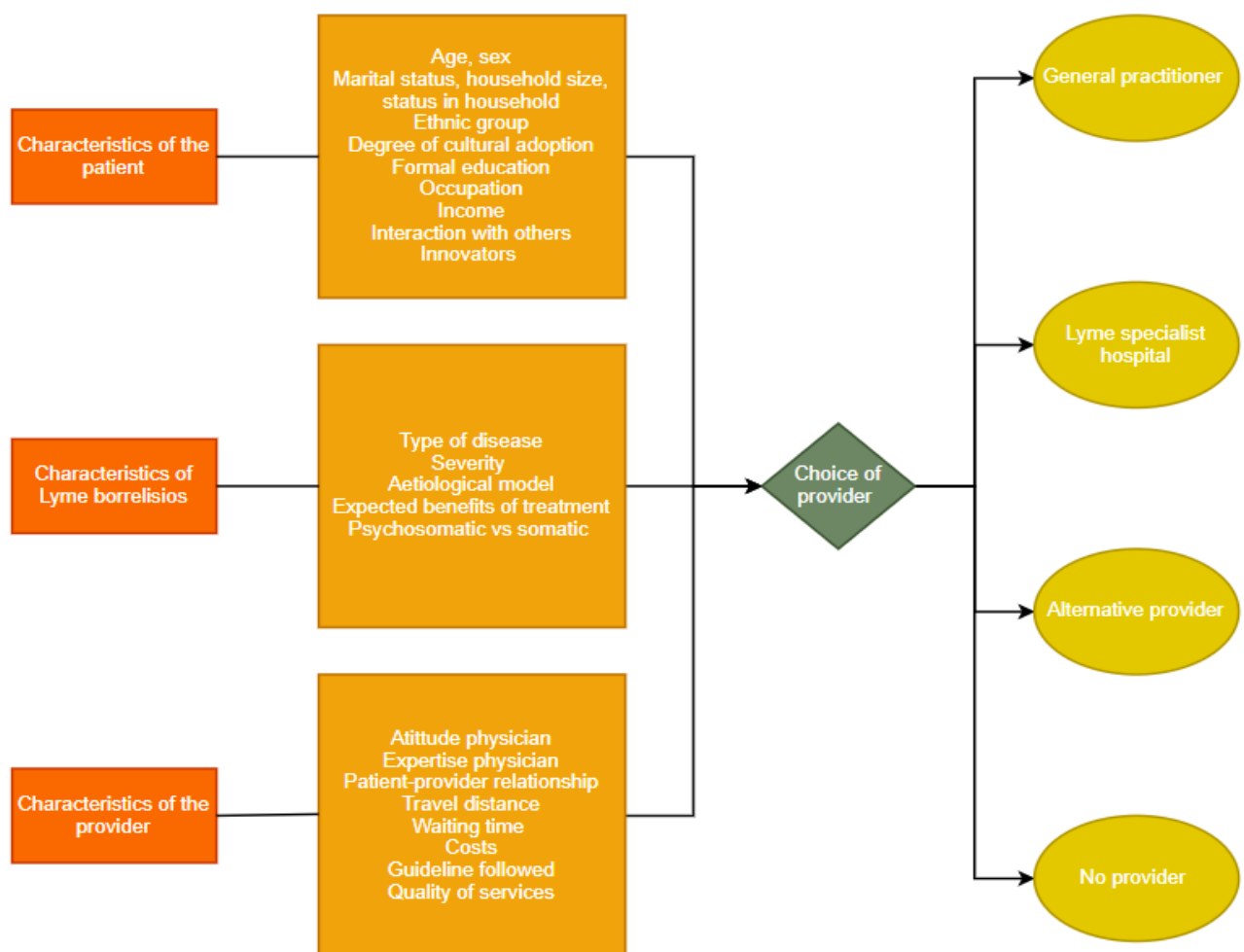


Figure 3: Adapted model of Kroeger showing determinants influencing choice of provider by Lyme patients (32)

## 2.5 Methods to analyse patients’ preferences

According to V. Soekhai et al (55), there are 32 possible methods to identify patients’ preferences. Identification of patient preferences is possible in both a qualitative, often called ‘explored methods’ and a quantitative, or ‘elicitation methods’ manner. The research of C. Boudreau et al. (14) is an example of an explorative research. Because quantitative research concerning the preference of Lyme patients is lacking even more than qualitative research, this research aimed to contribute to

the literature by using an elicitation method. Nevertheless, interviews were held with providers which also adds to the available qualitative research.

In total, there are four different groups covering all possible elicitation methods, namely a DCE, ranking, rating and indifference techniques (55). Different methods are classified within these overall groups (55), for example time-trade-off, which is an indifference technique. A distinction can be made between revealed preference- and stated preference methods. Revealed preference methods use real life market data. With a stated-preference method like a DCE, preferences are indirectly derived in a quantitative way with the use of questionnaires (56,57).

A DCE is a promising and increasingly used tool over the years to analyse patients preferences (55,58,59). In addition, stated-preference methods are based on multiple theories, as for example Random Utility Theory (RUT) which is explained in paragraph 2.5.1. DCEs can be used for many applications and examples are integrating patients in decision making processes or gaining insight into a patients' willingness to pay (56). Thus, a DCE is a real promising and increasingly used method. However, there has not been any DCE yet to measure Lyme patients' preferences, nor are there many discrete choice studies that analysed patients' preferences for provider characteristics published yet. This research therefore used a DCE to analyse Lyme patients' preferences for provider characteristics. In the next paragraph, the basics of a DCE are further explained.

### 2.5.1 Discrete choice experiment

Within a DCE, patients are asked to choose between different alternatives (57). These alternatives can for instance be treatments or providers. Sometimes, an option not to choose any of the alternatives, called a non-option, or an option to keep the current treatment or provider, called a status-quo option is included. The alternatives can be described by characteristics like travel distance, called attributes (57,60). These attributes can be described by different levels, think about one hour or 30 minutes. A question in which a respondent is asked to choose between the alternatives is called a choice task (57).

The theories behind DCEs are mainly RUT and Lancaster's theory of value (57,61). RUT is a Nobel-prize winning theory developed by McFadden (60), an econometrician. According to McFadden, the utility that a person, in this case a patient, derives consists of two components, namely, a systematic component ( $V$ ) and an unobserved component  $\epsilon$  (57,61,62). Lancaster's theory assumes that the utility a patient gains from a treatment or provider is based on the characteristics of the alternative (57).

Combining these two theories, it is possible to state that the utility a patient derives from a provider is based on the attributes and levels,  $V_j$ , of the alternative and an unobserved component,  $\epsilon$  (57,61,62). The utility gained from  $\epsilon$  is unobservable for the researcher, but can be caused by for instance measurement error (57). The utility which is perceived by a patient can be calculated by an analysis of the choices of patients. Within this DCE where patients choose between providers, rational patients will opt for the provider that delivers them the most utility.

### 2.5.2 Statistical models for analysing preferences

There are multiple factors important while designing a DCE, including the experimental design, which is basically the combination of attributes and levels (see chapter 3) and the statistical model (59). The experimental design influences the statistical model, and the statistical model influences the experimental design. Determining the statistical model upfront can increase the statistical efficiency of the DCE (63). Different statistical models can be used to analyse patients' preferences.



Almost every DCE uses a conditional logit model, also called multinomial logit (MNL) model, as a starting point, and to analyse preferences of the general (patient) population (61). This model however assumes homogeneity among preferences of patients. Two other often used models that can account for heterogeneity in preferences are the latent class model (LCM) and the mixed logit (MIXL) model (64). The three models are further explained in this paragraph.

#### 2.5.2.1 The multinomial logit model

The MNL uses the combination of McFadden's and Lancaster's theory (57,61,62) to analyse preferences and choice probabilities. As mentioned before, a Lyme patient will choose the provider with the most attractive attribute-level combination. The equation of the utility function is as follows (61):

$$U_j = \beta_j * X_j + \varepsilon \quad (1)$$

With  $V_j$ , the structural part of the utility function being  $(\beta_j * X_j)$ .  $\beta_j$  is the coefficient from which it is possible to identify preferences, since the coefficient shows the increase in utility caused by that specific attribute level compared to the reference level (61). A positive  $\beta_j$  indicates that the attribute level is preferred relative to the reference level, a negative  $\beta_j$  shows the opposite. Within this model, the choice probability for an alternative can be calculated by dividing the exponent of the utility derived from the chosen alternative ( $V_j$ ) by the sum of the exponent of the utility derived from all alternatives available ( $V_k$ ) (61). The choice probability is the probability a patient chooses alternative  $j$  above all other available alternatives.

$$Prob(Y = j) = \frac{\exp(V_j)}{\sum_{k=1}^j \exp(V_k)} \quad (2)$$

As mentioned before, this model assumes preference homogeneity, meaning every patient has the same preference (61). In addition, the random component ( $\varepsilon$ ) is assumed to be independently distributed and does not differ per patient either.

#### 2.5.2.2. The latent class model

The LCM does account for preference heterogeneity within classes (61). Between the classes with different patient groups, preferences are assumed to differ. While within the classes, preference homogeneity is assumed. The preferences within one class can be calculated with the use of the MLN calculations. Both the utility function and the choice probability calculations can be calculated with the use of equation (1) and (2) within each class. It is possible to analyse variables that could explain class-membership, think about demographic variables, as well (65). Such variables can indicate if for example an older patient is more likely to belong to a certain class.

#### 2.5.2.3 The mixed logit model

The MIXL model is also applicable to heterogenous preferences. However, where the LCM assumes that preferences within one class are equal, the MIXL model assumes that every patient has its own preference (61). Thus, there are differences between preferences on the individual level. Again, the model is still based on the same underlying theories, but the equations are adapted to account for heterogeneity. The utility equation is as follows (66):

$$U_j = x_j \beta_i + \varepsilon \quad (3)$$

Where  $V_j = x_j \beta_i$ .  $J$  again presents the chosen alternative and  $\beta_i$  are individual level coefficients (61,66). The choice probability function is equal to equation (2). The MIXL model makes estimations about the whole patient population but results in coefficients on the individual patient level. The

individual level coefficients are assumed to be normally distributed and therefore, the coefficients are presented as means with standard deviations (61,66). These standard deviations represent the amount of heterogeneity in the population (61). A bigger standard deviation is an indicator of greater preference heterogeneity. However, if these standard deviations are not significant, it is assumed that the attribute (level) is not random and no heterogeneity in preferences for this attribute (level) exist. With the MIXL model, attributes can be included as fixed and random attributes. Attributes in which preference heterogeneity is expected can be included as random (66). Again, the random parameter ( $\epsilon$ ) is independently distributed.

In the next chapter, choices about these statistical models as well as the DCE for this research are deliberated on.

## 3. Methods

To answer the research question, a mixed-method design was used. To assess patient preferences, a DCE was developed, which is an useful and increasingly used tool to measure preferences (56,57). With the DCE results in mind, providers were interviewed to gain further insight into patient preferences in practice.

### 3.1 Discrete choice experiment among patients

The DCE was used to gain insight into the preferences of the patients concerning the patients' characteristics as well as possible preference heterogeneity and choice probabilities. The results of the DCE were used to answer the first three sub-questions.

#### 3.1.1 Data collection of the discrete choice experiment

A DCE was held among Dutch patients with non-Local Lyme borreliosis. Patients with local Lyme borreliosis were excluded because they often experience a noncomplex treatment pathway (4). The survey focussed on the Netherlands; only Dutch speaking respondents were included. In addition, a respondent should currently have non-Local Lyme disease. No distinction was made between self-diagnosed, diagnosed by alternative provider or diagnosed within the regular healthcare sector. Patients could only continue with the survey if they gave their informed consent.

Respondents were mostly gathered using Social Media platforms. Recruitment messages were posted on multiple Facebook support groups, as well as WhatsApp, LinkedIn and Instagram. In additions, flyers were spread in public areas, doctors' offices (with permission) and in mailboxes. The aim was to include at least 100 respondents. The data collection for the pilot study started the 29<sup>th</sup> of March and ended the 3<sup>rd</sup> of April. The final DCE was open from the 5<sup>th</sup> of April until 13 May.

#### 3.1.2 Experimental design of the discrete choice experiment

As explained in chapter 2, a DCE consist of choice tasks where respondents choose between alternatives. In this case, the alternatives were two providers, and the attributes described the providers' characteristics. The choice of these attributes was based on the adapted model of Kroeger from chapter 2, and their levels were based on real life options. Table 1 presents the included attributes and levels. The adapted model of Kroeger (32) also included the variables waiting time and quality of services. However, none of the Lyme-specific research mentioned that waiting time influences patients' decision for their provider. Moreover, the perceived quality of services seems to be subjective in the case of Lyme disease, since there are many differences in what is perceived as 'good quality'. The quality of a service might also be correlated to other attributes, as for example the expertise. Therefore, both the waiting time and the quality of services were excluded.

The survey also included socio-demographic and disease related questions to analyse 'characteristics of the patients' and 'characteristics of Lyme borreliosis' included in the (adapted) model of Kroeger (32). Each attribute and level were explained within an information page to ensure understanding among all respondents. In example, the expertise of a provider was explained by the number of Lyme patients per year. The whole survey is included in appendix 1, in which the information page is also available. Each respondent answered sixteen choice tasks, including one dominant choice task. A dominated choice tasks is a question in which one alternative has a better level on all attributes compared to the other alternative (56). With this task, insight is gained into the internal validity of the DCE because the dominated choice task is a check of the quality of the responses.

Because there was no clear expectation of the preferred type of decision-maker, this level stayed equal for both options. The dominated alternative had the following aspects: the costs of the treatment was 385 euros, the provider supported the patient, the ILADS-guideline was followed, the

provider was specialised in Lyme disease and situated within the municipality. In figure 4, an example of a choice task is shown. An opt-out option was not included because it was not expected that many patients would opt for no-provider, since their symptoms will only deteriorate when no treatment is consumed. In addition, excluding the opt-out this reduces the number of choice tasks needed, which improves the response efficiency, and increases the information gained from each respondent per choice task (56).

*Table 1: Attributes and levels as included in the discrete choice experiment*

Attributes	Levels
Decision maker	Physician decides Patient makes informed decision Shared decision of physician and patient
Costs of treatment (euros)	385 1.000 5.000 10.000
Attitude of provider	Physician discourages patient Physician supports patient
Guideline followed	CBO*-guideline: short-term treatment (max. 1 month) ILADS**-guideline: long-term treatment (min. 1 month)
Expertise of provider	Basic experience (20 patients each year) Intermediate experience (100 patients each year) Specialised in Lyme disease (1 patient a day)
Travel distance	Within municipality Within province (outside municipality) Within the Netherlands (outside province) Within Europe (outside Netherlands) Outside Europe

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If you need to choose between these two providers for the treatment of your Lyme disease, which one would you choose?

(2 out of 16)



	Provider A	Provider B
Decision maker	 <p><b>Shared decision</b> of physician and patient</p>	 <p><b>Patient</b> makes informed decision</p>
Costs of treatment	€1.000	€5.000
Attitude of provider	Physician <b>supports</b> patient	<b>Physician</b> discourages patient
Guideline followed	<b>ILADS</b> guideline: long-term treatment (min. 1 month)	<b>CBO</b> -guideline: short-term treatment (max. 1 month)
Expertise of provider	<b>Basic expertise</b> with approximately 20 patients each year	<b>Average expertise</b> with approximately 100 patients each year
Travel distance	Within <b>municipality</b>	Within the <b>Netherlands</b> outside province

Figure 4: Example of choice task as presented in the discrete choice experiment

It is possible to present all respondents all possible choice tasks that can be made out of the combinations of the attribute (levels), which is called a full-factorial design (59). However, the number of the possible combinations is often much higher than what is possible to include in a DCE of a normal length. Therefore, a non-full factorial design was used because of the possibility to limit the number of choice tasks, which decreases the chance on measurement error caused by for example fatigue (56,57,59). A Bayesian design can increase the statistical efficiency of the DCE (63). With Bayesian designs, prior estimates of the coefficients (called priors) from the utility function are used to determine which combinations of attribute(levels) are presented in DCE, which is called the design. Then, the design with the highest statistical efficiency is chosen. The statistical efficiency is often presented in the form of a D-error (59,63) which is based on the variance-covariance matrix (59). The lower the variance, the lower the D-error (63). To summarize, this DCE was developed with the use of a non-full factorial Bayesian design.

This research used a pilot study to be able to compose better fitting priors which increases the statistical efficiency (63). With updating the priors, it is possible to increase the statistical efficiency, because the design has a higher change on fitting the actual preferences of the patient. The initial design was developed in Ngene (67) in which priors were based on intuitiveness. The priors were estimated with an uniform distribution and the design with the lowest D-error (0.29) was chosen and imported into Lighthouse 9.10.1 (68). The preference for guideline and for decision maker was unknown before the pilot. Therefore, these priors were set to zero, indicating that patients are indifferent between the levels.

In total, there were two versions of the questionnaire used to ensure that all levels appear an equal time (level balance) in all tasks except 'costs', and to limit the choice tasks per respondent. These versions (often called 'blocks') differed in their attribute levels presented in the choice tasks, except the dominated choice tasks which stayed the same in both versions. Respondents were assigned randomly to one of the two blocks. Lighthouse 9.10.1 (68) was used to develop and publish the questionnaire.

The survey was then tested face-to-face with four respondents to discover errors and ensure feasibility. The respondents were representative for the target group and included patients with neuroborreliosis, CLD and Lyme arthritis, three of them opted for alternative providers, but all had experience with providers from the regular sector. Only minor changes were made after the test-phase. Thereafter, the pilot study was held to be able to update the priors. Paragraph 3.1.4 provides more information about the pilot study. Ngene was then used again to develop a Bayesian efficient design. The D-error of the final design was 0.35. This D-error is higher caused by higher variances than the pilot study but fits the actual preferences better.

### 3.1.3 Statistical analysis of the discrete choice experiment

Stata 16.0 (69) was used for the statistical analysis of the DCE. Descriptive statistics were used to analyse variables of age, income, sex, education, disease stage, disease severity, duration of disease, the time before final diagnosis, current provider and their satisfaction with the provider, costs of treatment and travel distance. A MNL model has been used to analyse the general preferences (61). Equation 4 shows the utility function of patients' choice of provider, where levels are coded as categorical with dummy variables. No alternative specific constant has been included because left or right-bias was not expected.

$$U_j = \beta_1 Decision_{patient} + \beta_2 Decision_{shared} + \beta_3 Costs_{1000} + \beta_4 Costs_{5000} + \beta_5 Costs_{10000} + \beta_6 Attitude_{discouraging} + \beta_7 Guideline + \beta_8 Knowledge_{intermediate} + \beta_9 Knowledge_{specialist} + \beta_{10} Travel\ distance_{province} + \beta_{11} Travel\ distance_{Netherlands} + \beta_{12} Travel\ distance_{within\ Europe} + \beta_{13} Travel\ distance_{outside\ europe} + \varepsilon \quad (4)$$

The attribute level with the highest coefficient ( $\beta$ ) is the most preferred level of that attribute whereas the level with the lowest coefficient is the least preferred level of that attribute (61). The calculation of the relative importance of the attributes started by a deduction of the coefficients of the most- and least preferred levels of each attribute ( $\beta_{most} - \beta_{least}$ ). The most important attribute is the attribute with the biggest utility difference between the most- and least preferred levels. By dividing ( $\beta_{most} - \beta_{least}$ ) for any attribute with the coefficient of the most important attribute, the relative importance of the attribute was derived. With the calculation of the relative importance, the first sub-question was answered, and the first hypothesis was tested. If the travel distance and the costs are indeed the most important attributes, then their ( $\beta_{most} - \beta_{least}$ ) are the highest.

The LCM was used to find out possible preference heterogeneity. A LCM better fits this research than a MIXL model because of the relatively small respondent group. A MIXL model needs more respondents to be able to analyse preferences in a statistical efficient way. Moreover, no individual level differences in preferences were expected. With the LCM, the coefficients were calculated using the MNL model, using equation 4. Consistent Akaike Information Criterion (CAIC) measurement was used to analyse the optimum number of classes (65), considering the minimum share of data in one group (20%) and possible class-membership explanations. The CAIC is a way to analyse the quality of a model (65,70). The lower the CAIC, the better since the measurement shows the difference between the actual results and the model (70).

Each class then received its own utility function with its own parameters. Afterwards variables which could explain class-membership were determined. Explanatory variables that were included in the analyses were the current provider, satisfaction with the current provider, current costs paid for treatment, the travel distance to the latest provider, the current self-assessed health status, the time before final diagnosis, the type of the disease, duration of the disease, and age, education, and income. A significance level of 0.05 was used to indicate if explanatory variables were statistically significant. With the explanatory variable of current self-assessed health status, the second hypothesis, *'Lyme patients with a self-assessed poor health status are more likely to prefer alternative treatment compared to patients with a self-assessed good health status'* could be tested as well.

In addition, choice predictions were made to be able to analyse which type of provider has the highest probability to be chosen. With the calculation of these choice probabilities, sub-question three was answered and hypothesis three was tested. An alternative provider is in this case a provider that follows the ILADS-guideline and that is specialised in Lyme disease. Since the provider can be situated within and outside the Netherlands, calculations using all statistical levels of travel distance are made. In addition, the choice probability predictions for a specialised regular provider were calculated. This provider follows the CBO-guideline and is situated within the Netherlands. Therefore, predictions using all statistically significant levels of travel distance within the Netherlands were made. These choice probabilities could however present an overestimation, since no opt-out or status-quo option was included (57). This forces patients to choose for a provider, even if they would rather opt for no provider at all. The choice probability has been calculated according to the following formula (61):

$$Prob(Y = j) = \frac{\exp(V_j)}{\sum_{k=1}^j \exp(V_k)} \quad (5)$$

Where  $V_j$  indicates the utility gained from the alternative of interest within the structural part of the utility function and  $V_k$  the utility of all available alternatives. The probability of choosing alternative  $J$  over another alternative is calculated by dividing the exponent of the utility of the chosen provider by the sum of the utility of the available providers of the choice task,  $k$ .

#### 3.1.4 Pilot of the discrete choice experiment

In table 2, the priors for the pilot and the final study DCE design can be found. Based on the face-to-face tests, the priors for the pilot study concerning guideline were changed with preference for ILADS. In total, 54 respondents who have non-local Lyme disease and gave their informed consent started with the pilot questionnaire. The survey was completed by 18 respondents. 36 respondents were used to analyse preferences, including data from the four test respondents and participants that started with the choice tasks but did not finish the whole questionnaire. Including participants who did not finish the choice tasks might reduce statistical efficiency. Twenty percent of the respondents quitted during the demographic and disease related questions. While filling in the choice tasks, 30% of the respondents stopped. The data was analysed with the use of a MNL model, using a p-value of 0.05 as cut-off point. When coefficients were significant and logical, the final priors were based on these parameters with the use of the normal distribution and standard errors. When parameters were not significant, the results of the pilot study and the pilot priors were combined to determine the prior for the final DCE study.

Table 2: Prior information used for generating the pilot and final study discrete choice experiment design

		Priors					
		Pilot study		Final study		Prior	SD
Attribute	Level	Lower bound	Upper bound	Lower bound	Upper bound		
Decision maker	Physician	Ref.					
	Patient	0.00	0.00	0.01	0.05	n/a	
	Shared decision	0.00	0.00	0.10	0.20	n/a	
Costs of treatment	385	Ref.					
	1.000	-0.15	-0.05	-0.15	-0.05	n/a	
	5.000	-0.30	-0.20	-0.25	-0.15	n/a	
	10.000	-0.45	-0.35	n/a	-0.80	0.27	
Attitude of provider	Discourages	Ref.				-1.23	0.23
	Supports	0.40	0.50	n/a		Ref.	
Guideline followed	CBO*	Ref.					
	ILADS**	0.30	0.40	n/a		1.52	0.25
Expertise provider	Basic	Ref.					
	Intermediate	0.10	0.20	0.20	0.30	n/a	
	Specialised	0.30	0.40	n/a		0.61	0.26
Travel distance	Within municipality	Ref.					
	Within province	-0.05	0.00	-0.15	-0.05	n/a	
	Within country	-0.15	-0.10	-0.30	-0.15	n/a	
	Within Europe	-0.35	-0.25	-0.45	-0.30	n/a	
	Outside Europe	-0.45	-0.35	n/a		-1.05	0.38

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### 3.2 Interviews among providers

The second part of this research consisted of interviews with providers to gain insight into the expectations and experiences of providers in the preferences of patients. With the interviews, the last sub-question is answered. Semi-structured interviews were held with five providers of treatment of Lyme borreliosis in the Netherlands to discuss the DCE results and to gain more insight into physicians' opinions about patient preferences. The questions were based on the results of the DCE. Therefore, the interviews were planned after the analysis of the relative importance of the attributes was done. The interviews started general and open, with questions about physicians' experiences with Lyme disease. Then, physicians were asked to explain which attribute they thought would be most important for patients, which not and why. With this, the hypothesis concerning the lack of alignment between patients' preferences and providers expectations could be tested. The results of the DCE were introduced after the providers themselves explained their thoughts about patients' preferences. The interview guide is included in appendix 2.



Multiple GPs, Lyme specialists and alternative providers were approached with the use of e-mail, LinkedIn and WhatsApp. Interviews were held digitally and were, with permission, audio recorded. Informed consent was gained by, for example, explaining that participation is voluntary and anonymous and that the respondent can withdraw its participation until delivery of the research. Final results were sent to participants for a member check, no participant expressed any objections. The audios were transcribed manually in an anonymously way. The coding process was done in Atlas.ti using an inductive coding process (71,72).

Inductive coding was used because of the open approach of the interviews which resulted in were possible straight directions of codes before the interviews started. The inductive coding made it possible to find theories to answer the sub-question and thereby the research question. The coding process started with the use of open coding, in which summarizing labels are given to parts of sentences or paragraphs that fit within one subject (71,72). Only possible relevant parts of the interviews were given open codes. Then, open codes were classified within axial codes, using categorial coding (72). These axial codes were mostly based on the DCE attributes. In addition, three other axial codes were added to cover open codes that did not fit within one of the attributes. During this process, open codes were also adapted, merged when having synonyms, and removed when codes became irrelevant (71,72). The last part of the process was selective coding, in which connections between the different types of codes were found to be able to answer the sub-question. An example of the coding within Atlas.ti can be found in appendix 3. Quotations have been translated to English and were checked by another researcher to be able to identify possible misinterpretation caused by translation.

### 3.3 Ethical considerations

Since this research gathered data from human beings, there are some ethical considerations, related to both the survey and the interviews. For both data gathering methods, it was most important to gain informed consent. Before the start of the survey, respondents were informed about the subject and aim of the study. The researchers e-mail address was displayed to make sure that respondents could reach out with questions or objections. After that, they were asked to answer yes or no to ensure that they understood the aim of the research and that they knew that participation is voluntary, anonymous and without financial gain. Respondents were not able to proceed with the questionnaire without a yes in all boxes. It was also stated that the results of the research could be shared with third parties.

During the interviews with physicians, informed consent was gained orally. The aim of the research was explained. In addition, it was emphasized that participation is voluntary, the interview could be stopped at any moment and that data would be processed anonymously. Before the start of the interview, participants were asked to give permission for audio recording (twice). The member check ensured that participants again agreed with the anonymous use of their data for in example quotations. Respondents got one week to submit possible objections and/ or changes. In addition, the transcripts are only available for the researcher, and audio-recordings were deleted once the transcripts were written. This reduces the risk on privacy-issues.

## 4.Results

In this chapter, the results are presented, starting with the DCE among non-local Lyme patients. Then, the results of the interviews with providers of treatment of Lyme borreliosis are shown.

### 4.1 Results discrete choice experiment among Lyme patients

This chapter starts with a description of the patient characteristics. Then, the results from the DCE using both the MNL and the LCM are presented. The relative importance using MNL and LCM and choice probabilities using LCM are included as well.

#### 4.1.1 Demographic variables

In total, 223 respondents started with the DCE, from which 38 were excluded because they did not have Lyme disease. During the demographic and disease related questions, 25 respondents stopped filling in the survey. 60 respondents, taking test, pilot and final study together completely fulfilled the survey. Six respondents that fulfilled the questionnaire within less than 7 minutes were excluded from the analysis, since the average duration of respondents that ended the survey was 15 minutes. However, calculations could also be made with the choice data from respondents that did quit during the choice tasks. This resulted in a total of 95 respondents that could be included in the analysis, including 4 respondents who failed the dominant test. These respondents were included because it might be that these respondents do not want to receive treatment according to the ILADS-guideline, regardless of the costs and other attributes, as well as the already limited available responses on the questionnaire. Table 3 presents the demographic and disease related variable distribution of the respondents included in the calculations.

*Table 3: Demographic- and disease related variables of respondents of the discrete choice experiment*

<b>Variable</b>	<b>N</b>	<b>% of total</b>
<b>Gender</b>		
Male	16	17.2
Female	79	82.8
<b>Age</b>		
<18	3	2.8
18-30	15	15.5
31-50	35	37.1
51-70	40	42.2
>70	2	2.4
<b>Education</b>		
No grade	4	4.3
High school grade	10	10.1
MBO grade	29	30.9
HBO grade	31	32.8
Bachelor grade	3	3.3
Master grade	17	18.3
<b>Netto household income</b>		
<10.000	9	10.0
10.001-30.000	27	28.8
30.001-50.000	16	17.2
>50.000	15	16.1

Does not want to say	27	28.0
<b>Type of disease</b>		
Lyme arthritis	43	45.5
Lymecarditis	14	14.3
Neuroborreliosis	65	68.7
Acrodermatitis Chronica Atroficans	13	14.1
Chronical Lyme Disease	73	77.0
Post-Lyme disease syndrome	21	22.1
Other:	10	15.2
<i>Co-infections</i>	5	45.5
<i>Cognitive complaints</i>	2	18.2
<i>Epstein Barr Virus</i>	1	9.1
<i>Multiple Systemic Infectious Disease Syndrome</i>	1	9.1
<i>Relapsing fever</i>	1	9.1
<b>Time before diagnosis</b>		
<1 year	23	25.3
1-3 years	24	26.4
4-6 years	11	12.6
>6 years	32	35.3
<b>Years having Lyme disease</b>		
<1 year	13	13.7
1-3 years	26	27.4
4-6 years	11	11.6
>6 years	45	47.4
<b>Health status</b>		
Low ( $\leq 4$ )	52	54.9
Average (5-7)	34	35.6
High ( $\geq 8$ )	9	9.5
<b>Current provider</b>		
Physician	7	7.7
Specialist Lyme clinic	10	10.0
Alternative provider	50	52.6
No provider	28	29.9
<b>Satisfaction with provider</b>		
Low ( $\leq 3$ )	10	14.4
Average (4-5)	18	26.1
High ( $\geq 6$ )	41	59.4
<b>Cost paid for treatment</b>		
<385	6	8.0
385-1.000	12	16.5
1.000-5.000	17	22.9
5.000-10.000	18	24.0
>10.000	21	28.3

Do not know	15	20.4
<b>Travel distance</b>		
Within municipality	17	19.9
Within province (outside municipality)	17	20.3
Within Netherlands (outside province)	31	37.0
Within Europe (outside Netherlands)	16	18.8
Outside Europe	4	4.5

Most participants from the DCE are female, around mid-age and receive treatment from an alternative provider. Currently, patients are satisfied with their provider. Most patients receive treatment within the Netherlands. The costs paid for the treatment are relatively spread out. More than half of the respondents graded its own health status with less than a four. While the time until patients received their diagnosis is spread out, most respondents already have Lyme disease for over six years. More than half of the respondents have either perceived a MBO or HBO degree. The yearly household income is relatively spread-out, but most respondents that did answer earn less than modal.

#### 4.1.2 Preferences of the general Lyme patient population

Within table 4, the preferences of the general populations are presented. These preferences were calculated with the use of a MNL. Not all levels are statistically significant, but separate hypothesis testing showed that all attributes influence a patient choice. A negative sign shows that the attribute(level) is less desirable compared to the reference attribute level. A positive sign indicates that this attribute-level is desirable. It seems that higher costs negatively influence preference for a provider whereas being supportive, following the ILADS-guideline, higher expertise and lower travel distance positively influences a patient's preference.

*Table 4: Results of the discrete choice experiment using the multinomial logit model assuming homogeneity in patients' preferences*

Attitude(level)	Coefficient	Standard Error	P-value
<b>Decision maker</b>			
Physician (ref)	0.000		
Patient	0.007	0.113	0.948
Shared Decision	0.114	0.927	0.217
<b>Costs of treatment</b>			
385 (ref)	0.000		
1.000	-0.040	0.111	0.026
5.000	-0.248*	0.104	0.699
10.000	-0.795**	0.140	<0.001
<b>Attitude of provider</b>			
Supportive (ref)	0.000		
Discouraging	-0.906**	0.121	<0.001
<b>Guideline followed</b>			

CBO*** (ref)	0.000		
ILADS****	1.391**	0.162	<0.001
<b>Expertise of provider</b>			
Basic (ref)	0.000		
Average	0.462**	0.120	<0.001
Specialised	0.805**	0.183	<0.001
<b>Travel distance</b>			
Municipality (ref)	0.000		
Province	-0.049	0.114	0.666
Netherlands	-0.203	0.133	0.126
Europe	-0.204	0.112	0.068
Outside Europe	-1.195**	0.202	<0.001

\*= Statistically significant  $p < 0.05$

\*\*= Statistically significant  $p < 0.01$

\*\*\*Dutch quality institute for healthcare

\*\*\*\*International Lyme and Associated Disease Society

#### 4.1.3 Preferences of the 2 different classes

Based on CAIC measures and the relatively low number of respondents, only two classes were used in the analysis. As presented in figure 5, the two-class model had the lowest CAIC numbers. The CAIC numbers are steeply rising when moving from class three to class four. As explained before, a lower CAIC number presents a better fitting model. The difference between class two and class three is not that big, but considering the relatively low respondent number, a two-class model was used for analysis. No more than three classes were possible because of the then very low percentage of preference data (less than 20%) within a class. In addition, with two classes, it was possible to identify explanatory variables for class-membership. Within the two-class model, the share of respondents was respectively 40% within class one and 60% within class two.

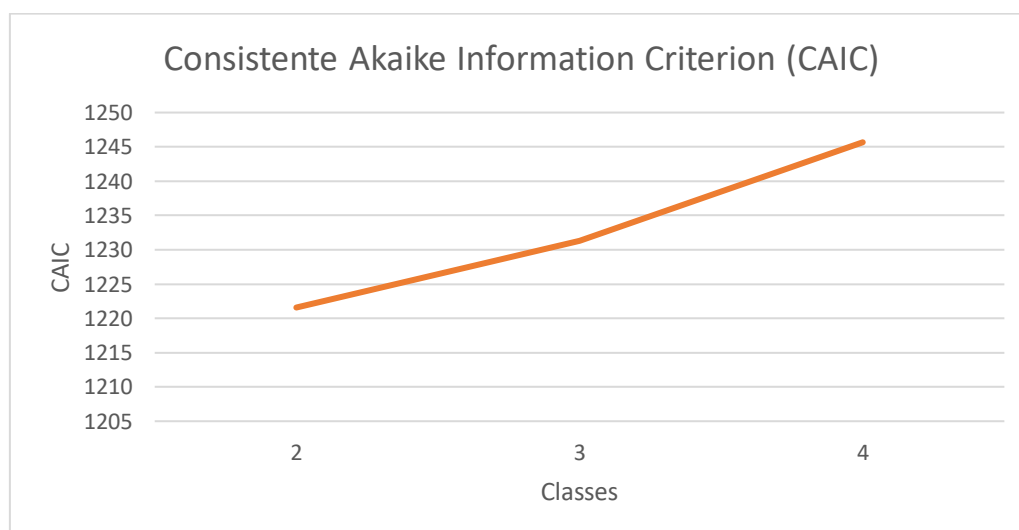


Figure 5: Consistent Akaike Information Criteria for two, three and four classes

The demographic and disease related variables were used to examine possible determinants that could explain class-membership. An individual's health status, costs paid for treatment and the travel

distance to the latest provider were statistically significant explanatory variables. The results of the LCM including explanatory variables are presented in table 5.

Table 5: Results of the discrete choice experiment using the latent class model assuming heterogeneity in patients' preferences

Attribute(level)	Class 1			Class 2		
	Coefficient	Standard Error	P-value	Coefficient	Standard Error	P-value
<b>Decision maker</b>						
Physician (ref)	0.000			0.000		
Patient	-0.095	0.231	0.683	-0.066	0.133	0.624
Shared Decision	0.007	0.241	1.000	0.193	0.141	0.174
<b>Costs of treatment</b>						
385 (ref)	0.000			0.000		
1.000	-0.692*	0.319	0.047	0.173	0.170	0.308
5.000	-0.745*	0.343	0.043	-0.263	0.167	0.115
10.000	-1,258*	0.395	0.003	-0.930**	0.177	<0.001
<b>Attitude of provider</b>						
Supporting (ref)	0.000			0.000		
Discouraging	-1.091*	0.337	0.002	-1.245**	0.133	<0.001
<b>Guideline followed</b>						
CBO*** (ref)	0.000			0.000		
ILADS****	3.656**	0.500	<0.001	0.671**	0.152	<0.001
<b>Expertise provider</b>						
Basic (ref)	0.000			0.000		
Average	0.554*	0.250	0.029	0.560**	0.144	<0.001
Specialised	1.285**	0.302	<0.001	0.721**	0.168	<0.001
<b>Travel distance</b>						
Municipality (ref)	0.000			0.000		
Province	-0.613	0.358	0.089	0.062	0.191	0.744
Netherlands	-0.510	0.334	0.133	0.014	0.185	0.941
Europe	-0.481	0.341	0.174	-0.241	0.191	0.207
Outside Europe	-1.125*	0.383	0.004	-1.400**	0.227	<0.001
<b>Explanatory variables</b>						
Health status low	1.648*	0.577	0.004			
High costs of treatment	1.500*	0.723	0.025			
Last provider within the Netherlands	-1.288*	0.575	0.038			
<b>Class shares</b>						
Class 1	0.404					
Class 2	0.596					

\*= Statistically significant  $p < 0.05$

\*\*= Statistically significant  $p < 0.001$

\*\*\*Dutch quality institute for healthcare

\*\*\*\* International Lyme and Associated Disease Society

Again, not all variables are statistically significant. Within both classes, there is no definitive result conserving the preferred decision maker. Class one and two seem to differ in preferences, see paragraph 4.1.4 for the overview relative importance of all attributes per class. Interestingly there is a strange order in the costs attribute within class two, with the level of 1.000 euros having a positive coefficient. However, this level is not significant. The same is the case in class two for the attribute levels in distance to provider: province and within the Netherlands. Respondents that rated their own health with a relatively low number (three or less) have a higher chance to be in class one. In addition, respondents that had high costs of their received treatment, more than 10.000 euros, are also more likely to belong to class one. When a patient has received treatment within the borders of the Netherlands, he/she is less likely to belong to class one.

#### 4.1.4 Relative importance of attributes

The relative importance of the attributes is presented in figure 6 for the MNL figure 7 for the LCM. The attribute that is seen as the most important within the general population is the guideline. However, using the LCM, the relative importance of the two different classes is not the same.

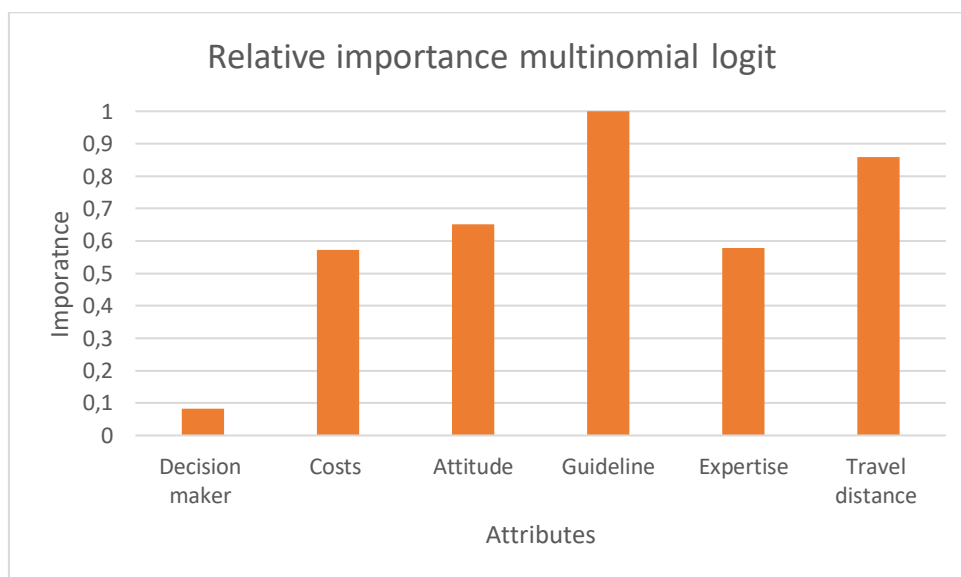


Figure 6: Relative importance of attributes included in the discrete choice experiment using the multinomial logit model

The relative importance using the MNL shows that the guideline is perceived within the general population as the most important attribute, followed by the travel distance and the attitude of the physician. The decision maker seems to be of much less importance than all other attributes, but the coefficients for this attribute are not significant.

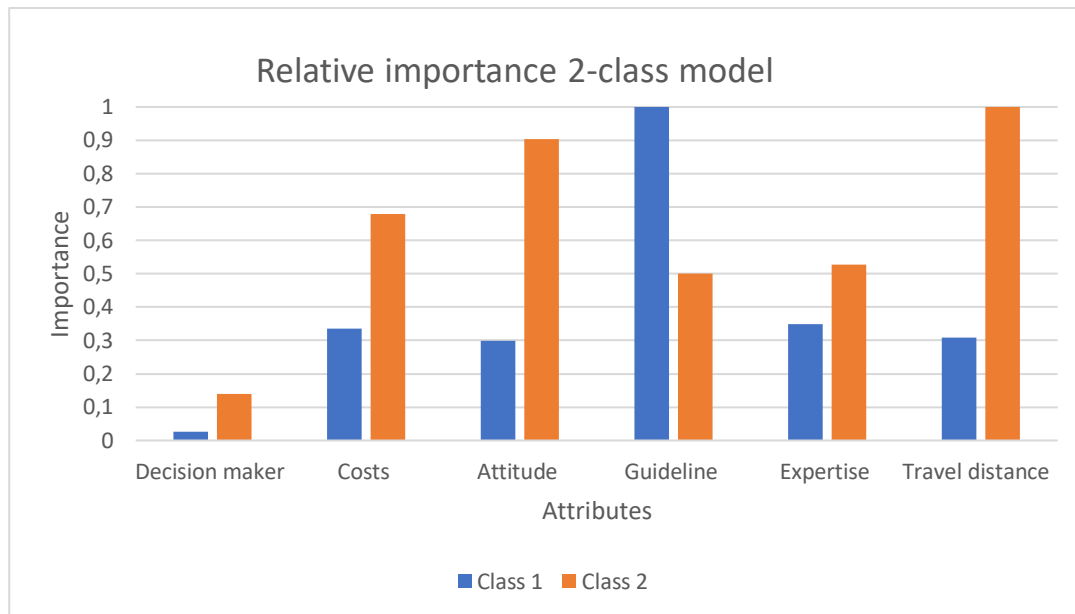


Figure 7: Relative importance of attributes included in the discrete choice experiment using the latent class model

While class one emphasizes the importance of the guideline followed by the provider, travel distance is the most important attribute for respondents from class two. The attitude is the second most important attribute for class two participants, followed by the costs, the expertise, the guideline and lastly the decision maker. After the guideline followed, in order from more to less important, the expertise, the costs, the travel distance, the attitude and the decision maker are important for class one participants in their decision.

Within class one, differences in importance between the attributes, excluding guideline followed and decision maker, are small. The importance of the guideline followed is in class one much higher than all other attributes. The differences between the relative importance are more within class two. Within both classes, the level of decision maker used to calculate the relative importance was not statistically significant, all other attribute levels used to calculate the relative important were significant.

#### 4.1.5 Predicted choice probabilities

The physician with the highest choice probability in both classes is a physician with low costs (385 euros), that supports the patient, that follows the ILADS-guideline, that is specialised in Lyme disease and situated at least within the Netherlands. It is not clear what the preference for decision-maker is, nor or if patients really prefer a physician within the municipality compared to within the province, since these levels were not significant. Therefore, the reference level for both attributes was used in this calculation.

Table 6 presents the choice probabilities. The choice probability for the 'best' (alternative) physician compared to the physician of reference within class one is 99% and within class two 80%. The 'worst-case' physician is a physician where patients must pay 10.000 euros, the CBO-guideline is followed, the attitude of the physician is discouraging, and the physician is situated outside Europe. Again, the reference level was used for the utility gained from the decision-maker. Only 2.9% of the individuals from class one is likely to opt for this physician compared to the reference physician and only 2.6% of class one. The choice probability of the alternative common physician was also calculated, this alternative physician is the best physician but then with the highest costs and the farthest travel



distance. Calculating choice probabilities with using other travel distances was not possible because these coefficients were not significant. The choice probability for the Lyme CBO specialist was calculated with the use of the reference level of the travel distance attribute for the same reason.

*Table 6: Choice probabilities of different types of providers using the latent class model*

Choice probability *	Class 1	Class 2
<b>Best provider: alternative within Netherlands (reimbursed)</b> <i>Levels: physician decides; 385 euros; supporting attitude; ILADS**; specialised; within municipality</i>	99.29%	80,09
<b>Alternative provider common</b> <i>Levels: physician decides; 10.000 euros; supporting attitude; ILADS**; specialised; outside Europe</i>	92.61%	28.12%
<b>Regular Lyme clinic specialist</b> <i>Levels: physician decides; 385 euros; supporting attitude; CBO***; specialised; within municipality</i>	21.67%	32.72%
<b>Worst provider</b> <i>Levels: physician decides; 10.000 euros; discouraging attitude; CBO***; basic; outside Europe</i>	2.92%	2.70%

*\*The choice probability was calculated relative to the reference option. A provider where the physician makes the decision, with costs of 385 euros, who's attitude is supporting, who follows the CBO-guideline, who has basic expertise and who is located within the municipality.*

*\*\*Dutch quality institute for healthcare*

*\*\*\* International Lyme and Associated Disease Society*

Within both classes, the choice probability for an alternative provider which is reimbursed and situated in the Netherlands is much higher (99% and 80%) than the choice probability for a regular reimbursed (specialised) provider from within the Netherlands (21% and 32%). However, when the alternative provider is located outside Europe, the choice probability of class two respondents decreases a lot, to 28%. In contrary, the choice probability in class one is still 92%. The choice probability of a regular specialised provider in the Netherlands is higher for class two respondents than the choice probability of an alternative specialised provider outside Europe.

#### 4.2 Results interviews with providers

In total, five providers were interviewed. The median duration of the interviews was 37 minutes. All physicians have gotten, due to privacy reasons, a numeric label, like physician 1, when referring to the interviews and quotes. All providers except one (physician 1) were GPs. One general physician was more experienced with Lyme disease (physician 4). Physician 5 is an expert from a Dutch Lyme clinic situated in a hospital. This paragraph starts with a description of experiences of the providers with Lyme disease and Lyme patients. After that, the experiences with preferences of patients are discussed, which is structured by the attributes.

#### 4.2.1 Overall experience with Lyme disease of providers

There is not one specific type of Lyme patient according to many providers. Nevertheless, it is possible to identify three different types of patients. The first type of patients are those who did not know they had Lyme disease and had no earlier Lyme disease related experiences. Often, these patients do not experience any problems in the regular healthcare system:

*“There is a type of patient that comes in with early Lyme disease, but clinical symptoms that suit a Lyme infection. And who are untreated. Those people are blank in their opinion. They do not know what they have, we diagnose them, and we treat them.”* (Physician 5)

*“And that are often the farmworkers, people that had tick bites for a longer time and haven’t done anything with it yet. Did not have the time, energy or they thought it was normal.”* (Physician 1)

The second type of patients are mostly patients who are afraid for a reinfection or reactivation. These patients also want to be certain and gain control over the situation, which was mentioned by three physicians. See for example:

*“But we also experience many people who already have had a long trajectory. And those could be persons [patients] that have already been diagnosed with Lyme elsewhere. And those have been treated but ask themselves, after sometimes even 20 years, if the symptoms they have are still caused by the infection. And whether they have been treated well in the past.”* (Physician 5)

*“People often come back and ask if they can be tested again. Like: ‘yeah but maybe it just did not show up the last time’.”* (Physician 1)

The last type of patients are patients who are convinced that they have Lyme disease and who diagnose themselves, regardless of possible clinical symptoms, blood tests or physician’s judgement:

*“There is also a group of people [patients] who think they have Lyme disease. And from who we [physicians] cannot prove that. And these patients come with different expectations.”* (Physician 5)

In general, (potential) Lyme patients are often scared. Sometimes this is caused by a lack of trust in treatment and diagnosis in the Netherlands. However, according to physician 5, the number of patients who self-diagnose is declined over the last few years. Not many physicians experienced patients who perceived alternative treatment. However, many patients did consume alternative diagnostic tests in for example Cologne. The second and third type of patients seem to be in a very long treatment pathway in which they are searching for an explanation for their symptoms. While physician 4 experienced this as a problem created by the lack of understanding and knowledge within the Dutch healthcare system, other physicians described this as patients being ‘shopping’:

*“That are people who keep seeking for a physician that fits within their script.”* (Physician 2)

One physician thereby mentioned that within this group of patients, Lyme is often used as a sort of alibi, covering other, mostly emotional related, problems. However, patients often feel denied and acknowledged if physicians address this, see for example:

*“Because often, they [patients] have already been at many places where they were not satisfied, or where they did not feel being heard sufficiently.”* (Physician 5)

In addition, many patients themselves gather information about Lyme disease and tend to be talkative. The current developments are sometimes better known by a patient than by the GP. Patients want to have knowledge because:

*“Because they [patients] experience many barriers in the Netherlands. Then, they will investigate this [information treatment].” (Physician 3)*

The amount of information gathered by the patient before visiting a physician, however, seems to differ between the groups:

*“And especially the people with chronic symptoms have often read a lot on the internet.” (Physician 5)*

Interestingly, two physicians mentioned that the problems related to Lyme disease, like the number of patients that feel denied, is not new and is a repetition of history. Every few years, a vague type of chronic complaints receives a new label and currently, these symptoms are labelled with (chronic) Lyme disease:

*“If you look back in history. The images that you can see. (...) but this is what we saw with many forgotten diseases as well”. (...) if you developed scripts of diseases, then they are available. (...) and that is what you see with many diseases. (...) you see repetitive patterns. From a small part of people that stay ill, even when the infection is gone. Thus, that is not new at all.” (Physician 2)*

#### 4.2.2 Preferences of patients in practice according to providers

The biggest part of the interviews consisted of the discussion of the importance of the attributes. This subparagraph further discusses the attributes and their importance in more detail. In table 7, an overview is presented which shows for each attribute the physicians who thought that attribute would or would not influence choice of the patient. The severity of disease could also influence the preferences of the patient, which is included in table 7 as well. Physician 2 answered when the interviewer asked which attributes were of most important for the patient the following:

*“And that [preference] depends on the phase that people are in.” (Physician 2)*

*Table 7: Importance of attributes included in the discrete choice experiment according to Lyme patients as expected by providers of Lyme treatment*

Attribute	Mentioned as important for patients	Mentioned as unimportant for patients	Mentioned that: importance for patients depends on diseases severity
Decision-maker	Physician 1	None	None
Attitude provider	Physician 2 Physician 3 Physician 4 Physician 5	None	None
Guideline	Physician 5 Physician 4	Physician 1	Physician 2 Physician 4*
Expertise	All physicians	None	None
Travel distance	Physician 5	Physician 1 Physician 3 Physician 5*	Physician 2 Physician 4 Physician 5 *
Costs	Physician 3*	Physician 1 Physician 2 Physician 3*	Physician 3* Physician 2*

*\*Physicians sometimes mentioned both perspectives of importance of the attributes. Providers are therefore included in multiple cells if they mentioned multiple points of view.*

#### 4.2.2.1 Decision maker

The decision-making process is an important aspect of the treatment pathway but does not seem to influence patients' decision for a particular provider. Interestingly, no provider specifically said that the decision maker is an unimportant attribute. Only one physician thought that shared-decision making could be a factor that is preferred by a patient and therefore important in the decision-making process. All physicians mentioned that, in general, decisions are made together with the patients and that shared-decision making is important. Physicians did mention that shared decision-making is necessary to create support and understanding from- and by the patient:

*“So, I think that it [shared decision-making] is important for the treatment and the outcome.”* (Physician 3)

*“And then I think the shared-decision-making. If you [physician] do not do that, you will get a big share of patients that eventually will join a patient association.”* (Physician 1)

However, in some cases, the patient or the provider becomes the main decision maker. For example, when the treatment pathway is not clear, the decision becomes in the hand of the patients. Some patients try to control the situation by taking the decision-maker position. On the other side, patients sometimes frame physicians as the main decision maker:

*“But you can see that a part of this kind of people (...) in their desperation, but also due to personal characteristics want you [physician] to take the responsibility for the disease”. (...) They make you responsible for their misery and the lack of possible solutions”. (...) There is a small group of people [patients] that indeed want the physician to tell them what should be done.”* (Physician 2)

#### 4.2.2.2 Attitude of provider

The attitude of the provider was extensively discussed in a direct and indirect way during the interviews. Three physicians thought that the attitude is the most important attribute, it is the second most mentioned most important attribute. However, the attitude was sometimes mentioned together with the expertise of the physician. Physician 2 and 4 both thought that attitude and expertise are intertwined:

*“But it [alternative provider] is a man with charisma. And if you think that is also expertise. Or attitude. All of that blends as well, right.”* (Physician 2)

*“I think that the attitude from the physician and the expertise. It is all in the same area. Because if you are a real expert (...) Then it becomes very difficult to separate those two.”* (Physician 4)

According to physician 2, the attitude of alternative provider differs from the attitude of a GP:

*“Often, they [alternative providers] are physicians who are very resolute. Who are positioning themselves as a certain kind of God (...). And maybe they [patients] are looking for that (...) someone that gives them trust, with no room for doubt. A physician that gives them an alibi (...). It [German physician] is a physician as we know from images from 50, 100 year ago. The omnipotent, omniscient physician. And that is important for people who are getting stuck.”* (Physician 2)

Patients attach value to this type of physician because they are desperate, and alternative providers give them hope:

*“They want a physician that maintains their story, that could be the most important.”* (Physician 2)

On the other side, physician 4 thought that regular providers are not supportive at all regarding the treatment and with the acknowledgement of Lyme patients:

*“You know, even when it is been told to the specialist [Neurologist hospital]: ‘it could be Lyme disease’. Even then they have the urge to think ‘whatever’.”* (Physician 4)

Regardless of being an alternative or regular provider, almost all physicians mentioned that the attitude of the provider is important for patients. Even when regular providers do not approve or promote alternative treatment, they should support and inform their patients about it. See for example:

*“I try to support and accompany [patients with alternative treatment] as best as possible. I think that that is important for me as a general physician. And do not give too much resistance to alternative treatments if it seems to be effective for the patient. (...) I think it is very important that a patient feels heard and that I do not immediately deny the possibility of Lyme disease. This is important for both the treatment and the outcome.”* (Physician 3)

In contrary to physician 3, physician 5 is less open for alternative treatment with contestable effectiveness:

*“If it [alternative treatments] are damaging treatments, I would definitely advise against it. Those treatments are just quackery and damaging.”* (Physician 5)

As partly already shown, the attitude of a provider influences patients’ acceptance of the disease, their treatment journey as well as possible treatment outcomes. It is for example the case that patients who do not align with their regular provider easier opt for alternative providers. These patients try to find a physician who fits their script of disease. Physicians should provide patients with the right information, in example about blood tests, symptoms and treatments. Informing patients is most often mentioned as an important aspect of the attitude of a physician, followed by being supportive and listening to patients:

*“In my experience, if you as a physician provide good information. (...) And you emphasize that no control is needed after treatment. (...) in my experience, you will see no persons [patients] coming back.”* (Physician 2)

*“I think that patients find it really important to be able to share their story. That they are being heard.”* (Physician 5)

#### *4.2.2.3 Guideline followed*

The guideline was only once mentioned as the most important attribute. Except physician 4, all providers ignored the guideline as an attribute influencing choice, until the researcher specifically asked the participants about it. One physician could then also imagine that the guideline is an important attribute:

*“Yes, I know people always say that they think that the guideline is important. (...) patients are asked to fill in a question form which includes something about the guideline (...) They all find it [following guideline] very important.”* (Physician 5)

However, physician 5 continues:

*“But in practice, they [patients] of course do not know at all what that [following guideline] means. And often they are not satisfied at all that we do not deviate from the guideline.”* (Physician 5)

This physician had some experience with patients who would rather receive treatment according to the ILADS-guideline. Physician 2 had never experienced a patient who asked to receive treatment according to ILADS-guidelines. The other providers did not specifically report their experience with

patients preferring the ILADS-guideline. Interestingly, two of the five physicians were before this interview not even familiar with the ILADS-guideline:

*“It is kind of funny, I did not even know that there is an ILADS-guideline.”* (Physician 1).

The more alternative oriented physician was the only physician that herself preferred the ILADS-guideline above the CBO-guideline. In contrary to this physician, physician 1 thought that the CBO-guideline is sufficient:

*“That you realise that the biggest part of the patient with the current followed guideline in the Netherlands ends up quite well.”* (Physician 1)

Except physician 4, all other physicians follow the CBO-guideline, and thereby also noticed that patients do not bother about which guideline is followed.

*“You do not have to tell them [patients] the guideline because it is often a little bit ‘clock and clapper’ what the patient knows, in my opinion.”* (Physician 1)

One physician thought patients think it is important that providers stick to a guideline. However, the interviewees could also imagine that the more desperate the patients, the more alternative ways of perceiving care are explored. According to them, this could explain patients’ preference for the ILADS-guideline. The physician from the Lyme clinic told that in fact, the treatments provided within the ILADS-guideline are also possible to provide within the Netherlands, but they just do not do it.

#### 4.2.2.4 Expertise of provider

All physicians thought that expertise is of importance for patients. The expertise of a physician is mentioned four times as most important attribute influencing choice of provider:

*“Yes, I was thinking about expertise (...) I have the idea that patients think expertise (...) is important.”* (Physician 3)

*“I think when people visit us [Lyme clinic], they come for our expertise.”* (Physician 5)

The physicians differed in their thoughts about what kind of physician is perceived as an expert. Physician 2 thought an alternative provider is not an example of an expert because their treatments are not based on scientific research:

*“That physician, professor in Cologne (...) I do not perceive that person as someone with much expertise in the area of Lyme disease, at least not evidence-based expertise.”* (Physician 2)

However, it seems that patients themselves identify these alternative providers as having expertise. On the contrary, one physician thought that providers following the CBO-guideline do not have enough expertise:

*“You know, if someone says that he/ she read the CBO-guideline and thinks that this is fantastic. Then, I think ‘dude, that guideline is from 2013 and is completely outdated’.”* (Physician 4)

Three out of five physicians specifically mentioned that a Lyme clinic from the Dutch hospital is a centre of expertise. Many physicians refer patients to the Lyme clinic if they are uncertain about diagnosis or treatment. One physician said she could not judge about the expertise of Lyme specialist and physician 4 thinks that specialists from the Lyme clinic actually lack knowledge:

*“But I trust on their [Lyme clinic] expertise. (...) And I tell patients, well they monitor what is happening throughout the whole world.”* (Physician 1)

*“They [neurologist Lyme clinic] deny that Lyme is a clinical disease, and they have very little knowledge about it”. (...) He [neurologist] said: ‘no, but that is not included in our protocol’. So, he just put it aside. And he does know better. And, that man considers himself as an expert.”* (Physician 4)

Often, patients themselves requested a referral to a Lyme clinic. Patients are more likely to listen to and accept a diagnosis from a Lyme specialist according to multiple providers, including the Lyme specialist herself:

*“We hope that people [patients], when they receive the diagnosis [no Lyme disease] from us, will accept it better than when the general physician tells them.”* (Physician 5)

*“They [patients] have the idea, I think, and they expect, that they [Lyme clinic] have world-wide available knowledge (...) and often, they do nothing else than what I did, or would propose.”* (Physician 1).

The answer on the question if GPs have enough knowledge about Lyme disease is not unambiguously. While physician 4 mentioned the limited knowledge of GPs, physician 1 and 2, thought their knowledge was sufficient concerning non-complex cases. One physician explained that having enough knowledge is necessary to have because of the great number of (possible) Lyme patients in the general practice. However, complex cases of Lyme disease are sometimes too difficult for GPs and are hence referred to the Lyme clinic:

*“But that is, yeah, advanced Lyme disease, borrelia infection that is of course not my expertise.”* (Physician 2)

*“I think that Lyme disease is very complicated and therefore, I refer relatively quickly.”* (Physician 3)

In addition, the specialist from the Lyme clinic also mentioned that some GPs have difficulties with correctly diagnosing Lyme patients.

#### 4.2.2.5 Travel distance

The travel distance was never mentioned as the most important attribute influencing patient's choice of provider. In most cases, it was not perceived as an attribute influencing choice. Physician 1 thought that travel distance was one of the least important attributes. Within the borders of the Netherlands, for most patients, travel distance does not matter at all according to providers:

*“I think that many patients are looking within the borders of the country indeed. Because they are very mobile to just drive a few hours to get there.”* (Physician 1)

In addition, it depends on where the patient lives if for example treatment in Germany is considered as a travelling a long distance for treatment. However, the willingness to overcome big distances depends on the severity of the disease and the feeling of being desperate by the patient. The more severe complaints a patient has, the more difficult it becomes to travel to foreign countries:

*“I can also imagine that if you are as sick as I have been, that the travel distance, that you think oh dear. This is not possible at all.”* (Physician 4)

*“And they of course hope that a treatment is available close to their house (...). Especially when you are really ill.”* (Physician 3)

However, even patients with severe Lyme disease are sometimes prepared to travel long distances:

*“You often experience that they [patients] start close because it is familiar, but yeah.. if you do not have an answer which helps, in accepting what they have. Then yeah, they are prepared to take those next steps. (...) and then, the travel distance is becoming less of a problem as well.”* (Physician 2)

*“I have a Lyme patient that is very scared for a re-infection and that is indeed thinking about travelling to the United States.”* (Physician 3)

According to the specialist, patients do know that in foreign countries treatment is not any different from within the Netherlands. This stimulates them to:

*“I think that they [patients] rather ‘shop’ within the Netherlands until they find something that wants to prescribe it [alternative treatment], than that they get on a plane for it.”* (Physician 5)

#### *4.2.2.6 Costs of treatment*

In general, the costs of the treatment were not extensively discussed during the interviews. Costs paid for treatment were never mentioned as an important aspect influencing choice. Some physicians (physician 1,2,3) expected costs not to matter at all:

*“But people are not asking us when we request a blood test ‘well, what will the costs be’? Well, yeah, I basically never experienced patients considering those.”* (Physician 1)

In addition, one physician explained that patients probably do not think about the costs because they expect their insurance company to reimburse the treatment costs. Nevertheless, physician 3 mentioned that she could imagine that patients care about the costs of alternative treatment. However, she did not have any insight into the magnitude of these costs. Lastly, it also seems that the willingness to pay depends on the severity of the symptoms, the preferred type of treatment and the travel distance:

*“To be able to live your life, people are more and more prepared to invest in their disease.”* (Physician 2)

*“But okay, that [importance of costs] is maybe also a difference in how severe the disease symptoms are and how.. what type of therapy you want?”* (Physician 3)



## 5. Discussion

In this chapter, the sub-questions are answered and the hypotheses are accepted or rejected. Then, a short comparison is made with already existing literature, and, in addition, the strengths and limitations of this research are presented. This chapter ends with some recommendations for future research and treatment practices.

### 5.1 What determinants are important for Lyme patients in choice of provider for the treatment of non-local Lyme borreliosis, and what trade-offs do they make between them?

With the use of the DCE, this research found out that, as expected, all attributes in this research influence patients' choice of provider. It seems that the general Lyme patient population prefers a provider, called the 'best provider', who follows the ILADS-guideline, who consults one patient a day, who is situated as close as possible and where out of pocket payments for treatment is low.

Taking the whole Lyme patient population who participated in this research, the guideline followed is the most important attribute influencing choice. Patients prefer the ILADS-guideline. The second most important attribute is the travel distance. However, the utility differences between the levels within Europe (in example municipality to province) were small, but most often not significant. Only a provider outside Europe provides patients with relatively much disutility. The relative importance of costs paid for treatment, attitude and the expertise of the provider are close to each other. From the DCE, it is not possible to conclude anything definitive about preferences for decision-maker, since all levels were insignificant. The differences in utility between the different types of decision-makers, however, are small. While the hypothesis stated that the travel distance and the costs of treatment would be the most and equally important attributes, in reality, this is not the case. Therefore, the first hypothesis is rejected.

### 5.2 Is there preference heterogeneity among Lyme patients in choice of provider for the treatment of non-local Lyme borreliosis?

In addition to the use of a MNL, a LCM was used to be able to analyse potential preference heterogeneity in all attributes. This analysis resulted in two classes with different preferences. Within both classes, there are differences in the relative importance of the attributes and choice probabilities. An analysis of the class-membership explanatory variables showed that class one participants are more likely to have a lower health status, having paid higher costs for their treatment and are less likely to have their provider situated in the Netherlands.

Using the relative importance calculations, this research found out that within class one, the guideline is by far the most important attribute influencing choice. Class one patients have a strong preference for an alternative provider, a provider who follows the ILADS-guideline. The guideline followed is even three times more important than the second most important attribute, expertise. In contrast to the preferences from class one, class two participants think travel distance is the most important attribute, followed by the attitude of the provider.

The differences between the relative importance are much smaller in class two compared to class one, with travel distance and attitude being almost equally important. Interestingly, the guideline followed is for these patients the second least important attribute, but class two participants still prefer the ILADS-guideline. Having these preferences of both classes and the class-membership explanatory variable of self-assessed health status in mind, it is possible to conclude that the second hypothesis: *'Lyme patients with a self-assessed poor health status have a higher preference for alternative treatment compared to patients with a self-assessed good health status'* can be accepted.

### 5.3 What are the choice probabilities of Lyme patients for a regular Dutch Lyme specialist and an alternative Lyme specialist?

Next to the relative importance, choice probabilities were also calculated for both classes. The choice probability for the best provider is almost 100% in class one and 80% for class two participants. However, it is important to notice that such a provider is not (yet) available in the Netherlands. The worst provider is not likely at all to be chosen in both classes, with choice probabilities less than 3%. Interestingly, even when an alternative provider is situated outside Europe and out of pocket costs are 10.000 euros, class one participants are still very likely to choose for this provider (92%). In contrast, the choice probability for this provider is only 28% within class two. Class two patients are more likely to opt for a CBO Lyme specialist than an alternative provider who is not being reimbursed and situated outside Europe, since the choice probability of a CBO specialist is around 33%. Whilst the choice probability within class one is lower for a CBO specialist than an alternative, not reimbursed provider outside Europe, being approximately 22%. Nevertheless, the choice probability for a CBO specialist is low in both classes. However, it is important to mention that the calculated choice probabilities might be an overestimation, since no status-quo or opt-out option was included in the DCE (57). This was also mentioned by two patients in the comment section. In fact, many of the respondents currently have no provider, so an overestimation is likely to be present.

Summarizing, the choice probabilities for class one participants are higher for all alternative physicians compared to class two, whereas the choice probability for an CBO specialist is higher in class two compared to class one. However, both classes are most likely to opt for an alternative provider when being reimbursed and situated in the Netherlands. Nevertheless, when out of pocket payments and travel distance are high, class two patients are more likely to opt for an CBO specialist. Therefore, it is not possible to accept the third hypothesis: *'The choice probability for an alternative Lyme specialist is higher for all types of Lyme patients compared to a regular Dutch Lyme specialist'*. The choice probability is only higher for all types of patients considering the best possible alternative provider.

### 5.4 What are providers expectations of the preference of Lyme patients in choice of provider?

The preferences of patients were also discussed with five providers. These providers expected the attitude and the expertise of a provider to influence a patients' choice the most. However, the expertise of (alternative) Lyme specialists was questioned. While the alternative provider criticized the Dutch Lyme clinic as a non-expert, one GP though the same about alternative specialists. All regular GPs refer their patients to the Lyme clinic because of their specialism. Sometimes because patients themselves asked for a referral, sometimes because GPs themselves lack the knowledge about complex cases.

The attitude of alternative providers is more supporting and acknowledging to patients, according to the interviewees. Nevertheless, regular providers mentioned the need to encourage patients, even if they opt for alternative care. Patients want to be heard and will search for a provider until they find one that fits their perspective of Lyme disease. Only one physician expected the guideline to be the most important attribute. Two GPs were not even familiar with the ILADS-guideline before the interview. The specialist provider did mention that she expected patients to care about the guideline, but this was more related to guideline adherence.

The three attributes that were not expected to influence choice were the decision-maker, the costs and the travel distance. While shared-decision making was an important factor because it influences treatments' outcomes and patients understanding, it was never mentioned as an attribute

influencing choice. Travel distance and costs are not important because when patients are desperate and experience severe symptoms, they are willing to invest more in their treatment. The providers expected patients not to care about travelling within the borders of the Netherlands. Moreover, some GPs were unfamiliar of the extreme height of the costs, which could explain their expectations.

It is possible to identify differences in preferences between different patient groups resulting from the interviews as well. In general, it is possible to identify three groups of patients, general speaking: the farmworkers, the scared patients and the self-diagnosed patients. Patients with more severe symptoms, type two and type three often shop and have a longer treatment pathway. In addition, they are more likely to prefer the ILADS-guideline and are willing to invest more in their treatment. Their willingness to overcome great distances depends on their ability to travel. Whereas more desperate patients seem to care less about travel distances, patients with severe Lyme disease are less able to travel.

When comparing the results of the DCE and the interviews, it is possible to identify differences between the actual preferences resulted from the DCE and the expected preferences by the providers. Thus, the hypothesis that the expectations and the preferences do not align can be accepted. The providers expected the attitude and expertise to be of most importance, while the DCE results showed the guideline followed and the travel distance as most important attributes. However, within class two, attitude is indeed the second most important attribute. In addition, all regular providers expected that most patients would opt for a specialist for the Lyme clinic instead of an alternative provider. Possible explanations for these diverging results are related to the disease-related characteristics of the respondents from the DCE. Most respondents are having CLD, and/ or have neuroborreliosis and have either an alternative provider or no provider at all. Therefore, it might be possible that the preferences of the participants differ from the preferences of the patients that the interviewed providers are in familiar with.

Nevertheless, there are also some similarities between the expectations of the providers and the results of the DCE. The results of the DCE and the providers both show that the decision-maker does not influence the choice of provider that much. In addition, the providers also mentioned preference heterogeneity. They could in example imagine that more desperate and ill patients are more likely to explore alternative options. This suits the results of the class-membership explanatory variables. Travel distance is indeed considered as less important by class one participants, which also aligns with the results of the interviews.

## 5.5 Theoretical implications

The attributes included in DCE were based on the adapted model of Kroeger which included possible determinants that influence choice of provider (32). All attributes included in this research influence patients' decisions and therefore align with the findings of Kroeger and other literature (49–51) as described in paragraph 2.3. Despite the fact that the interviewees did not expect costs to be of influence, both the DCE and earlier research (32,49,51,52) showed that in fact, the costs indeed influence patients' choices. The DCE also showed that patients prefer providers who follow the ILADS-guideline. While this was again not expected by four of the providers, both the Canadian research (14) and the report of *Lymedisease.org* (52) also showed that patients prefer long-term treatment.

According to Boudreau et al. (14), both the expertise and attitude of a provider influence the choice of a patient. The *Lymevereniging* also mentioned the attitude of a provider as an crucial factor (24). All providers expected the attitude to be of great importance for patients in their choice. While the DCE showed that indeed both the expertise and attitude influence choice, other attributes are

considered as more important within both classes and in general. Thus, these findings of the earlier research might better fit within the thoughts of the interviewed providers.

Moreover, Boudreau et al. (14) explained that many patients seek care at LLMDs as well. The DCE and the interviews also showed that patients prefer specialised providers. Some GPs acknowledged their own lack of knowledge, which suits the findings of earlier reports as well (23,25). As also shown in other research (22), the providers confirmed that specialist have more knowledge about complex cases. The DCE results showed that the decision-maker influences choice and this aligns with previous research (51). However, the results were not definitive about the preferred type, and it was the least important attribute in both classes. Almost all providers expected the decision-maker not to influence choice.

The preference heterogeneity also fits earlier research. The model of Kroeger (32) included this in 'characteristics of the disease' and 'characteristics of the patient'. This research found three explanatory variables related to the 'characteristics of the disease'. These disease-related variables also align with the findings of *Lymedisease.org* (52). They found that in example the severity of the illness of a patient is an important factor in treatment

There were also findings of this research that have not been found by earlier research. In example, the great importance of the travel distance within class two found within the DCE does not fit within earlier research related to Lyme disease. This research contributed to already existing literature by finding out which attributes were most important in choice of provider for patients, as well by identifying two different classes with different preferences. Moreover, this research contributed by calculating choice predictions and giving insight into to alignment between patients' preferences and providers expectations of preferences. With this, the knowledge gap about Lyme patients' preferences has become smaller.

## 5.6 Methodological implications

This research has several strengths and limitations. Different types of measurement were taken to increase the validity and reliability of this study. During the data-collection, support groups were contacted, which often consist of CLD patients with negative experiences with regular care. To prevent non-generalizable results, effort was made to incorporate patients that might be more positive, and/ or perceived treatment within the regular system. However, the patient population included in the DCE are still mostly patients with CLD and often have alternative providers. This might reduce the generalizability of the results of the DCE to the whole Lyme patient population (56). Nevertheless, the interviews with the providers gave some insight into the preferences of the more general Lyme population. In addition, the currently most unsatisfied patients are those with CLD.

This research included a dominated choice task to be able to judge the internal validity (56,73). Only four respondents (4%) chose the non-dominated choice. This indicates that according to this measure, the internal validity is guaranteed. The test questionnaire positively contributed to the internal validity as well (71,74), because for example, the exclusion of attributes was discussed.

As mentioned before, DCEs deal with both statistical and response efficiency. Since a DCE is a controlled, experimental environment, it is possible to use measures to increase statistical efficiency. In this research, statistical efficiency is increased with the use of a Bayesian design with priors (59). This made it possible to generate statistically significant results, despite the low respondent number. The small sample size however, still reduces the statistical efficiency (59). Despite the efforts made to increase sample size, the drop-out rate is still high. Nevertheless, 33% of the respondents thought they still could have answered more choice tasks. The length of the DCE was discussed during the

test phase, but opinions about the length were diverging. With the use of more blocks, statistical efficiency might not have been reached within each block (59), and removal of choice tasks reduces the information gained about preferences. Both methods are therefore not applied. Other ways used to increase the sample size was the spread of extra flyers and the emphasizes on the importance of the research. Moreover, since this research did not include an alternative specific constant in the utility function, it has not been possible to analyse error caused by left or right bias. However, this bias was not expected.

Since a DCE is based on RUT, there is possible randomness in the preferences caused by either a non-inclusive list of attributes, unobserved patient characteristics or measurement error (59,73). None of the interviewed physicians nor participants from the test phase thought any attribute was missing in the DCE, randomness is thus not caused by this. In addition, many demographic- and disease-related variables were included in the research, of which only three were statistically significant to explain preference heterogeneity. Therefore, it is more likely that possible randomness is caused by measurement error, which is related to the response efficiency (59).

Measurement error can be caused by fatigue due to the length of the questionnaire, or complex choice questions. However, only 12% of the respondents thought that the tasks were unclear, most respondents could easily analyse the differences between the alternatives and only 5% of the respondents could not have answered any additional task. Another way in which measurement error can arise is lexicographic behaviour, then, patients do not consider all attributes in their choice (57). Only 3% of the respondents stated they did not consider all attributes at all. However, some patients specifically mentioned they in example only cared about the guideline followed, which might make the guideline their dominant attribute. The possible error caused by this behaviour is reduced by including overlap between alternatives. Keeping attributes equally between alternatives makes it possible to analyse preferences of non-dominating attributes (59). Other efforts to increase the response efficiency have been done by the use of different blocks and alternating questions between the choice tasks to reduce fatigue (56,59).

The DCE included attribute combinations which are not (yet) available, because placing constraints on the design reduces statistical efficiency (56,59). However, this might have resulted in measurement error. One patient and one physician mentioned that the DCE consisted of alternatives which are not being available in real life. Nevertheless, it is possible that some of these will become available in the future and therefore, insight into the preferences of patients of such not yet existing providers is still useful. Moreover, the fact that one of the attributes was included visually to make it easier and more attractive for respondents to answer the choice tasks, might also have influenced the results of the DCE (75).

The interviews contributed to the reliability of the DCE by giving insight into real-life practices (71). Combining interviews with the questionnaire is a method of triangulation (72), which increases internal validity. The use of anonymous quotation reduces the risk on social desired answers (71). Moreover, the researcher tried to be as neutral and open as possible to reduce the possible influence of the presence of the researcher. The generalisation and reliability of the experiences and expectations of the regular GPs is potentially high, since in the last interview, saturation was reached since no new information was gained. However, the generalisation of the experiences and expectations of the alternative GP and the specialists might be limited, it only reflects the view of one provider. However, the specialists had very similar thoughts as the GP. The validity of the translation of the quotes has been increased by having another researcher checking all the translations. In addition, a member check has been used to increase the internal validity as well (72).

## 5.7 Recommendations

Some recommendations for future research are possible. Firstly, it would be advisable to hold a DCE among Lyme patients with a greater sample size, including more non-alternative oriented patients. This could for example be done in corporation with Dutch Lyme clinics. To be able to calculate market shares, an opt-out option should be included. Moreover, extra interviews can be held with alternative providers to gain more insight into their expectations of the preferences of patients.

While this research provided insight into the preferences of patients relating to provider characteristics, it might also be useful to analyse their preferences related to treatment characteristics. Think for example about effectiveness and possible side effects. Research on treatment preferences combined with this research about provider preferences together could show what the perfect provider-treatment combination is according to Lyme patients, and how the regular healthcare sector could change to improve satisfaction.

In addition to recommendations for future research, some recommendations for the practice are also possible. Since the expectations of providers do not align with the actual preferences of patients, it is important that providers understand what patients want, and what they could possibly change in their own practice. Most importantly, providers, especially GPs should improve their knowledge about the ILADS-guideline. With this, they can advise patients about possible treatments and extensively explain why they do not follow this guideline and what the reasoning behind that is. This might reduce the number of patients opting for alternative treatment. However, if patients do, it is still advisable that providers support their patients. Generally, it is very important to take the preferences of the Lyme patients into account, because patients' satisfaction influences treatment outcomes.

## 6. Conclusion

With the use of a DCE and interviews, this research aimed to find an answer on the following research question: *"What are patients' preferences in the choice of provider for the treatment of non-local Lyme borreliosis"*.

The DCE results showed that it seems that in general, non-local Lyme patients prefer a provider that is located within the municipality, where costs of treatment are low, who is an expert in Lyme disease and who provides treatment according to the ILADS-guideline. However, when the preference data is divided into two different classes, preference heterogeneity arises. Patients who rate their own health status badly, have had high costs for their own treatment and have a provider outside the Netherlands think the guideline followed is the most important attribute. These patients opt for an alternative provider, despite the costs and travel distance. The second group of patients places greater importance on the travel distance and the attitude of the provider. These patients still prefer an alternative provider, but when they must travel far distances and have to pay high costs, they are more likely to choose a specialist from the Lyme clinic. Interestingly, the majority of the providers who participated with the interviews expected the expertise and the attitude to be of most importance, which is somewhat in contrast with the results of the DCE. In addition, providers expected patients to prefer shared decision making. However, they did recognize the preference heterogeneity. It seems that the more severe complaints a patient has, the more the patient is willing to invest to find the best provider.

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## Appendix 1: Discrete choice experiment

Start

### Enquête behandeling ziekte van Lyme

Voor mijn Master thesis aan de Erasmus Universiteit doe ik (Vera Niessink) onderzoek naar de voorkeuren van patiënten met betrekking tot een behandelaar voor de ziekte van Lyme. Deze enquête is bedoeld voor **patiënten met niet-lokale Lymeziekte**. Hiermee worden alle soorten Lyme patiënten bedoeld, met uitzondering patiënten die één "rode kring" hebben, ook wel "Erythema Migrans" genoemd.

Het is bekend dat veel patiënten niet tevreden zijn met- of zich onbegrepen voelen door reguliere behandelaars en vaak kiezen voor een alternatieve behandeling. Het doel van deze enquête is daarom het achterhalen van de voorkeuren van de patiënt met betrekking tot verschillende kenmerken van behandelaars.

Wij willen graag een zo accuraat mogelijk beeld krijgen van uw voorkeuren. U wordt daarom gevraagd zo goed mogelijk te antwoorden. De enquête duurt ongeveer 15 minuten.

De enquête is anoniem en de resultaten kunnen worden gedeeld met bijvoorbeeld de Lymevereniging. Er zullen van u geen persoonsgegevens naar buiten worden gebracht. U ontvangt geen vergoeding voor deelname aan dit onderzoek.

Voor vragen kunt u contact opnemen met Vera Niessink: 548468vn@eur.nl

*Alvast bedankt voor uw deelname!*



Volgende

LymePatient

Ik ben een Lyme patiënt met niet-lokale Lyme ziekte. Hiermee worden alle soorten Lyme patiënten bedoeld, met uitzondering patiënten die één "rode kring" hebben, ook wel "Erythema Migrans" genoemd.

LymePatient=1

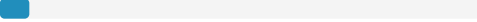
Ja

LymePatient=2

Nee

Vorige

Volgende

0%  100%

Informedconsent

Geef aan of u akkoord bent met het volgende:

Ja

Nee

Ik begrijp dat mijn deelname aan dit onderzoek vrijwillig is en ik ten allen tijde kan stoppen

Informedconsent\_r1=1

Informedconsent\_r1=2

Ik begrijp dat het doel van dit onderzoek het achterhalen van patiëntenvoorkeuren voor behandelaren is

Informedconsent\_r2=1

Informedconsent\_r2=2

Ik begrijp dat mijn antwoorden anoniem worden verkregen en verwerkt

Informedconsent\_r3=1

Informedconsent\_r3=2

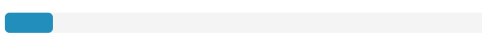
Ik begrijp dat mijn antwoorden gebruikt worden voor onderzoek en de resultaten (anoniem) gedeeld kunnen worden

Informedconsent\_r4=1

Informedconsent\_r4=2

Vorige

Volgende

0%  100%

Gender

## Algemene informatie

Met welke gender identificeert u zichzelf?

- Gender=1 Man
- Gender=2 Vrouw
- Gender=3 Non-binair

Leeftijd2

In welke leeftijdscategorie bevindt u zich?

- Leeftijd2=1 Jonger dan 18
- Leeftijd2=2 18-30
- Leeftijd2=3 31-50
- Leeftijd2=4 51-70
- Leeftijd2=5 Ouder dan 70 jaar

Provincie

In welke provincie bent u woonachtig?

- Provincie=1 Noord-Holland
- Provincie=2 Zuid-Holland
- Provincie=3 Zeeland
- Provincie=4 Noord-Brabant
- Provincie=5 Limburg
- Provincie=6 Utrecht
- Provincie=7 Gelderland



Provincie=8



Overijssel

Provincie=9



Drenthe

Provincie=10



Friesland

Provincie=11



Flevoland

Provincie=12



Groningen

Inkomen

Wat was het totale gezamenlijke inkomen van uw huishouden in 2020?

Inkomen=1



Minder dan €10.000

Inkomen=2



€10.000-€30.000

Inkomen=3



€30.001-€50.000

Inkomen=4



Meer dan €50.000

Inkomen=5



Wil ik liever niet zeggen

Educatie

Wat is het hoogste opleidingsniveau dat u hebt behaald?

Educatie=1



Geen diploma

Educatie=2



Middelbare schooldiploma

Educatie=3



MBO-diploma

Educatie=4



HBO-diploma

Educatie=5



Bachelordiploma universiteit

Educatie=6



Masterdiploma universiteit

Educatie=7

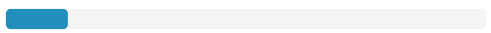


PhD

Vorige

Volgende

0%



100%

JarenZiek

Er worden nu wat algemenere vragen gesteld over uw Lymeziekte

Hoe lang weet u al dat u Lymeziekte heeft?

- JarenZiek=1 Minder dan 1 jaar
- JarenZiek=2 1-3 jaar
- JarenZiek=3 4-6 jaar
- JarenZiek=4 Meer dan 6 jaar

Diagnose

Hoeveel jaar zat er tussen de eerste keer dat u naar de huisarts ging met klachten, en uw uiteindelijke diagnose met Lymeziekte?

- Diagnose=1 Minder dan 1 jaar
- Diagnose=2 1-3 jaar
- Diagnose=3 4-6 jaar
- Diagnose=4 Meer dan 6 jaar

Gezondheidsstatus

Welk cijfer zou u uw huidige gezondheidstatus geven?

1= ernstig ziek

10= volledig gezond

Cijfer

1	2	3	4	5	6	7
<input type="radio"/> Gezondheidsstatus_r1=1	<input type="radio"/> Gezondheidsstatus_r1=2	<input type="radio"/> Gezondheidsstatus_r1=3	<input type="radio"/> Gezondheidsstatus_r1=4	<input type="radio"/> Gezondheidsstatus_r1=5	<input type="radio"/> Gezondheidsstatus_r1=6	<input type="radio"/> Gezondheidsstatus_r1=7

Soort

Onder welke soort Lymeziekte zou u zichzelf indelen? *Meerdere antwoorden zijn mogelijk*

- Soort\_1 Lyme artritis  
*Gewrichtsontstekingen*
- Soort\_2 Lymecarditis  
*Hartklachten*
- Soort\_3 Neuroborreliose  
*Infectie in het zenuwstelsel*
- Soort\_4 Acrodermatitis Chronica Atroficans (ACA)  
*Paarse verkleuringen van de huid*
- Soort\_5 Chronische Lymeziekte
- Soort\_6 Post-Lymeziekte
- Soort\_7\_ other Anders, namelijk:

Behandelaar

Wie is uw huidige behandelaar voor Lymeziekte?

- Behandelaar=1 Huisarts
- Behandelaar=2 Specialist van Lyme poli in ziekenhuis
- Behandelaar=3 Andere behandelaar
- Behandelaar=4 Geen behandelaar

Vorige

Volgende

0%  100%

Tevredenheid

Op een schaal van 1 (geheel ontevreden) tot 7 (geheel tevreden), hoe tevreden bent u met uw huidige behandelaar?

Geheel ontevreden 1 2 3 4 5 6 Niet tevreden of ontevreden

Tevredenheid

Tevredenheid\_r1=1

Tevredenheid\_r1=2

Tevredenheid\_r1=3

Tevredenheid\_r1=4

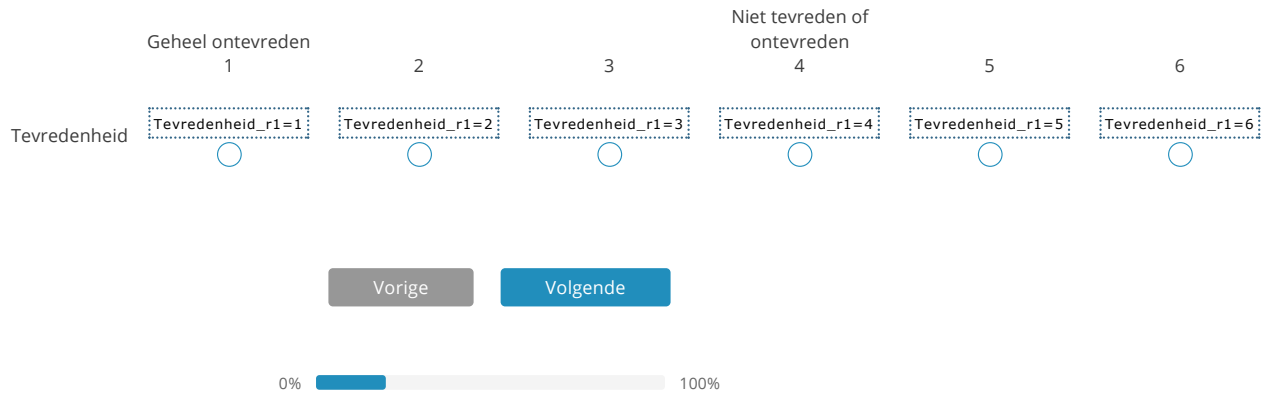
Tevredenheid\_r1=5

Tevredenheid\_r1=6

Vorige

Volgende

0% 100%

The form displays a horizontal Likert scale with six radio buttons labeled 1 through 6. Above the scale, the text 'Geheel ontevreden' is positioned above '1' and '2', and 'Niet tevreden of ontevreden' is positioned above '4'. Below the scale, the word 'Tevredenheid' is written. Each radio button is enclosed in a dashed box with a label: 'Tevredenheid\_r1=1' through 'Tevredenheid\_r1=6'. Below the scale are two buttons: 'Vorige' (grey) and 'Volgende' (blue). At the bottom, a progress bar shows 0% on the left and 100% on the right, with a blue segment extending from 0% to approximately 15%.

## Algemene informatie

Binnen en buiten Nederland zijn er veel verschillende behandelaars beschikbaar voor Lymeziekte. Veel patiënten met de ziekte van Lyme zijn ontevreden over behandeling door reguliere artsen, en kiezen daardoor vaak voor een alternatieve arts of behandeling in het buitenland.

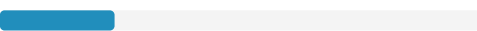
Deze behandelaars hebben verschillende kenmerken. Zo schrijven sommige artsen kortdurige antibiotica behandeling voor, waar andere artsen meer open staan voor langdurige antibiotica of een andersoortige behandeling.

Met deze enquête wordt gepoogd inzicht te krijgen in de voorkeur van de patiënt met betrekking tot verschillende behandelaars.

U zult straks gevraagd worden 16 keer te kiezen tussen twee behandelaars die verschillen op meerdere aspecten. Deze vragen lijken iedere keer heel erg op elkaar, maar verschillen wel. Om inzicht te krijgen in uw voorkeuren is het nodig om u 16 keer deze keuze te laten maken. Om beter te begrijpen wat er van u wordt gevraagd start u met een oefenvraag.

Vorige

Volgende

0%  100%

Oefenvraag2\_Fixed1

Een behandelaar kan grofweg twee soorten richtlijnen volgen namelijk de CBO-richtlijn en de ILADS-richtlijn. Waar de CBO-richtlijn kortdurende antibiotica (maximaal 1 maand) voorschrijft, adviseert de ILADS langdurige behandeling (minimaal 1 maand). Reguliere Nederlandse artsen volgen de CBO-richtlijn. Daarnaast kan tijdens het behandelproces de besluitvormer ook verschillen. Het is mogelijk dat of u als patiënt of de arts de beslissing neemt. Het is ook mogelijk dat u gezamenlijk een beslissing neemt.

**Als u zou moeten kiezen tussen twee behandelaars die verschillen in richtlijn en besluitvormer. Welke behandelaar zou u dan kiezen?**

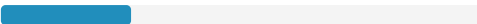
*Het kan zijn dat géén van behandelaren voor u de perfecte behandelaar is. Toch is het belangrijk dat u dan kiest voor de behandelaar die u het meeste aanspreekt.*

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Gezamenlijke beslissing</b> van arts en patiënt	 <b>Patiënt</b> maakt geïnformeerde beslissing
Richtlijn	<b>ILADS-richtlijn:</b> langdurige behandeling (min. 1 maand)	<b>CBO-richtlijn:</b> kortdurige behandeling (max. 1 maand)
	<p>Oefenvraag2_Fixed1 <input type="button" value="Kiezen"/></p>	<p>Oefenvraag2_Fixed1 <input type="button" value="Kiezen"/></p>

Klik op "kiezen" voor het maken van een keuze

Vorige

Volgende

0%  100%

## Belangrijk!

### Informatie over kenmerken behandelaar

U bent nu aangekomen bij de keuzetaken over behandelaars. Iedere behandelaar heeft 6 kenmerken, zoals bijvoorbeeld de reisafstand, welke weer meerdere niveaus hebben. U wordt gevraagd te kiezen voor de behandelaar met de kenmerken en niveaus dat u het meeste aanspreekt.

De volgende kenmerken zijn van belang:

#### Besluitvormer

Hiermee wordt de persoon bedoeld die het besluit maakt over welke behandeling gaat worden uitgevoerd. Dit kan de arts of u als patiënt zijn. De arts zal altijd uw akkoord vragen. Wanneer u als patiënt een beslissing maakt, wordt u uitvoerig door een arts geïnformeerd over de verschillende mogelijkheden. Het is ook mogelijk dat u samen met de arts een beslissing maakt. Dit wordt een "gezamenlijke beslissing" genoemd.



#### Kosten van behandeling

Dit zijn de kosten die u als patiënt zelf betaald en dus niet worden vergoed door een verzekeraar. De niveaus van kosten zijn: €385, €1.000, €5.000 en €10.000.

#### De attitude van de behandelaar

Dit is de manier waarop een behandelaar zich gedraagt. Een behandelaar kan u ondersteunen door het actief onderzoeken van de mogelijkheden en het erkennen van uw ziekte. Een behandelaar kan u ook ontmoedigen, waarbij hij/zij uw ziekte niet erkent en bijvoorbeeld niet open staat voor uw gewenste behandeling.

#### Gevolgde richtlijn

Zoals u wellicht bekend is zijn er in het algemeen twee richtlijnen die gevolgd worden door artsen, namelijk de CBO-richtlijn en de ILADS-richtlijn. De CBO-richtlijn adviseert kortdurige behandeling met antibiotica (maximaal 1 maand) en wordt gevolgd door reguliere Nederlandse artsen. De ILADS-richtlijn adviseert langdurige behandeling met antibiotica (minimaal 1 maand).

#### Expertise van behandelaar

Behandelaren kunnen verschillen in kennis over Lymeziekte. Sommige behandelaars zien meerdere Lyme patiënten op een dag, waar anderen maar een paar patiënten per jaar ontvangen. Er zijn in deze enquête drie niveaus van expertise namelijk:

### **1. Basis ervaring**

*Ongeveer 20 patiënten per jaar*

### **2. Gemiddelde ervaring**

*Ongeveer 100 patiënten per jaar*

### **3. Gespecialiseerd in Lymeziekte**

*Ongeveer 1 patiënt per dag*

#### **Reisafstand**

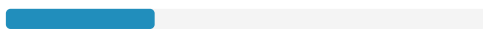
De vestigingsplaat van de behandelaar bepaald uw reisafstand. Een behandelaar kan zich binnen uw gemeente bevinden, binnen de provincie (buiten uw gemeente) of binnen Nederland (buiten uw provincie). Een behandelaar kan zich ook binnen Europa (niet in Nederland) of buiten Europa bevinden.

*U zult nu starten met de eerste 6 keuzetaken.*

Vorige

Volgende

0%





100%



KeuzeTakenBehandelaar\_Random1


Als u zou moeten kiezen tussen deze twee behandelaars voor de behandeling van uw Lymeziekte, welke zou u kiezen?

(1 uit 16)

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Patiënt</b> maakt geïnformeerde beslissing	 <b>Arts</b> maakt beslissing
Kosten van behandeling	€1.000	€5.000
Attitude van behandelaar	Arts <b>ondersteunt</b> patiënt	Arts <b>ontmoedigt</b> patiënt
Gevolgde richtlijn	<b>CBO</b> -richtlijn: kortdurige behandeling (max. 1 maand)	<b>ILADS</b> -richtlijn: langdurige behandeling (min. 1 maand)
Ervaring behandelaar	<b>Gemiddelde ervaring</b> met ongeveer 100 patiënten per jaar	<b>Basis ervaring</b> met ongeveer 20 patiënten per jaar
Reisafstand	Binnen <b>gemeente</b>	Binnen <b>Europa</b> (buiten Nederland)
	<input type="text" value="KeuzeTakenBehandelaar_Random1"/>	<input type="text" value="KeuzeTakenBehandelaar_Random1"/>

Vorige



Volgende

0%  100%

KeuzeTakenBehandelaar\_Random2


Als u zou moeten kiezen tussen deze twee behandelaars voor de behandeling van uw Lymeziekte, welke zou u kiezen?

(2 uit 16)

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Gezamenlijke beslissing</b> van arts en patiënt	 <b>Patiënt</b> maakt geïnformeerde beslissing
Kosten van behandeling	€1.000	€5.000
Attitude van behandelaar	Arts <b>ondersteunt</b> patiënt	Arts <b>ontmoedigt</b> patiënt
Gevolgde richtlijn	<b>ILADS</b> -richtlijn: langdurige behandeling (min. 1 maand)	<b>CBO</b> -richtlijn: kortdurige behandeling (max. 1 maand)
Ervaring behandelaar	<b>Basis ervaring</b> met ongeveer 20 patiënten per jaar	<b>Gemiddelde ervaring</b> met ongeveer 100 patiënten per jaar
Reisafstand	Binnen <b>gemeente</b>	Binnen <b>Nederland</b> (buiten provincie)
	<input type="text" value="KeuzeTakenBehandelaar_Random2"/>	<input type="text" value="KeuzeTakenBehandelaar_Random2"/>

Vorige



Volgende

0%  100%

KeuzeTakenBehandelaar\_Random3


Als u zou moeten kiezen tussen deze twee behandelaars voor de behandeling van uw Lymeziekte, welke zou u kiezen?

(3 uit 16)

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Patiënt</b> maakt geïnformeerde beslissing	 <b>Arts</b> maakt beslissing
Kosten van behandeling	€5.000	€10.000
Attitude van behandelaar	Arts <b>ontmoedigt</b> patiënt	Arts <b>ondersteunt</b> patiënt
Gevolgde richtlijn	<b>ILADS</b> -richtlijn: langdurige behandeling (min. 1 maand)	<b>CBO</b> -richtlijn: kortdurige behandeling (max. 1 maand)
Ervaring behandelaar	<b>Gemiddelde ervaring</b> met ongeveer 100 patiënten per jaar	<b>Gespecialiseerd</b> in Lymeziekte met ongeveer 1 patiënt per dag
Reisafstand	Binnen <b>gemeente</b>	Binnen <b>provincie</b> (buiten gemeente)
	<input type="text" value="KeuzeTakenBehandelaar_Random3"/>	<input type="text" value="KeuzeTakenBehandelaar_Random3"/>

Vorige



Volgende

0%  100%

KeuzeTakenBehandelaar\_Random4


Als u zou moeten kiezen tussen deze twee behandelaars voor de behandeling van uw Lymeziekte, welke zou u kiezen?

(4 uit 16)

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Gezamenlijke beslissing</b> van arts en patiënt	 <b>Patiënt</b> maakt geïnformeerde beslissing
Kosten van behandeling	€1.000	€385
Attitude van behandelaar	Arts <b>ontmoedigt</b> patiënt	Arts <b>ondersteunt</b> patiënt
Gevolgde richtlijn	<b>CBO</b> -richtlijn: kortdurige behandeling (max. 1 maand)	<b>ILADS</b> -richtlijn: langdurige behandeling (min. 1 maand)
Ervaring behandelaar	<b>Gemiddelde ervaring</b> met ongeveer 100 patiënten per jaar	<b>Basis ervaring</b> met ongeveer 20 patiënten per jaar
Reisafstand	Binnen <b>Europa</b> (buiten Nederland)	Binnen <b>provincie</b> (buiten gemeente)
	<input type="text" value="KeuzeTakenBehandelaar_Random4"/>	<input type="text" value="KeuzeTakenBehandelaar_Random4"/>

Vorige



Volgende

0%  100%

KeuzeTakenBehandelaar\_Fixed1


Als u zou moeten kiezen tussen deze twee behandelaars voor de behandeling van uw Lymeziekte, welke zou u kiezen?

(5 uit 16)

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Gezamenlijke beslissing</b> van arts en patiënt	 <b>Arts</b> maakt beslissing
Kosten van behandeling	€385	€10.000
Attitude van behandelaar	Arts <b>ondersteunt</b> patiënt	Arts <b>ontmoedigt</b> patiënt
Gevolgde richtlijn	<b>CBO-richtlijn</b> : kortdurige behandeling (max. 1 maand)	<b>CBO-richtlijn</b> : kortdurige behandeling (max. 1 maand)
Ervaring behandelaar	<b>Gespecialiseerd</b> in Lymeziekte met ongeveer 1 patiënt per dag	<b>Basis ervaring</b> met ongeveer 20 patiënten per jaar
Reisafstand	Binnen <b>gemeente</b>	Buiten <b>Europa</b>
	<input type="text" value="KeuzeTakenBehandelaar_Fixed1 zen"/>	<input type="text" value="KeuzeTakenBehandelaar_Fixed1 zen"/>

Vorige



Volgende

0%  100%

KeuzeTakenBehandelaar\_Random5

Als u zou moeten kiezen tussen deze twee behandelaars voor de behandeling van uw Lymeziekte, welke zou u kiezen?

(6 uit 16)

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Arts</b> maakt beslissing	 <b>Gezamenlijke beslissing</b> van arts en patiënt
Kosten van behandeling	€10.000	€5.000
Attitude van behandelaar	Arts <b>ontmoedigt</b> patiënt	Arts <b>ondersteunt</b> patiënt
Gevolgde richtlijn	<b>ILADS</b> -richtlijn: langdurige behandeling (min. 1 maand)	<b>CBO</b> -richtlijn: kortdurige behandeling (max. 1 maand)
Ervaring behandelaar	<b>Basis ervaring</b> met ongeveer 20 patiënten per jaar	<b>Gespecialiseerd</b> in Lymeziekte met ongeveer 1 patiënt per dag
Reisafstand	Binnen <b>provincie</b> (buiten gemeente)	Binnen <b>Nederland</b> (buiten provincie)
	<input type="text" value="KeuzeTakenBehandelaar_Random5"/>	<input type="text" value="KeuzeTakenBehandelaar_Random5"/>

Vorige

Volgende

0%  100%

Kosten

## Halverwege

Goed bezig! Er zijn nog 10 keuzes te gaan.

Ter afwisseling even een andersoortige vraag.

Wat zijn de totale kosten die u heeft gemaakt voor uw behandeling tot nu toe?

- Kosten=1** Tot €385
- Kosten=2** €385-€1.000
- Kosten=3** €1.000-€5.000
- Kosten=4** €5.000-€10.000
- Kosten=5** Meer dan €10.000
- Kosten=6** Weet ik niet
- Kosten=7** Wil ik liever niet zeggen

Vorige



Volgende

0%  100%

KeuzeTakenBehandelaar\_Random6

Als u zou moeten kiezen tussen deze twee behandelaars voor de behandeling van uw Lymeziekte, welke zou u kiezen?

(7 uit 16)

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Arts</b> maakt beslissing	 <b>Gezamenlijke beslissing</b> van arts en patiënt
Kosten van behandeling	€1.000	€10.000
Attitude van behandelaar	Arts <b>ondersteunt</b> patiënt	Arts <b>ontmoedigt</b> patiënt
Gevolgde richtlijn	<b>ILADS</b> -richtlijn: langdurige behandeling (min. 1 maand)	<b>CBO</b> -richtlijn: kortdurige behandeling (max. 1 maand)
Ervaring behandelaar	<b>Gespecialiseerd</b> in Lymeziekte met ongeveer 1 patiënt per dag	<b>Basis ervaring</b> met ongeveer 20 patiënten per jaar
Reisafstand	Binnen <b>Europa</b> (buiten Nederland)	Buiten <b>Europa</b>
	<input type="text" value="KeuzeTakenBehandelaar_Random6"/>	<input type="text" value="KeuzeTakenBehandelaar_Random6"/>

Vorige

Volgende



0%  100%



KeuzeTakenBehandelaar\_Random7

Als u zou moeten kiezen tussen deze twee behandelaars voor de behandeling van uw Lymeziekte, welke zou u kiezen?

(8 uit 16)

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Patiënt</b> maakt geïnformeerde beslissing	 <b>Gezamenlijke beslissing</b> van arts en patiënt
Kosten van behandeling	€10.000	€1.000
Attitude van behandelaar	Arts <b>ontmoedigt</b> patiënt	Arts <b>ondersteunt</b> patiënt
Gevolgde richtlijn	<b>CBO</b> -richtlijn: kortdurige behandeling (max. 1 maand)	<b>ILADS</b> -richtlijn: langdurige behandeling (min. 1 maand)
Ervaring behandelaar	<b>Gespecialiseerd</b> in Lymeziekte met ongeveer 1 patiënt per dag	<b>Gemiddelde ervaring</b> met ongeveer 100 patiënten per jaar
Reisafstand	Binnen <b>Europa</b> (buiten Nederland)	Buiten <b>Europa</b>
	<input type="text" value="KeuzeTakenBehandelaar_Random7"/>	<input type="text" value="KeuzeTakenBehandelaar_Random7"/>

Vorige



Volgende

0%  100%

KeuzeTakenBehandelaar\_Random8

Als u zou moeten kiezen tussen deze twee behandelaars voor de behandeling van uw Lymeziekte, welke zou u kiezen?

(9 uit 16)

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Gezamenlijke beslissing</b> van arts en patiënt	 <b>Patiënt</b> maakt geïnformeerde beslissing
Kosten van behandeling	€385	€1.000
Attitude van behandelaar	Arts <b>ontmoedigt</b> patiënt	Arts <b>ondersteunt</b> patiënt
Gevolgde richtlijn	<b>CBO</b> -richtlijn: kortdurige behandeling (max. 1 maand)	<b>ILADS</b> -richtlijn: langdurige behandeling (min. 1 maand)
Ervaring behandelaar	<b>Gemiddelde ervaring</b> met ongeveer 100 patiënten per jaar	<b>Gespecialiseerd</b> in Lymeziekte met ongeveer 1 patiënt per dag
Reisafstand	Binnen <b>Europa</b> (buiten Nederland)	Binnen <b>gemeente</b>
	<input type="text" value="KeuzeTakenBehandelaar_Random8"/>	<input type="text" value="KeuzeTakenBehandelaar_Random8"/>

Vorige


Volgende

0%  100%

KeuzeTakenBehandelaar\_Random9

Als u zou moeten kiezen tussen deze twee behandelaars voor de behandeling van uw Lymeziekte, welke zou u kiezen?

(10 uit 16)

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Gezamenlijke beslissing</b> van arts en patiënt	 <b>Arts</b> maakt beslissing
Kosten van behandeling	€385	€1.000
Attitude van behandelaar	Arts <b>ondersteunt</b> patiënt	Arts <b>ontmoedigt</b> patiënt
Gevolgde richtlijn	<b>CBO</b> -richtlijn: kortdurige behandeling (max. 1 maand)	<b>ILADS</b> -richtlijn: langdurige behandeling (min. 1 maand)
Ervaring behandelaar	<b>Gespecialiseerd</b> in Lymeziekte met ongeveer 1 patiënt per dag	<b>Gemiddelde ervaring</b> met ongeveer 100 patiënten per jaar
Reisafstand	Buiten <b>Europa</b>	Binnen <b>Europa</b> (buiten Nederland)
	<input type="text" value="KeuzeTakenBehandelaar_Random9"/>	<input type="text" value="KeuzeTakenBehandelaar_Random9"/>

Vorige



Volgende

0%  100%

KeuzeTakenBehandelaar\_Random10

Als u zou moeten kiezen tussen deze twee behandelaars voor de behandeling van uw Lymeziekte, welke zou u kiezen?

(11 uit 16)

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Patiënt</b> maakt geïnformeerde beslissing	 <b>Arts</b> maakt beslissing
Kosten van behandeling	€5.000	€10.000
Attitude van behandelaar	Arts <b>ondersteunt</b> patiënt	Arts <b>ontmoedigt</b> patiënt
Gevolgde richtlijn	<b>ILADS</b> -richtlijn: langdurige behandeling (min. 1 maand)	<b>CBO</b> -richtlijn: kortdurige behandeling (max. 1 maand)
Ervaring behandelaar	<b>Basis ervaring</b> met ongeveer 20 patiënten per jaar	<b>Gemiddelde ervaring</b> met ongeveer 100 patiënten per jaar
Reisafstand	Binnen <b>Europa</b> (buiten Nederland)	Binnen <b>Nederland</b> (buiten provincie)
	<input type="text" value="KeuzeTakenBehandelaar_Random10"/>	<input type="text" value="KeuzeTakenBehandelaar_Random10"/>

Vorige



Volgende

0%  100%

KeuzeTakenBehandelaar\_Random11

Als u zou moeten kiezen tussen deze twee behandelaars voor de behandeling van uw Lymeziekte, welke zou u kiezen?

(12 uit 16)

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Arts</b> maakt beslissing	 <b>Gezamenlijke beslissing</b> van arts en patiënt
Kosten van behandeling	€5.000	€1.000
Attitude van behandelaar	Arts <b>ondersteunt</b> patiënt	Arts <b>ontmoedigt</b> patiënt
Gevolgde richtlijn	<b>ILADS</b> -richtlijn: langdurige behandeling (min. 1 maand)	<b>CBO</b> -richtlijn: kortdurige behandeling (max. 1 maand)
Ervaring behandelaar	<b>Gespecialiseerd</b> in Lymeziekte met ongeveer 1 patiënt per dag	<b>Basis ervaring</b> met ongeveer 20 patiënten per jaar
Reisafstand	Buiten <b>Europa</b>	Binnen <b>provincie</b> (buiten gemeente)
	<input type="text" value="KeuzeTakenBehandelaar_Random11"/>	<input type="text" value="KeuzeTakenBehandelaar_Random11"/>

Vorige

Volgende

0%  100%

AfstandBehandelaar

U bent nu bijna klaar met de keuzetaken! U heeft nog maar 4 keuzes te gaan.

Ter afwisseling weer even een andersoortige vraag.

Waar bevond zich uw laatste behandelaar?

- AfstandBehandelaar=1 Binnen gemeente
- AfstandBehandelaar=2 Binnen provincie (buiten gemeente)
- AfstandBehandelaar=3 Binnen Nederland (buiten provincie)
- AfstandBehandelaar=4 Binnen Europa (buiten Nederland)
- AfstandBehandelaar=5 Buiten Europa

U zal nu de laatste 8 keuzetaken beantwoorden.

Vorige



Volgende

0%  100%

KeuzeTakenBehandelaar\_Random12

Als u zou moeten kiezen tussen deze twee behandelaars voor de behandeling van uw Lymeziekte, welke zou u kiezen?

(13 uit 16)

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Arts</b> maakt beslissing	 <b>Gezamenlijke beslissing</b> van arts en patiënt
Kosten van behandeling	€5.000	€1.000
Attitude van behandelaar	Arts <b>ondersteunt</b> patiënt	Arts <b>ontmoedigt</b> patiënt
Gevolgde richtlijn	<b>CBO</b> -richtlijn: kortdurige behandeling (max. 1 maand)	<b>ILADS</b> -richtlijn: langdurige behandeling (min. 1 maand)
Ervaring behandelaar	<b>Gemiddelde ervaring</b> met ongeveer 100 patiënten per jaar	<b>Gespecialiseerd</b> in Lymeziekte met ongeveer 1 patiënt per dag
Reisafstand	Binnen <b>Nederland</b> (buiten provincie)	Buiten <b>Europa</b>
	<input type="text" value="KeuzeTakenBehandelaar_Random12"/>	<input type="text" value="KeuzeTakenBehandelaar_Random12"/>

Vorige



Volgende

0%  100%

KeuzeTakenBehandelaar\_Random13

Als u zou moeten kiezen tussen deze twee behandelaars voor de behandeling van uw Lymeziekte, welke zou u kiezen?

(14 uit 16)

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Gezamenlijke beslissing</b> van arts en patiënt	 <b>Arts</b> maakt beslissing
Kosten van behandeling	€10.000	€5.000
Attitude van behandelaar	Arts <b>ontmoedigt</b> patiënt	Arts <b>ondersteunt</b> patiënt
Gevolgde richtlijn	<b>CBO</b> -richtlijn: kortdurige behandeling (max. 1 maand)	<b>ILADS</b> -richtlijn: langdurige behandeling (min. 1 maand)
Ervaring behandelaar	<b>Basis ervaring</b> met ongeveer 20 patiënten per jaar	<b>Gemiddelde ervaring</b> met ongeveer 100 patiënten per jaar
Reisafstand	Binnen <b>gemeente</b>	Binnen <b>provincie</b> (buiten gemeente)
	<input type="text" value="KeuzeTakenBehandelaar_Random13"/>	<input type="text" value="KeuzeTakenBehandelaar_Random13"/>

Vorige

Volgende



0%  100%



KeuzeTakenBehandelaar\_Random14

Als u zou moeten kiezen tussen deze twee behandelaars voor de behandeling van uw Lymeziekte, welke zou u kiezen?

(15 uit 16)

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Arts</b> maakt beslissing	 <b>Patiënt</b> maakt geïnformeerde beslissing
Kosten van behandeling	€5.000	€385
Attitude van behandelaar	Arts <b>ontmoedigt</b> patiënt	Arts <b>ondersteunt</b> patiënt
Gevolgde richtlijn	<b>CBO</b> -richtlijn: kortdurige behandeling (max. 1 maand)	<b>ILADS</b> -richtlijn: langdurige behandeling (min. 1 maand)
Ervaring behandelaar	<b>Gespecialiseerd</b> in Lymeziekte met ongeveer 1 patiënt per dag	<b>Basis ervaring</b> met ongeveer 20 patiënten per jaar
Reisafstand	Buiten <b>Europa</b>	Binnen <b>Nederland</b> (buiten provincie)
	<input type="text" value="KeuzeTakenBehandelaar_Random14"/>	<input type="text" value="KeuzeTakenBehandelaar_Random14"/>

Vorige



Volgende

0%  100%

KeuzeTakenBehandelaar\_Random15

Als u zou moeten kiezen tussen deze twee behandelaars voor de behandeling van uw Lymeziekte, welke zou u kiezen?

(16 uit 16)

	Behandelaar A	Behandelaar B
Besluitvormer	 <b>Arts</b> maakt beslissing	 <b>Patiënt</b> maakt geïnformeerde beslissing
Kosten van behandeling	€385	€1.000
Attitude van behandelaar	Arts <b>ontmoedigt</b> patiënt	Arts <b>ondersteunt</b> patiënt
Gevolgde richtlijn	<b>ILADS</b> -richtlijn: langdurige behandeling (min. 1 maand)	<b>CBO</b> -richtlijn: kortdurige behandeling (max. 1 maand)
Ervaring behandelaar	<b>Basis ervaring</b> met ongeveer 20 patiënten per jaar	<b>Gespecialiseerd</b> in Lymeziekte met ongeveer 1 patiënt per dag
Reisafstand	Binnen <b>gemeente</b>	Binnen <b>provincie</b> (buiten gemeente)
	<input type="text" value="KeuzeTakenBehandelaar_Random15"/>	<input type="text" value="KeuzeTakenBehandelaar_Random15"/>

Vorige

Volgende

0%  100%

## Evaluatie

### Evaluatie

U bent nu bijna aan het einde van de enquête. De volgende vragen zijn ter evaluatie van de keuzetaken.

Geef per stelling aan in hoeverre u het hiermee eens bent

	Volledig mee oneens			Niet eens/ oneens			Volledig ee
De keuzetaken waren duidelijk	Evaluatie_r1=1 <input type="radio"/>	Evaluatie_r1=2 <input type="radio"/>	Evaluatie_r1=3 <input type="radio"/>	Evaluatie_r1=4 <input type="radio"/>	Evaluatie_r1=5 <input type="radio"/>	Evaluatie_r1=6 <input type="radio"/>	Evaluati <input type="radio"/>
Het was makkelijk om te kiezen tussen de behandelaars	Evaluatie_r2=1 <input type="radio"/>	Evaluatie_r2=2 <input type="radio"/>	Evaluatie_r2=3 <input type="radio"/>	Evaluatie_r2=4 <input type="radio"/>	Evaluatie_r2=5 <input type="radio"/>	Evaluatie_r2=6 <input type="radio"/>	Evaluati <input type="radio"/>
Het was makkelijk om de verschillen tussen de behandelaars te zien	Evaluatie_r3=1 <input type="radio"/>	Evaluatie_r3=2 <input type="radio"/>	Evaluatie_r3=3 <input type="radio"/>	Evaluatie_r3=4 <input type="radio"/>	Evaluatie_r3=5 <input type="radio"/>	Evaluatie_r3=6 <input type="radio"/>	Evaluati <input type="radio"/>
Ik had nog meer keuzetaken kunnen beantwoorden	Evaluatie_r4=1 <input type="radio"/>	Evaluatie_r4=2 <input type="radio"/>	Evaluatie_r4=3 <input type="radio"/>	Evaluatie_r4=4 <input type="radio"/>	Evaluatie_r4=5 <input type="radio"/>	Evaluatie_r4=6 <input type="radio"/>	Evaluati <input type="radio"/>
Ik nam alle kenmerken van de behandelaars in overweging bij het maken van mijn keuze	Evaluatie_r5=1 <input type="radio"/>	Evaluatie_r5=2 <input type="radio"/>	Evaluatie_r5=3 <input type="radio"/>	Evaluatie_r5=4 <input type="radio"/>	Evaluatie_r5=5 <input type="radio"/>	Evaluatie_r5=6 <input type="radio"/>	Evaluati <input type="radio"/>

Vorige

Volgende

0%  100%

Termination:

**U bent nu bij het einde van de enquête. Hartelijk dank voor uw deelname!**

Indien u graag de resultaten ontvangt kunt u een mail sturen naar:

548468vn@eur.nl

# BEDANKT



Heeft u nog opmerkingen over de enquête?

*Wanneer u op volgende klikt beëindigt u de enquête.*

Vorige

Volgende

0%



100%

## Appendix 2: Interview guide providers of treatment Lyme borreliosis

### Begin

1. Kunt u wat vertellen over u en uw ervaring met patiënten met de ziekte van Lyme?
2. Hoe kijken, in uw ogen, lymepatiënten naar de behandeling en diagnose van Lyme in Nederland?
  - Zijn patiënten positief of negatief en waarom?
3. Kunt u iets vertellen over de “attitude” van lymepatiënten?

### Ranking kenmerken

Tijdens het “discrete choice experiment” dat ik heb uitgevoerd met patiënten zijn er 6 kenmerken geïnccludeerd met betrekking tot de behandelaars. Kenmerken: kosten, besluitvormer, reisafstand, expertise van arts (hoeveelheid patiënten per jaar), gevolgde richtlijn, en attitude van behandelaar.

4. Wat denkt u dat voor patiënten het belangrijkste kenmerk van behandelaar is en waarom?
5. Wat denkt u dat voor patiënten het minst belangrijke kenmerk van behandelaar is en waarom?
6. Zijn er in uw ogen kenmerken van behandelaars die meespelen in de keuze van de patiënt, maar die niet zijn opgenomen in dit onderzoek?
  - Zo ja, welke kenmerken zijn dit en in welke mate beïnvloeden deze de keuze van de patiënt?

Resultaten van de enquête wanneer je iedereen als één groep neemt (1= meest belangrijk, 6= minst belangrijk maar wél belangrijk):

1. Richtlijn
2. Reisafstand
3. Expertise
4. Attitude
5. Kosten
6. Besluitvormer (niet significant)

Wat mij opviel is dat reisafstand hier op de tweede plek komt, terwijl ik uit gesprekken met patiënten juist haalde dat zij dit niet zouden meenemen.

7. Hoe denkt u hierover? Op welke manier beïnvloed reisafstand, volgens u, de keuze van de patiënt voor een behandelaar?

### Besluitvormer

De bevindingen over de voorkeur voor een besluitvormer zijn niet eenduidig.

8. Op welke manier wordt er meestal in uw praktijk met betrekking tot lymepatiënten het besluit genomen voor een bepaalde behandeling of vervolgstappen en waarom gebeurt dat op deze manier?
  - Gezamenlijke beslissing, patiënt, arts

### Diverse patiëntengroepen

Het blijkt dat er patiëntengroepen zijn die verschillen m.b.t. hun voorkeuren. Zo is er bijv. een groep met sterkte voorkeur voor ILADS, waar andere patiënten reisafstand of attitude van behandelaar belangrijker lijken te vinden dan de gevolgde richtlijn.

9. Hoe verschillen de voorkeuren tussen patiënten in de dagelijkse praktijk?
10. Wat zouden, volgens u, deze verschillen kunnen verklaren?

### Appendix 3: Example of open- and axial codes interviews

In table 8 an example of the axial and open codes is presented. Both the open and axial codes are a selection of all codes included.

Table 8: example of coding process as done in *Atlas.ti*

Axial code	Open code	Mentioned by	Example of quotation
Guideline	Guideline is important	Physician 4 Physician 5	“Yes, I know that people always say that they think that the guideline is important.” (Physician 5)
	Patients’ preference for ILADS	Physician 2 Physician 4 Physician 5	“Yes. Some people have studied that [ILADS-guideline]. And would like to have that.” (Physician 5)
	Guideline not important	Physician 1 Physician 5	“You do not have to tell them [patients] the guideline because it is often a little bit ‘clock and clapper’ what the patient knows, at my opinion.” (Physician 1)
Attitude Lyme patients	Resistance of patients	Physician 1 Physician 3 Physician 2 Physician 3 Physician 4	“If you ask them directly to it [psychological complaints], then yes. Then anger arises.” (Physician 2)
	Lyme patients are scared	Physician 1 Physician 2 Physician 3 Physician 5	“Fear for misunderstood complaints that eventually might result in a severe Lyme disease for the rest of their life. Yes, surely the fear.” (Physician 2)
	Knowledge of patients	Physician 1 Physician 3	“I mean, patients can have very strange ideas about what can be consequences [of Lyme disease].” (Physician 3)