



Patient Preferences in the treatment of age-related macular degeneration

Dear Patient,

We kindly invite you to participate in our study on the elicitation of patient preferences for different treatments of age related macular degeneration (AMD). The study is coordinated by the University Hospital Cologne. The results of the study will contribute to develop therapies based on patients needs and to improve patient involvement in treatment decisions. You have been invited to participate in this study because you as an affected patient know best about treatment aspects, which are important to patients. For the study we ask you to complete a questionnaire, which consists of 13 questions. Completing the questionnaire takes between 30 and 40 minutes. We are happy to help you with the questionnaire.

In the questionnaire you will be presented with two different treatment options in each question. Of those options, we ask you to indicate the treatment option you prefer. There are no

incorrect answers for this questionnaire as we are solely interested in your personal opinion on the treatments. Your answers in this questionnaire do not influence your actual treatment.

Participation in this questionnaire is completely voluntary. All questionnaires will be analyzed anonymously and cannot be combined with your name.

The study is supported financially by Bayer HealthCare. The ethics review board of the University Hospital consented to this study.

Each question should be answered, because incomplete questionnaires complicate data analysis.

Thank you very much for participating in this study.

Part 1 Personal data

At first, we would like you to provide some personal information, which helps us during the analysis of the questionnaires.

1. At the present time, how would you describe your eyesight using both eyes (with glasses or contact lenses

excellent	
good	
fair	
poor	
very poor	

2. In general, would you describe your overall health

excellent	
good	
fair	
poor	
very poor	

3. What is your gender?

female	
male	

4. Please indicate your age group:

younger than 45 years	
45- 54 years	
55- 64 years	
65- 74 years	
75 years or older	

5. How long have you been diagnosed with AMD?

Less than 1 year	
1-5 years	
6 years or more	

6. Are one or both eyes affected by AMD

One eye	
Both eyes	

7. How many injections did you receive already

1-5 Injections	
6-12 Injections	
more than 12 Injections	

8. Please tick your highest educational level

No degree	
Lower secondary education	
College	
Academic or comparable degree	

Part 2 Introduction

Please imagine that your eye disease is currently active and you already received three initial injections for treating the AMD. Now you have to decide about the treatment you prefer to receive for the next year. Your doctor offers different drugs between which you have to choose.

The drugs differ with regard to various treatment attributes: effect on visual function, injection frequency, monitoring frequency, approval status of the drug and side effects. These treatment characteristics will now be explained in more detail.

Treatment Characteristics

Monitoring frequency

During the treatment of your disease, monitoring examinations are performed in order to see whether there is still or again fluid in your eye. At these monitoring visits a vision test is performed and a photograph of your eyes by means of an Optical Coherence Tomography (OCT) is taken.

The monitoring visits can take place

- **monthly,**
- **every two months,**
- **every four months.**

Injection frequency:

The Injection frequency indicates how often injections will be performed. The injections can be performed in the following frequencies

- **scheduled, monthly:** Every month you receive an injection in the eye.
- **scheduled, every two months:** Every two months you receive an injection in the eye.
- **scheduled, every four months:** Every four months you receive an injection in the eye.
- **on demand, following monthly monitoring:** You have to attend monthly monitoring visits. In case fluid in your eye is diagnosed or your visual function decreased, you receive another injection at a subsequent appointment.

Effect on visual function:

The effect on visual functioning indicates the influence of the treatment on your visual functioning.

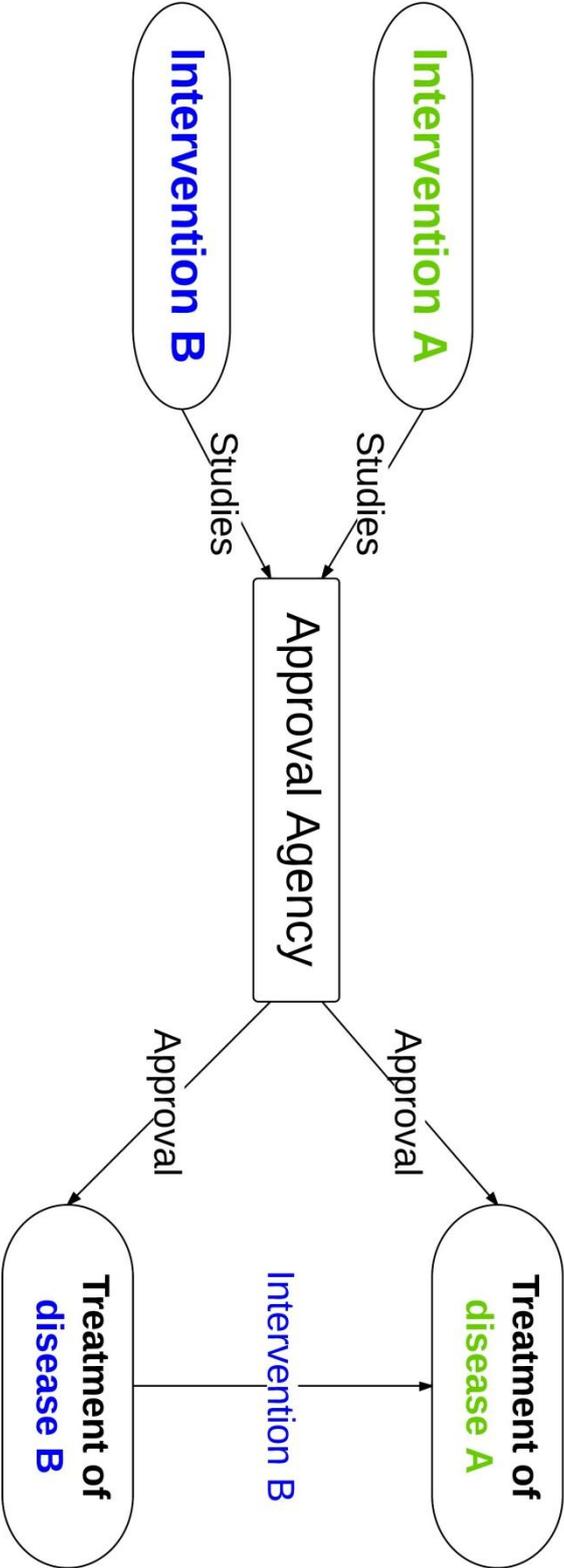
- **Stabilization:** Your current visual functioning will be stabilized, which means that your visual functioning for the moment will neither decrease nor improve.
- **Improvement:** The treatment leads to an improvement of your visual functioning. An improvement might be different for different patients. You might for example be able to read without magnifying glasses, recognize faces or be able to drive a car.

Approval status:

In Germany new drugs have to be tested in clinical trials. If a new drug is safe and effective for treating a specific disease, it can be approved by the approval authority. This approval means that the drug can be used for treating the disease for which it has been tested and received the approval. Sometimes it may happen that a drug seems to be effective for treating another disease as well. Even though the drug is not approved for the second disease, it might be used for treating AMD and the insurance companies might reimburse the drug.

- **Approved for AMD:** The drug has been assessed by the approval authority and was approved for the treatment of AMD.
- **Not approved for AMD:** The drug was has not been assessed by the approval authority and therefore is not approved for the treatment of AMD.

The flow chart was used to support written & verbal explanation of the approval process.



Side effects:

Different drugs have different side effects. The information on the side effects refers to 1000 patients who are treated with injections for one year.

- **Mild-moderate side effects in the eye, which occur frequently:** These side effects occur often, which means that around half of the patients who are treated for one year will be affected. These side effects do not need to be treated. Examples of these side effects are sensitivity to light or foreign body sensation in the eye.
- **Severe side effects in the eye, which occur rarely:** These side effects occur seldom, which means that 1-2 of 1000 patients who are treated for one year will be affected. These side effects need to be treated immediately. Examples of these side effects are inflammation in the eye or injuries of the retina.
- **Very severe systemic side effects, which occur very rarely:** These side effects occur very rarely, which means that less than 1 of 1000 patients who are treated for one year will be affected. These side effects need to be

treated immediately. Examples of these side effects include stroke or heart attack.

Choice of treatments

In each of the following 13 questions you will be presented with two treatment options. Please indicate the treatment you prefer. The following example will illustrate the task.

You are in a restaurant and have to choose between two dishes. Take a look at all the components of the dish and choose the preferred dish.

	Dish A	Dish B
Garnish	Potatoe	Rice
Meat	Beef	Fish
Salad	Tomatoe salad	Mixed Salat
Tick preferred dish		

In the following 13 questions you won't have to choose between dishes, but treatments. Carefully read the complete description of treatments and tick the treatment you prefer.

Question 1	Treatment A	Treatment B
Monitoring frequency	every four months	monthly
Effect on visual function	improvement	stabilization
Injection frequency	scheduled, every two months	on demand, following monthly monitoring
Approval status	not approved	approved
Side effects	mild–moderate, frequent, eye related	severe, rare, eye related
(Asked verbally: Which treatment do you prefer?)		

Question 2	Treatment A	Treatment B
Monitoring frequency	monthly	every two months
Effect on visual function	improvement	stabilization
Injection frequency	scheduled, every month	scheduled, every two months
Approval status	not approved	approved
Side effects	severe, rare, eye related	mild–moderate, frequent, eye related
(Asked verbally: Which treatment do you prefer?)		

Question 3	Treatment A	Treatment B
Monitoring frequency	every four months	monthly
Effect on visual function	improvement	improvement
Injection frequency	scheduled, every four months	scheduled, every month
Approval status	not approved	approved
Side effects	severe, rare, eye related	mild–moderate, frequent, eye related
(Asked verbally: Which treatment do you prefer?)		

Question 4	Treatment A	Treatment B
Monitoring frequency	every four months	every two months
Effect on visual function	stabilization	improvement
Injection frequency	scheduled, every two months	scheduled, every month
Approval status	approved	not approved
Side effects	severe, rare, eye related	mild–moderate, frequent, eye related
(Asked verbally: Which treatment do you prefer?)		

Question 5	Treatment A	Treatment B
Monitoring frequency	monthly	monthly
Effect on visual function	stabilization	stabilization
Injection frequency	on demand, following monthly monitoring	scheduled, every four months
Approval status	not approved	not approved
Side effects	mild–moderate, frequent, eye related	very severe, very rare, systemic
(Asked verbally: Which treatment do you prefer?)		

Question 6	Treatment A	Treatment B
Monitoring frequency	monthly	every four months
Effect on visual function	stabilization	improvement
Injection frequency	scheduled, every four months	scheduled, every two months
Approval status	approved	not approved
Side effects	mild–moderate, frequent, eye related	very severe, very rare, systemic
(Asked verbally: Which treatment do you prefer?)		

Question 7	Treatment A	Treatment B
Monitoring frequency	every two months	every four months
Effect on visual function	improvement	stabilization
Injection frequency	scheduled, every four months	scheduled, every month
Approval status	not approved	approved
Side effects	very severe, very rare, systemic	severe, rare, eye related
(Asked verbally: Which treatment do you prefer?)		

Question 8	Treatment A	Treatment B
Monitoring frequency	every two months	monthly
Effect on visual function	improvement	stabilization
Injection frequency	scheduled, every month	on demand, following monthly monitoring
Approval status	approved	not approved
Side effects	severe, rare, eye related	very severe, very rare, systemic
(Asked verbally: Which treatment do you prefer?)		

Question 9	Treatment A	Treatment B
Monitoring frequency	every four months	monthly
Effect on visual function	stabilization	improvement
Injection frequency	scheduled, every month	scheduled, every two months
Approval status	approved	not approved
Side effects	very severe, very rare, systemic	severe, rare, eye related
(Asked verbally: Which treatment do you prefer?)		

Question 10	Treatment A	Treatment B
Monitoring frequency	every two months	every four months
Effect on visual function	stabilization	improvement
Injection frequency	every two months	scheduled, every four months
Approval status	approved	approved
Side effects	very severe, very rare, systemic	mild–moderate, frequent, eye related
(Asked verbally: Which treatment do you prefer?)		

Question 11	Treatment A	Treatment B
Monitoring frequency	monthly	every two months
Effect on visual function	improvement	stabilization
Injection frequency	on demand, following monthly monitoring	scheduled, every two months
Approval status	approved	not approved
Side effects	very severe, very rare, systemic	severe, rare, eye related
(Asked verbally: Which treatment do you prefer?)		

Question 12	Treatment A	Treatment B
Monitoring frequency	monthly	every two months
Effect on visual function	stabilization	improvement
Injection frequency	scheduled, every two months	scheduled, every four months
Approval status	not approved	approved
Side effects	mild–moderate, frequent, eye related	very severe, very rare, systemic
(Asked verbally: Which treatment do you prefer?)		

Question 13	Treatment A	Treatment B
Monitoring frequency	every four months	monthly
Effect on visual function	improvement	improvement
Injection frequency	scheduled, every four months	scheduled, every month
Approval status	not approved	approved
Side effects	severe, rare, eye related	mild–moderate, frequent, eye related
(Asked verbally: Which treatment do you prefer?)		

How do you rate the difficulty of this questionnaire?

difficult	rather difficult	neutral	rather easy	easy