

Willingness-to-pay questionnaire – translation by the authors

Dear Patients,

as a university hospital we are committed to medical research to continuously improve treatments in respect of the demands of our patients.

Personalized Medicine

New promising methods are recently investigated to improve the personalization of medical treatments (i.e. precisely adapted to the individual patient).

Your current treatment is already personalized e.g. in terms of age, state of health and by an individualized radiation treatment planning. However, further personalization is focus of current research approaches.

For example, your genotype or genetic changes of the tumour could elucidate your individual response to cancer treatments (probability of successful therapies) or predict the most effective pharmaceutical. Furthermore, recent imaging technologies that, for example, determine the tumour's perfusion or metabolism could enable a more individual treatment.

There are many more diagnostics conceivable. However, the present questionnaire is designed to go into detail of imaging technologies and genetic testing.

Why do we perform this survey?

Techniques of personalized medicine are promising but have frequently not been evaluated in large studies in respect of their effectiveness, yet. In addition, they are cost-intensive. Due to rising costs and limited resources in health care, the decision makers need to closely monitor expenses and to evaluate the most beneficial spending policy. Furthermore, the money should be invested in accordance with the interests of the patients.

"Willingness-to-pay analyses" can help to inform decision-making and financial allocation in health care. By "Willingness-to-pay analyses" patients evaluate how much out-of-pocket money they would be willing to spend for a particular diagnostic tool or treatment – in a hypothetical (i.e. not real) scenario. The intention is particularly not to raise costs for the patients "in reality" but to learn about their personal valuation of the benefit in monetary values (in Euro).

Of course, this questionnaire is of voluntary character and anonymous. In this way we cannot identify who handed back the questionnaire. Thus, please do not note your name or further personal information (e.g. please do not note the date of birth). However, as the questionnaire will not be referable any more, you won't be able to withdraw your consent to participate in this survey in future.

To interpret your „willingness-to-pay“ data it is important to know about your monthly income. However, if you prefer not to answer these - or other - questions (in spite of the anonymous character) just leave the respective questions unanswered.

We would highly appreciate your support to investigate "willingness-to-pay" in terms of personalized medicine in radiation oncology.

Personal data

1) age: _____ (in years)

2) gender: female ☐ male ☐

3) I am currently treated because of a tumour of the:

breast	<input type="checkbox"/>	lung	<input type="checkbox"/>	head and neck	<input type="checkbox"/>
prostate	<input type="checkbox"/>	lymphoma	<input type="checkbox"/>	other location: _____	
bowel	<input type="checkbox"/>	sarcoma	<input type="checkbox"/>	I don't know	<input type="checkbox"/>
brain	<input type="checkbox"/>	brain metastases	<input type="checkbox"/>	benign disease	<input type="checkbox"/>
bone	<input type="checkbox"/>	bone metastases	<input type="checkbox"/>		

4) education (adapted from the German educational system):

junior high school	<input type="checkbox"/>	high school	<input type="checkbox"/>	professional school	<input type="checkbox"/>
university	<input type="checkbox"/>	higher education	<input type="checkbox"/>	other: _____	

5) How many persons live in your household? _____ person(s)

6) What is your average income (total income of your household)?

monthly (pre-tax): _____ € or:

annually (pre-tax): _____ €

7) Have you ever heard of the term „personalized medicine“ before and if so, would you have been able to explain this concept?

- ☐ Yes, I would have been able to explain this concept.
- ☐ I have heard of personalized medicine before but I have not been able to define it.
- ☐ No, I have not heard of personalized medicine before.

8) After having heard the explanation of the approach of personalized therapeutic strategies: do you agree with the statement that personalized medicine is a promising strategy and would you expect a health benefit?

I fully agree	I generally agree	I rather disagree	I don't think so / no	I don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The aim of recent **imaging technologies** is not only to “detect” a tumour but also to find out more about biological characteristics. For example, in **PET** imaging glucose consumption of the tumour or the supply of oxygen can be determined. Potentially, in radiation oncology, the irradiated volume could be adapted according to these biological characteristics (e.g. dose escalation on very aggressive parts of the tumour).

9) Have you ever received PET/CT or PET/MRI imaging?

Yes, once ☐ Yes, several times ☐ No ☐ I am not sure ☐

Please imagine the **following scenario** (probabilities vary and therefore do not meet your “real” situation): After having received the diagnosis of a malignant tumour PET imaging is offered to you to improve the probability of a precise and thereby successful treatment. How much out-of-pocket money would you be willing to pay for this diagnostic tool (in Euro)? (Please either mark an amount on the left or use the slot on the right for a maximal amount if the suggested numbers do not match.)

10) How much would you be willing to pay if the probability of a successful treatment would rise from **5%** (standard treatment) to **10%**?

- ☐ I would not pay any out-of-pocket money for this intervention.
- | | |
|--|--------------------------|
| <input type="checkbox"/> up to 50€ | or rather maximal _____€ |
| <input type="checkbox"/> up to 100€ | or rather maximal _____€ |
| <input type="checkbox"/> up to 500€ | or rather maximal _____€ |
| <input type="checkbox"/> up to 1000€ | or rather maximal _____€ |
| <input type="checkbox"/> up to 5000€ | or rather maximal _____€ |
| <input type="checkbox"/> more than 5000€ | namely maximal _____€ |

11) How much would you be willing to pay if the probability of a successful treatment would rise from **20%** (standard treatment) to **40%**?

- ☐ I would not pay any out-of-pocket money for this intervention.
- | | |
|--|--------------------------|
| <input type="checkbox"/> up to 50€ | or rather maximal _____€ |
| <input type="checkbox"/> up to 100€ | or rather maximal _____€ |
| <input type="checkbox"/> up to 500€ | or rather maximal _____€ |
| <input type="checkbox"/> up to 1000€ | or rather maximal _____€ |
| <input type="checkbox"/> up to 5000€ | or rather maximal _____€ |
| <input type="checkbox"/> more than 5000€ | namely maximal _____€ |

Imaging diagnostics:

12) How much would you be willing to pay if the probability of a successful treatment would rise from **50%** (standard treatment) to **60%**?

- ☐ I would not pay any out-of-pocket money for this intervention.
- ☐ up to 50€ or rather maximal _____ €
- ☐ up to 100€ or rather maximal _____ €
- ☐ up to 500€ or rather maximal _____ €
- ☐ up to 1000€ or rather maximal _____ €
- ☐ up to 5000€ or rather maximal _____ €
- ☐ more than 5000€ namely maximal _____ €

13) How much would you be willing to pay if the probability of a successful treatment would rise from **60%** (standard treatment) to **80%**?

- ☐ I would not pay any out-of-pocket money for this intervention.
- ☐ up to 50€ or rather maximal _____ €
- ☐ up to 100€ or rather maximal _____ €
- ☐ up to 500€ or rather maximal _____ €
- ☐ up to 1000€ or rather maximal _____ €
- ☐ up to 5000€ or rather maximal _____ €
- ☐ more than 5000€ namely maximal _____ €

14) How much would you be willing to pay if the probability of a successful treatment would rise from **90%** (standard treatment) to **95%**?

- ☐ I would not pay any out-of-pocket money for this intervention.
- ☐ up to 50€ or rather maximal _____ €
- ☐ up to 100€ or rather maximal _____ €
- ☐ up to 500€ or rather maximal _____ €
- ☐ up to 1000€ or rather maximal _____ €
- ☐ up to 5000€ or rather maximal _____ €
- ☐ more than 5000€ namely maximal _____ €

Genetic testing of a tumour has the potential to predict the effectiveness and therefore the success of particular therapies. Here, the main focus is laid on pharmacological treatments, recently. However, in future, potentially also the effectiveness of radiation therapy could be estimated by genetic testing. If so, for example, the radiation dose could be adapted to the estimated response of the tumour.

15) Have you ever received genetic testing before?

Yes ☐ No ☐ I am not sure ☐

Please imagine the **following scenario**:

After having received the diagnosis of a malignant tumour genetic testing is offered to you to improve the probability of a precise and thereby successful treatment (either by a targeted pharmacological therapy or adapted radiation therapy). How much out-of-pocket money would you be willing to pay for this diagnostic tool (in Euro)?

16) How much would you be willing to pay if the probability of a successful treatment would rise from **5%** (standard treatment) to **10%**?

- ☐ I would not pay any out-of-pocket money for this intervention.
- | | |
|--|--------------------------|
| <input type="checkbox"/> up to 50€ | or rather maximal _____€ |
| <input type="checkbox"/> up to 100€ | or rather maximal _____€ |
| <input type="checkbox"/> up to 500€ | or rather maximal _____€ |
| <input type="checkbox"/> up to 1000€ | or rather maximal _____€ |
| <input type="checkbox"/> up to 5000€ | or rather maximal _____€ |
| <input type="checkbox"/> more than 5000€ | namely maximal _____€ |

17) How much would you be willing to pay if the probability of a successful treatment would rise from **20%** (standard treatment) to **40%**?

- ☐ I would not pay any out-of-pocket money for this intervention.
- | | |
|--|--------------------------|
| <input type="checkbox"/> up to 50€ | or rather maximal _____€ |
| <input type="checkbox"/> up to 100€ | or rather maximal _____€ |
| <input type="checkbox"/> up to 500€ | or rather maximal _____€ |
| <input type="checkbox"/> up to 1000€ | or rather maximal _____€ |
| <input type="checkbox"/> up to 5000€ | or rather maximal _____€ |
| <input type="checkbox"/> more than 5000€ | namely maximal _____€ |

Genetic testing:

18) How much would you be willing to pay if the probability of a successful treatment would rise from **50%** (standard treatment) to **60%**?

- ☐ I would not pay any out-of-pocket money for this intervention.
- ☐ up to 50€ or rather maximal _____ €
- ☐ up to 100€ or rather maximal _____ €
- ☐ up to 500€ or rather maximal _____ €
- ☐ up to 1000€ or rather maximal _____ €
- ☐ up to 5000€ or rather maximal _____ €
- ☐ more than 5000€ namely maximal _____ €

19) How much would you be willing to pay if the probability of a successful treatment would rise from **60%** (standard treatment) to **80%**?

- ☐ I would not pay any out-of-pocket money for this intervention.
- ☐ up to 50€ or rather maximal _____ €
- ☐ up to 100€ or rather maximal _____ €
- ☐ up to 500€ or rather maximal _____ €
- ☐ up to 1000€ or rather maximal _____ €
- ☐ up to 5000€ or rather maximal _____ €
- ☐ more than 5000€ namely maximal _____ €

20) How much would you be willing to pay if the probability of a successful treatment would rise from **90%** (standard treatment) to **95%**?

- ☐ I would not pay any out-of-pocket money for this intervention.
- ☐ up to 50€ or rather maximal _____ €
- ☐ up to 100€ or rather maximal _____ €
- ☐ up to 500€ or rather maximal _____ €
- ☐ up to 1000€ or rather maximal _____ €
- ☐ up to 5000€ or rather maximal _____ €
- ☐ more than 5000€ namely maximal _____ €

21) If you marked once or several times „I would not pay any out-of-pocket money for this intervention” in the questions above, this was because:

- ☐ I could not afford this but would in principle favor the diagnostic test.
- ☐ I don't consider the diagnostic test to be reasonable.
- ☐ The benefit seems too small to pay money for.
- ☐ _____

22) There are only limited funds available in health care. Please imagine that only one of the two methods for personalized medicine described above could be covered by the insurances. Which diagnostic procedure would you consider to be more promising, imaging or genetics? Which tool should be covered by the health insurances if only one could be paid for (if you like you can state the reason for your decision)?

- ☐ Imaging, because _____
- ☐ Genetic testing, because _____
- ☐ I don't know, because _____

23) Would you in principle agree to genetic testing?

- ☐ Yes, I would agree if it seems reasonable to me or if it has been recommended.
- ☐ No, I disapprove genetic testing even if it would be free of charge.

24) In genetic testing it is possible to limit the test to “tumour specific changes only”. Hereditary pathogenic variants (genetic changes that are familial) are not investigated in this case. Would you have reservations about this kind of genetic testing?

- ☐ No, because _____
- ☐ Yes, because _____
- ☐ I don't know

25) Genetic testing cannot only reveal results about the tumour itself but also about hereditary (familial) changes. These hereditary changes could, for example, promote tumour formation in general or cause further diseases. In this case, other family members could be affected as well. However, in many cases also these changes are relevant for tumour evaluation.

Would you have reservations about this kind of (hereditary) genetic testing (multiple answers are permitted)?

- ☐ No, because _____
- ☐ No, if I received results that could also affect my family (familial changes) I would like to know about these hereditary pathogenic variants (e.g. for preventive medical care for my family).
- ☐ No, if I received results that make tumour formation more likely in principal (compared to the average of population) I would like to know about these hereditary pathogenic variants for preventive medical care for myself (e.g. to allow early detection in case of further tumours).
- ☐ Yes, if I received results that could affect my family (genotype) I would prefer not to know about it (to prevent my family from being worried).
- ☐ Yes, I would be concerned about privacy issues / personal data.
- ☐ Yes, as adverse results (e.g. worse prognosis, higher risk of a second tumour, hereditary diseases) would make me anxious.
- ☐ Yes, because _____
- ☐ I am undecided / don't know.

26) Who should decide about imaging diagnostics or genetic testing?

myself ☐ the physician ☐ shared decision-making ☐

27) Would you rate the questionnaire and the scenarios to be comprehensible?

- ☐ Yes, well explained, well understandable.
- ☐ Yes, there were only minor uncertainties.
- ☐ Unfortunately, I only partly understood the survey.
- ☐ No, the questionnaire was incomprehensible.