

Appendix 2. Physician questionnaire.

1. What do you think is the most important source of information about treatment options for your patients?

- The internet
- The cardiologist
- The cardiac surgeon
- Patient information leaflets
- Other,
namely.....

2. In my opinion, patients are sufficiently informed about treatment options.

Strongly disagree 1 2 3 4 5 Strongly agree

Explanation:

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3. The information about treatment options that is available to patients is reliable.

Strongly disagree 1 2 3 4 5 Strongly agree

Explanation:

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4. In my opinion, better informed patients will ... decision-making:

Hinder 1 2 3 4 5 Support

Explanation:

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5. Should patients be involved in the choice for a certain treatment?

Never Sometimes Regularly Often Always

I don't know

Explanation:

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6. If a patient does not wish to be involved in the choice for a certain treatment, should the physician still try to involve the patient in the decision?

Never Sometimes Regularly Often Always

I don't know

Explanation:

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7. 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

Explanation:

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8. In decision-making the advantages and drawbacks of the different treatment options are considered. Do you think that physicians are capable of determining how important each advantage and drawback is to each patient?

Never Sometimes Regularly Often Always

I don't know

Explanation:

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9. Should patients be informed about *all* drawbacks of a certain treatment option (even if the risk is low)?

Never Sometimes Regularly Often Always

I don't know

Explanation:

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10. How often do you inform your patients about the following factors concerning valve replacement with a mechanical valve?

Lifelong anticoagulation
Never Sometimes Regularly Often Always

Regular INR checks
Never Sometimes Regularly Often Always

Risks of anticoagulation
Never Sometimes Regularly Often Always

Thrombogenicity of the valve/thromboembolism
Never Sometimes Regularly Often Always

Ticking valve sound
Never Sometimes Regularly Often Always

Risk of reintervention lower than with other treatment options, but certainly not zero
Never Sometimes Regularly Often Always

Risk of endocarditis
Never Sometimes Regularly Often Always

Explanation:

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11. How often do you inform your patients about the following factors concerning valve replacement with a bioprosthesis, allograft, the Ross procedure or valve repair?

Risk of reintervention
 Never Sometimes Regularly Often Always

Risk of endocarditis
 Never Sometimes Regularly Often Always

Risk of thromboembolism
 Never Sometimes Regularly Often Always

Anticoagulation may still be(come) necessary
 Never Sometimes Regularly Often Always

Percutaneous or transapical valve replacement as a possible option for reintervention
 Never Sometimes Regularly Often Always

Explanation:

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12. If the decision concerns quality of life versus life expectancy after a certain treatment, do you think that physicians are capable of weighing these on the patients behalf?

Never Sometimes Regularly Often Always

I don't know

Explanation:

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13. In your experience, what are barriers/obstacles in involving patients in decision-making?

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14. In your opinion, what are the most important shortcomings in patient information on congenital aortic and pulmonary valve disease? And what would you like to improve?

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15. Which essential components should a newly developed patient information portal contain to support you in patient information, decision-making and patient communication?

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