

Appendix 1. Example of patient questionnaire. This example concerns a questionnaire for an adult patient (as opposed to a parent/caregiver of a pediatric patient) who had undergone aortic valve surgery (as opposed to pulmonary valve surgery).

1. Patient information and knowledge

1.1. Did you know that there are different treatment options?

- Yes
- No

1.2. Which treatment did you undergo? (If you underwent multiple treatments, this question concerns the most recent treatment)

- Valve replacement with a mechanical valve
- Valve replacement with a biological valve
- Valve repair
- Other, namely.....
- I don't know

1.3. Which treatment provides the most durable result (i.e. the lowest risk of reoperation)?

- Valve replacement with a mechanical valve
- Valve replacement with a biological valve
- Valve repair
- I don't know

1.4. What is the largest risk after valve repair?

- Reoperation
- Bleeding and thrombosis (blood clots)
- I don't know

1.5. What is the largest risk after valve replacement with a mechanical valve?

- Reoperation
- Bleeding and thrombosis (blood clots)
- I don't know

1.6. What is the largest risk after valve replacement with a biological valve?

- Reoperation
- Bleeding and thrombosis (blood clots)
- I don't know

1.7. Did your physician inform you about the various treatment options?

- Yes
- No

1.8. Did your physician inform you about the advantages and drawbacks of the various treatment options?

- Yes
- No

1.9. Do you feel like you had sufficient knowledge about the advantages and drawbacks of the various treatment options at the time of surgery?

Strongly disagree 1 2 3 4 5 Strongly agree

1.10. What was your most important source of information about your condition and the treatment options?

- The internet
- Patient information leaflets
- The cardiologist
- The heart surgeon
- Friends/relatives
- Other, namely.....

1.11. And what were other important sources of information about your condition and the treatment options?

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1.12. The information about my condition and the treatment options that i obtained from different care providers and/or other sources of information did not always correspond.

Strongly disagree 1 2 3 4 5 Strongly agree

Explanation:
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1.13. It was easy to find reliable information.

Strongly disagree 1 2 3 4 5 Strongly agree

What was the source of this information?

2. Decision-making

2.1. Was there a choice between different treatment options for you?

- Yes
- No

Explanation:

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2.2. With whom did you have the consultation regarding treatment options? (Multiple answers possible)

- With the cardiologist
- With the heart surgeon
- Other, namely.....
- I did not have such a consultation

2.3. How long prior to surgery was this consultation? (If you had multiple consultations regarding treatment options, this question concerns the first consultation)

- Less than one day prior to surgery
- More than one day, but less than 1 week prior to surgery
- More than one week prior to surgery
- I did not have such a consultation

2.4. The final decision for a treatment should be made by:

- The physician
- The physician, after considering the patient's opinion
- The patient and physician together
- The patient, after considering the physician's opinion
- The patient

2.5. Did you have enough time to make a well-thought-out decision?

- Yes
- No
- I don't know
- Not applicable

2.6. Besides your care providers, was anyone else involved in the decision for a certain treatment? (multiple answers possible)

- Yes, family
- Yes, a good friend
- Yes,
- No
- Not applicable

2.7. The doctor involved me in the decision for a certain treatment.

Strongly disagree 1 2 3 4 5 Strongly agree

- I don't know
- Not applicable

2.8. I think it is important to be involved in the decision for a certain treatment.

Strongly disagree 1 2 3 4 5 Strongly agree

- I don't know
- Not applicable

2.9. Do you feel like you had a choice in the decision for a certain treatment?

- Yes
- No
- I don't know
- Not applicable

Explanation:

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2.10. What could have gone better when the decision for a certain treatment was being made?

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	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
2.11. This decision was difficult for me to make	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.12. I was clear about the best choice for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.13. I was not sure what to choose	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.14. I knew which treatment options were available to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.15. I knew the benefits of each treatment option	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.16. I knew the risks and side effects of each treatment option	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.17. I would like to have had more advice and information about the treatment options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.18. I was clear about which benefits mattered most to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly disagree		Disagree		Neutral		Agree		Strongly agree
2.19. I was clear about which risks and side effects mattered most to me	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
2.20. It was difficult to decide whether the benefits or the risks and side effects were more important to me	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
2.21. I felt pressured by others while making this decision	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
2.22. I had enough support from others while making a decision	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
2.23. I feel I have made an informed choice	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
2.24. My decision shows what is important to me	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
2.25. I expect to stick with my decision	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
2.26. I am satisfied with my decision	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>

2.27. I am afraid of bleeding.

Never 1 2 3 4 5 Always
 Not applicable

2.28. I am afraid of thrombosis (blood clots).

Never 1 2 3 4 5 Always
 Not applicable

2.29. I have problems with taking medication.

Never 1 2 3 4 5 Always
 Not applicable

2.30. I am afraid of possibly needing another valve operation in the future.

Never 1 2 3 4 5 Always
 Not applicable

2.31. I am afraid that my valve may fail.

Never 1 2 3 4 5 Always
 Not applicable

2.32. Taking anticoagulation for the rest of my life bothers me.

Never 1 2 3 4 5 Always
O Not applicable

2.33. Is there a valve sound that bothers me?

Never 1 2 3 4 5 Always
O Not applicable

2.34. Following my valve surgery, the frequency of doctor visits and blood tests bothers me.

Never 1 2 3 4 5 Always
O Not applicable

2.35. I am satisfied with my new/repared aortic valve.

Never 1 2 3 4 5 Always
O Not applicable

2.36. If i had to do it over again, would I make the same decision?

No 1 2 3 4 5 Yes
O Not applicable

A person taking drug A has a 1% chance of having an allergic reaction. If 1,000 people take drug A, how many would you expect to have an allergic reaction?

..... person(s) out of 1,000.

2.37. A person taking drug B has a 1 in 1,000 chance of having an allergic reaction. What percentage of people taking drug B will have an allergic reaction?

..... %

2.38. Imagine that a coin was flipped 1,000 times. Out of 1,000 flips, how many times do you expect the coin to come up heads?

..... keer van de 1000.

2.39. Imagine the risk of reoperation after heart valve replacement is 5 percent (%). This is represented in the figures below. Please rank the figures based on how clear they are to you. 1 = most clear, 4 = least clear. Please fill in Figure A, B, C or D corresponding to each number. Each letter can only be used once.

Most clear

↓

Least clear

1. Figure

2. Figure

3. Figure

4. Figure

Figure A:

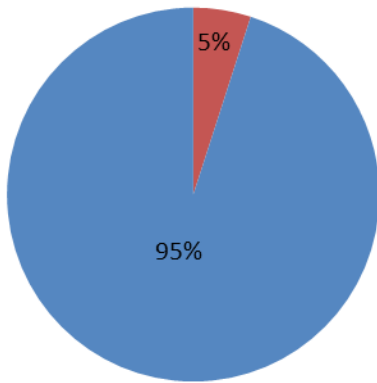


Figure B:

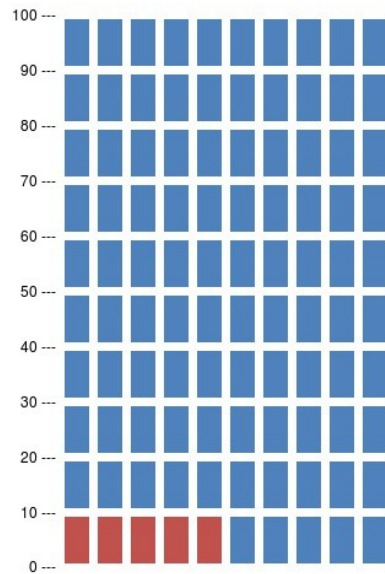


Figure C:

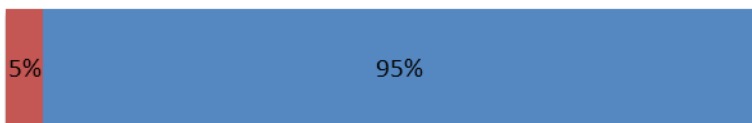
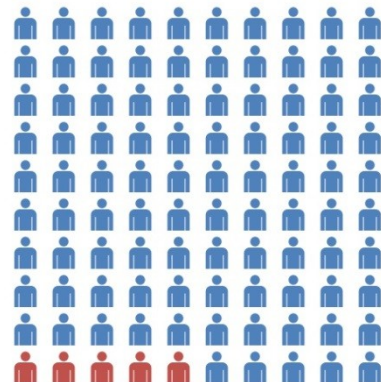


Figure D:



Explanation:

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