

**Part 1: To be filled in by the study doctor/assistant:**

<b>Patient</b>	
1.00 Questionnaire number	<input type="checkbox"/> _____
1.01 Age	<input type="checkbox"/> _____ in years
1.02 Sex	<input type="checkbox"/> Female <input type="checkbox"/> Male
1.03 Eye diseases related to the presentation at the University Eye Hospital Bonn: (multiple answers possible)	<input type="checkbox"/> Cataract <input type="checkbox"/> Diabetic retinopathy <input type="checkbox"/> Glaucoma <input type="checkbox"/> Age-related macular degeneration <input type="checkbox"/> Vascular occlusion <input type="checkbox"/> Retinal detachment <input type="checkbox"/> Epiretinal gliosis <input type="checkbox"/> (suspicion of) monogenic retinal disease <input type="checkbox"/> Uveitis <input type="checkbox"/> Others: _____
1.04 Visus (c.c.m. or c.c.s.)	<input type="checkbox"/> RA _____ <input type="checkbox"/> LA _____
1.05 Relationship to the University Eye Hospital Bonn	<input type="checkbox"/> First presentation on own initiative <input type="checkbox"/> Initial referral by family eye doctor <input type="checkbox"/> Outpatient follow-up (no surgery at the University Eye Hospital Bonn) <input type="checkbox"/> Outpatient follow-up (following surgical procedures at the University Eye Clinic Bonn [except IVOM]) <input type="checkbox"/> Connection to IVOM consultation <input type="checkbox"/> Study patient
1.06 Insurance	<input type="checkbox"/> Private health insurance <input type="checkbox"/> Public health insurance
<b>accompanying person</b>	
1.07 Age	<input type="checkbox"/> _____ in years
1.08 Sex	<input type="checkbox"/> Female <input type="checkbox"/> Male
1.09 personal relation to patient	<input type="checkbox"/> No <input type="checkbox"/> Spouse <input type="checkbox"/> Parent <input type="checkbox"/> Child <input type="checkbox"/> Grandparent <input type="checkbox"/> Friend <input type="checkbox"/> Other: _____

**Part 2: To be filled in by the patient**

2.01 What language do you speak at home?	<input type="checkbox"/> _____
2.02 Highest level of education	<input type="checkbox"/> No school leaving certificate <input type="checkbox"/> Primary school leaving certificate <input type="checkbox"/> Intermediate secondary school leaving certificate (Realschule) <input type="checkbox"/> Secondary school leaving certificate (Gymnasium) <input type="checkbox"/> Completed training for professional classification <input type="checkbox"/> Tertiary education <input type="checkbox"/> Doctorate degree
2.03 I generally have full trust in doctors:	<input type="checkbox"/> Does apply (1) <input type="checkbox"/> Does rather apply (2) <input type="checkbox"/> Partly-partly (3) <input type="checkbox"/> Does rather not apply (4) <input type="checkbox"/> Does not apply (5)
2.04 Are you an organ donor (general) or do you have an organ donor card?	<input type="checkbox"/> No <input type="checkbox"/> Yes (-> continue with question 2.06)
2.05 If previous question was "No": Which reasons do you give against <b>general organ donation</b> ? (Multiple answers possible)	<input type="checkbox"/> I have no or not enough awareness of the topic <input type="checkbox"/> I am afraid or uncertain about death in organ donation process <input type="checkbox"/> I am afraid or uncertain about the distortion of my body in the donation process <input type="checkbox"/> I have religious, ethic or spiritual reasons against a donation <input type="checkbox"/> I believe that my organs are not suitable because of a preexisting disease <input type="checkbox"/> I believe that my organs are not suitable because of my age <input type="checkbox"/> I am afraid of abuse, have lack of trust (due to negative reporting) <input type="checkbox"/> Other: _____
2.06 Would you agree to donate your <b>eyes</b> after your death for one or more of the following purposes? (Multiple answers possible)	<input type="checkbox"/> No, I generally refuse to donate eyes (-> directly to question 2.9) <input type="checkbox"/> Yes, for tissue transplantation for immediate healing of another patient (e.g. cornea transplantation) <input type="checkbox"/> Yes, for research (e.g. microscopic examination of the retina) <input type="checkbox"/> Yes, for teaching medical students (e.g. training in anatomy) <input type="checkbox"/> Yes, for teaching prospective ophthalmologists (e.g. surgical training) <input type="checkbox"/> Other: _____
2.07 If previous question was "Yes": For a better organization of the donation process, I would be willing to enter a putative eye donation registry.	<input type="checkbox"/> Does apply (1) <input type="checkbox"/> Does rather apply (2) <input type="checkbox"/> Partly-partly (3) <input type="checkbox"/> Does rather not apply (4) <input type="checkbox"/> Does not apply (5) (-> continue with question 2.09)
2.08 If 2.07 was "1-4": I would be willing to have my personal ophthalmological data stored in such a <u>hypothetical</u> registry.	<input type="checkbox"/> Does apply (1) <input type="checkbox"/> Does rather apply (2) <input type="checkbox"/> Partly-partly (3) <input type="checkbox"/> Does rather not apply (4) <input type="checkbox"/> Does not apply (5)

<p>2.09 What are the (most likely) reasons for you not to donate your <b>eyes</b> after death? (multiple answers possible)</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> I have no or not enough awareness of the topic</li> <li><input type="checkbox"/> I am afraid or uncertain about death in organ donation process</li> <li><input type="checkbox"/> I am afraid or uncertain about the distortion of my body in the donation process</li> <li><input type="checkbox"/> I have religious, ethic or spiritual reasons against a donation</li> <li><input type="checkbox"/> I believe that my eyes are not suitable because of a preexisting disease</li> <li><input type="checkbox"/> I believe that my eyes are not suitable because of my age</li> <li><input type="checkbox"/> I am afraid of abuse, have lack of trust (due to negative reporting)</li> <li><input type="checkbox"/> Other: _____</li> </ul>
<p>2.10 <u>Regardless of my actual decision</u>, I think it would be appropriate for my ophthalmologist to address the topic of postmortem eye donation openly.</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Does apply (1) - "It is a doctor's job to educate about this subject."</li> <li><input type="checkbox"/> Does rather apply (2)</li> <li><input type="checkbox"/> Partly-partly (3)</li> <li><input type="checkbox"/> Does rather not apply (4)</li> <li><input type="checkbox"/> Does not apply (5) - "It would be inappropriate to be addressed by my doctor on this subject"</li> </ul>
<p>2.11 I consider an education regarding the topic of <b>eye donation</b> to be appropriate through the following channels: (multiple answers possible)</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Personal education by ophthalmologist</li> <li><input type="checkbox"/> Personal education by medical assistant staff (e.g. medical assistant[r])</li> <li><input type="checkbox"/> Personal education by family doctor</li> <li><input type="checkbox"/> Education through an information leaflet</li> <li><input type="checkbox"/> Education via television, radio, internet</li> <li><input type="checkbox"/> Other: _____</li> </ul>
<p>2.12 The opinion of my family members is an important factor in my decision regarding eye donation</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Does apply (1)</li> <li><input type="checkbox"/> Does rather apply (2)</li> <li><input type="checkbox"/> Partly-partly (3)</li> <li><input type="checkbox"/> Does rather not apply (4)</li> <li><input type="checkbox"/> Does not apply (5)</li> </ul>

**Part 3: To be completed by the accompanying person**

The following questions refer to you personally (the accompanying person).	
3.01 What language do you speak at home?	<input type="checkbox"/> _____
3.02 Highest level of education	<input type="checkbox"/> No school leaving certificate <input type="checkbox"/> Primary school leaving certificate <input type="checkbox"/> Intermediate secondary school leaving certificate (Realschule) <input type="checkbox"/> Secondary school leaving certificate (Gymnasium) <input type="checkbox"/> Completed training for professional classification <input type="checkbox"/> Tertiary education <input type="checkbox"/> Doctorate degree
3.03 I generally have full trust in doctors:	<input type="checkbox"/> Does apply (1) <input type="checkbox"/> Does rather apply (2) <input type="checkbox"/> Partly-partly (3) <input type="checkbox"/> Does rather not apply (4) <input type="checkbox"/> Does not apply (5)
3.04 Are you an <b>organ donor</b> (general) or do you have an organ donor card?	<input type="checkbox"/> No <input type="checkbox"/> Yes (-> continue with question 3.06)
3.05 If the previous question is "No": What reasons do <b>you yourself</b> have against general organ donation? (Multiple answers possible)	<input type="checkbox"/> I have no or not enough awareness of the topic <input type="checkbox"/> I am afraid or uncertain about death in organ donation process <input type="checkbox"/> I am afraid or uncertain about the distortion of my body in the donation process <input type="checkbox"/> I have religious, ethic or spiritual reasons against a donation <input type="checkbox"/> I believe that my organs are not suitable because of a preexisting disease <input type="checkbox"/> I believe that my organs are not suitable because of my age <input type="checkbox"/> I am afraid of abuse, have lack of trust (due to negative reporting) <input type="checkbox"/> Other: _____

The following questions refer to the patient (from the perspective of the accompanying person).	
3.06 Would you agree to <b>donate the patient's eyes</b> after death? (Multiple answers possible)	<input type="checkbox"/> No, I generally refuse to donate <input type="checkbox"/> Yes, for tissue transplantation for immediate healing of another patient (e.g. cornea transplantation) <input type="checkbox"/> Yes, for research (e.g. microscopic examination of the retina) <input type="checkbox"/> Yes, for teaching medical students (e.g. training in anatomy) <input type="checkbox"/> Yes, for teaching prospective ophthalmologists (e.g. surgical training) <input type="checkbox"/> Other: _____
3.07 If you have answered question 3.06 with "no": In your opinion, what are the reasons for not <b>donating the patient's eyes</b> after his/her death? (Multiple answers possible)	<input type="checkbox"/> I have no or not enough awareness of the topic <input type="checkbox"/> I am afraid or uncertain about death in organ donation process <input type="checkbox"/> I am afraid or uncertain about the distortion of the donor's body in the donation process <input type="checkbox"/> I have religious, ethic or spiritual reasons against a donation <input type="checkbox"/> I believe that the patient's eyes are not suitable because of a preexisting disease <input type="checkbox"/> I believe that the patient's eyes are not suitable because of her/his age <input type="checkbox"/> I am afraid of abuse, have lack of trust (due to negative reporting) <input type="checkbox"/> Other: _____
3.08 <u>Regardless of my actual decision</u> , I think it would be appropriate for the ophthalmologist to address me openly on the subject of <b>eye donation after the death of the patient</b> I am accompanying.	<input type="checkbox"/> Does apply (1) - "It is a doctor's job to educate about this subject." <input type="checkbox"/> Does rather apply (2) <input type="checkbox"/> Partly-partly (3) <input type="checkbox"/> Does rather not apply (4) <input type="checkbox"/> Does not apply (5) - "No, it would be inappropriate to be addressed by my doctor on this subject"
3.09 <u>Regardless of my actual decision</u> , I think it would be appropriate for the ophthalmologist to openly discuss the topic of <b>eye donation with the patient during his/her lifetime</b> .	<input type="checkbox"/> Does apply (1) - "It is a doctor's job to educate about this subject." <input type="checkbox"/> Does rather apply (2) <input type="checkbox"/> Partly-partly (3) <input type="checkbox"/> Does rather not apply (4) <input type="checkbox"/> Does not apply (5) - "No, it would be inappropriate to be addressed by my doctor on this subject"
3.10 I consider an education regarding the topic of <b>eye donation</b> to be appropriate through the following channels: (multiple answers possible)	<input type="checkbox"/> Personal education by ophthalmologist <input type="checkbox"/> Personal education by medical assistant staff (e.g. medical assistant[r]) <input type="checkbox"/> Personal education by family doctor <input type="checkbox"/> Education through an information leaflet <input type="checkbox"/> Education via television, radio, internet <input type="checkbox"/> Other: _____
3.11 My opinion as an accompanying person plays a significant role in <u>the patient's decision</u> to donate eyes after death.	<input type="checkbox"/> Does apply (1) <input type="checkbox"/> Does rather apply (2) <input type="checkbox"/> Partly-partly (3) <input type="checkbox"/> Does rather not apply (4) <input type="checkbox"/> Does not apply (5)