Appendix 1. Original 50-item QUALITII questionnaire

Section 1: Questions about you

1. What language do you prefer?
   a. English
   b. Spanish

2. What is your age in years?

3. What is your gender?
   a. Male
   b. Female

4. What is your ethnicity or race?
   a. Caucasian (white)
   b. African American (black)
   c. Latino (Hispanic)
   d. Asian
   e. American Indian
   f. Pacific Islander
   g. Other

5. What type of health insurance do you have?
   a. Private health insurance policy
   b. Marketplace insurance policy (Obamacare)
   c. Military health care (like TRICARE)
   d. Public health insurance policy (Medicare or Medicaid)
   e. No insurance/self-pay

6. For which condition do you receive repeated eye injections?
   a. Age-related macular degeneration (AMD)
   b. Diabetic macular edema (DME) and/or Diabetic retinopathy (DR)
   c. Retinal vein occlusion (RVO)
   d. Other
   e. Uncertain

7. Approximately when were you diagnosed with this condition?
   a. Within the last year
   b. 1 – 4 years ago
   c. 5 – 10 years ago
   d. Over 10 years ago
   e. Uncertain

Section 2: Questions about your eye disease and treatment

8. Which doctor performs your eye injections (Select all that apply)?
   a. (Multiple choice of physician names will be added appropriate to site)
   b. Uncertain

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9. Which medication do you currently have injected into your eye? (Select all that apply)
   a. Avastin (bevacizumab)
   b. Eylea (aflibercept)
   c. Lucentis (ranibizumab)
   d. Ozurdex (dexamethasone)
   e. Other
   f. Uncertain

10. Have you and your doctor tried more than one of the above medications to see which works best for you?
   a. Yes
   b. No
   c. Uncertain

11. Approximately how frequently do you receive eye injections?
   a. Every 4-5 weeks
   b. Every 6-8 weeks
   c. Every 10-12 weeks
   d. Every 13-16 weeks
   e. Only as needed (PRN)

12. How often do you see your retina doctor?
   a. Every 4-5 weeks
   b. Every 6-8 weeks
   c. Every 10-12 weeks
   d. Every 13-16 weeks
   e. Every 6 months or more
   f. Other

13. Approximately how many total eye injections have you received so far?
   a. 0-5
   b. 6-10
   c. 11-20
   d. 20-50
   e. Greater than 50

14. What type of pain medication is used prior to your eye injections?
   a. Numbing drops and/or numbing gel only
   b. Injection of numbing medicine
   c. Q-tips soaked with numbing medicine pushed onto your eye
   d. Uncertain

15. Does your doctor use an instrument (called a “speculum”) to keep your eye open during the injection?
   a. Yes

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b. No

16. Do you currently receive injections into both eyes at the same visit?
    a. Yes
    b. No
    c. Sometimes

Section 3: Questions about your experience with treatment

17. How satisfied are you with the treatment of your eye disease?
    0 - Very unsatisfied
    1
    2
    3
    4
    5
    6 - Very satisfied

18. In your opinion, how effectively do your eye injections preserve your vision?
    0 - Very ineffective
    1
    2
    3
    4
    5
    6 - Very effective

19. What side effects or after effects have you experienced as a result of your eye injections? (select all that apply)
    a. Eye pain or discomfort
    b. Increased floaters after the first day
    c. Increased sensitivity to light
    d. Decreased vision beyond the first hour after an injection
    e. I do not routinely experience side effects or after effects
    f. Other (if other, please describe)

20. How often do you experience these side effects after your eye injections?
    a. Rarely
    b. About half the time
    c. More than half the time
    d. Every time

21. How bothered are you with the side effects or after effects experienced with eye injections?
    0 - Not at all bothered

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1
2
3
4
5
6 - Very bothered

22. Are you bothered enough by the side effects that you consider discontinuing the injections?
    a. Yes
    b. No

23. Please rate your pain or discomfort that result from your eye injections.
    0 - Insignificant
    1
    2
    3
    4
    5
    6 - Very significant

24. How long after injection does your pain or discomfort last?
    a. I do not experience pain or discomfort
    b. Less than 10 minutes
    c. Between 10 minutes and 1 hour
    d. Between 1 and 2 hours
    e. Between 2 and 4 hours
    f. Between 4 and 8 hours
    g. Between 8 and 24 hours
    h. Between 1 and 2 days
    i. More than 2 days

25. What aspect of the treatment do you think causes you the most discomfort or pain?
    a. Numbing the eye before injection
    b. Use of instrument (the “speculum”) to hold the eyelid open for injection
    c. Use of a brown antiseptic liquid (called “betadine”) applied before injection
    d. Injection of medicine into the eye
    e. Washing eye after injection
    f. The feeling after the numbing medicine wears off
    g. I do not feel pain from treatment
    h. Other (please specify)

26. How do you manage your pain or discomfort after treatment? (free response or “not applicable (N/A)”

27. Do you need to use pain medication at home (such as Tylenol or ibuprofen) before or after your treatment?

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a. Yes
b. No

28. After your injections, are you restricted because of discomfort from your injections beyond your usual activity level?
a. Yes
b. No

29. How many hours are you usually restricted before returning to normal activity?

30. Do you schedule appointments at a specific time of day to reduce disruption in your daily activities?
a. Yes
b. No

31. How anxious are you <u>before</u> your treatments?
0 - Very anxious
1
2
3
4
5
6 - Not at all anxious

32. How anxious are you <u>during</u> your treatments?
0 - Very anxious
1
2
3
4
5
6 - Not at all anxious

33. How anxious are you <u>after</u> your treatments?
0 - Very anxious
1
2
3
4
5
6 - Not at all anxious

34. Do you experience symptoms of sadness or anxiety for reasons <u>not</u> related to your eye treatments?
a. Yes
b. No

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35. If you experience anxiety at any time regarding your treatment, what is the reason for your anxiety? (free response or "not applicable (N/A)")

36. If you experience any anxiety at all, what, if anything, lessens your anxiety surrounding your visit? (free response or "not applicable (N/A)")

37. If you experience any anxiety at all, what, if anything, worsens your anxiety surrounding your visit? (free response or "not applicable (N/A)")

38. If you experience any anxiety at all, how do you manage your anxiety related to your treatment? (free response or "not applicable (N/A)")

39. Have you required use of anti-anxiety medication to cope with your treatment?
    a. Yes
    b. No

40. Have you ever had the following complications as a result of eye injections? (Select all that apply)
    a. Infection in the eye
    b. Bleeding from the eye
    c. Retinal detachment
    d. High pressure in the eye
    e. Inflammation of the eye
    f. None of the above

41. How time consuming is your eye treatment?
    0 - Not at all time consuming
    1
    2
    3
    4
    5
    6 - Very time consuming

42. How many hours do you typically spend in the clinic for each eye appointment?
    a. Less than 1 hour
    b. Between 1 and 3 hours
    c. Between 3 and 4 hours
    d. More than 4 hours

43. How many hours in total does it take to travel to, complete, and return from your eye appointment?
    a. Less than 1 hour
    b. Between 1 and 4 hours
    c. Between 4 and 8 hours
    d. More than 8 hours

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44. Do you require someone to bring you to your appointment?
    a. Yes
    b. No

45. How convenient is it for your escort to bring you to your appointment?
    0 - Not at all convenient
    1
    2
    3
    4
    5
    6 – Very convenient

46. For each visit, how many hours does your escort devote to each visit, including helping you during recovery?

47. Compared to visits where you receive injections in just one eye, please indicate how you are affected by receiving injections in both eyes? (select all that apply)
    a. More pain or discomfort
    b. Longer recovery time
    c. More anxiety
    d. More inconvenience
    e. No difference compared to injections in one eye only
    f. Other (please specify)

48. Would you encourage someone else with an eye condition like yours to have this kind of treatment?
    a. Yes, I would definitely encourage them
    b. No, I would definitely not encourage them
    c. Uncertain

49. What is your motivation to continue eye injections?

50. Are there any other aspects of the treatment causing satisfaction or dissatisfaction that have not been covered already? If yes, please explain.