“The right not to know” and its implications for psychiatric genetics

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Abstract

“The right not to know”, i.e.an individual’s right to be shielded from information that might change his or her lifestyle or dramatically impact on the quality of life, is gaining increasing importance in times of sophisticated brain research and genetic sequencing projects. The “right not to know” epitomizes the core conflict of values between the two poles of „patient autonomy“ and „medical care“. Foreseeable technological developments result in new ethical conflicts that need to be resolved. The issue of how to deal with incidental findings may be considered the most prominent one. However, so far, not much research has been conducted to assess both societal and individual aspects of the “right not to know.

To fill this gap, we have established an interdisciplinary collaboration between the departments of law, human genetics, and psychiatric genetics at the University of Göttingen and the Department of Medical Ethics at the University of Ulm. This collaboration will entail several theoretical and practical research projects at the respective departments. Eventually, we aim at formulating normative statements governing our understanding and practical application of the “right not to know”. The development of an empirical questionnaire will constitute an integral part of the overall project. The aim of this questionnaire is to measure the attitudes of several groups (health professionals, patients, relatives, general population etc.) toward the “right not to know”. Therefore, we are developing useful and standardized measurement criteria to determine the ethical and legal foundations of the “right not to know”.

In this presentation, we will summarize the current state of research on the ”right not to know”, introduce parts of the questionnaire dealing with the psychiatric aspects of our collaborative effort, and present first results based on this questionnaire.

Study objective

For so long there is no empirical fundament on the perspective “the right not to know”.

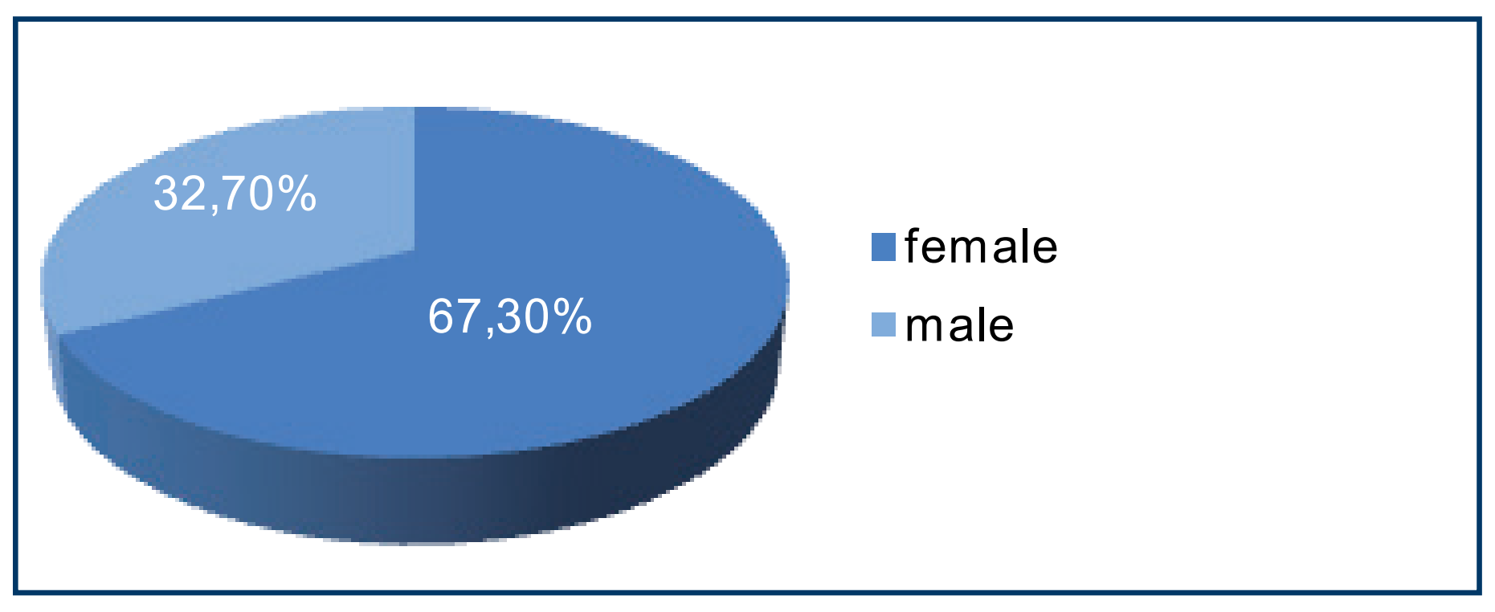
With our empirical questionnaire-based study we want to collect the individual „attitude“ (from the right for information in contrast to non-acceptance) of several groups of subjects (psychiatric patients, relatives, medical professionals, etc.) Needs and fears within the confrontation with (genetic or non-genetic) test results should be determined.

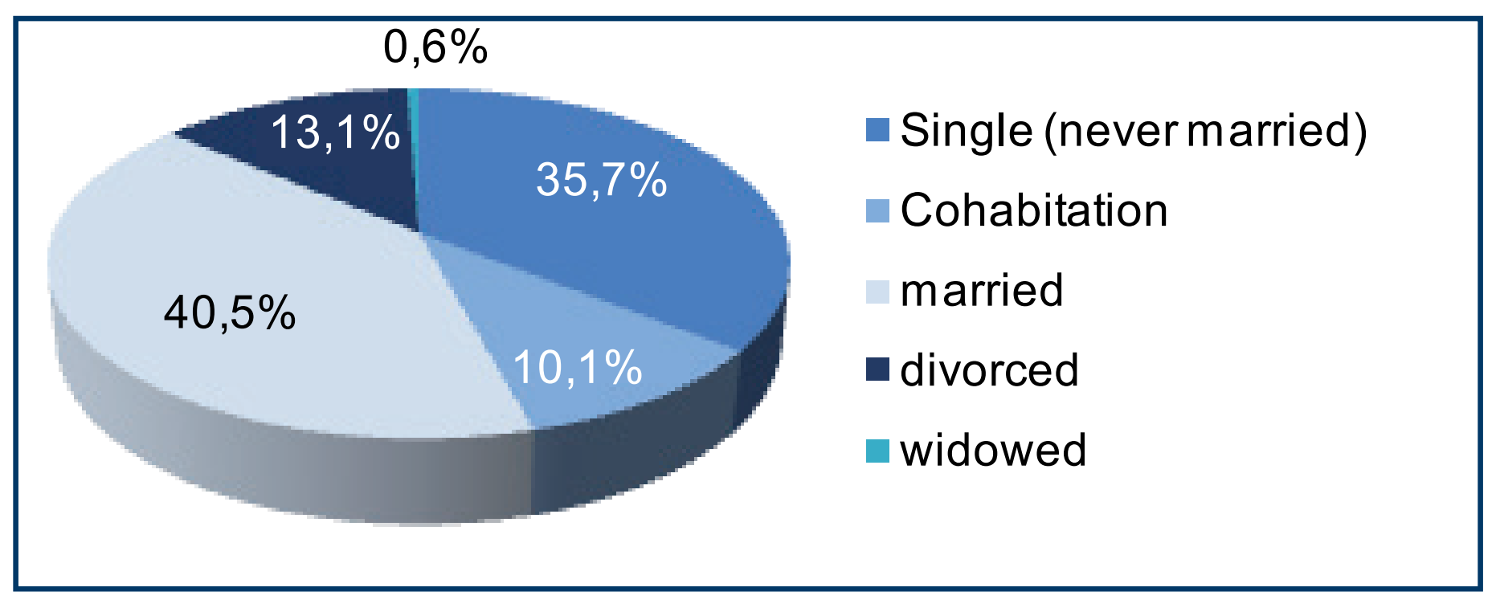
At the moment we are testing the questionnaire in a pilot study to validate our questions and possible biases. We want to develop a tool with a highest possible amount of objectivity, reliability and validity. At the moment 16 persons answered the questions. At this point we focused on genetic researchers and psychiatrists.

Our questionnaire has several parts with different functions:

Part 1: Social demographic questions

Here we collect information about the subjects, who are willing to answer our questions. This information (age, gender, education, etc.) might be very useful to distinguish between several groups with their individual needs. Here some interesting parts:



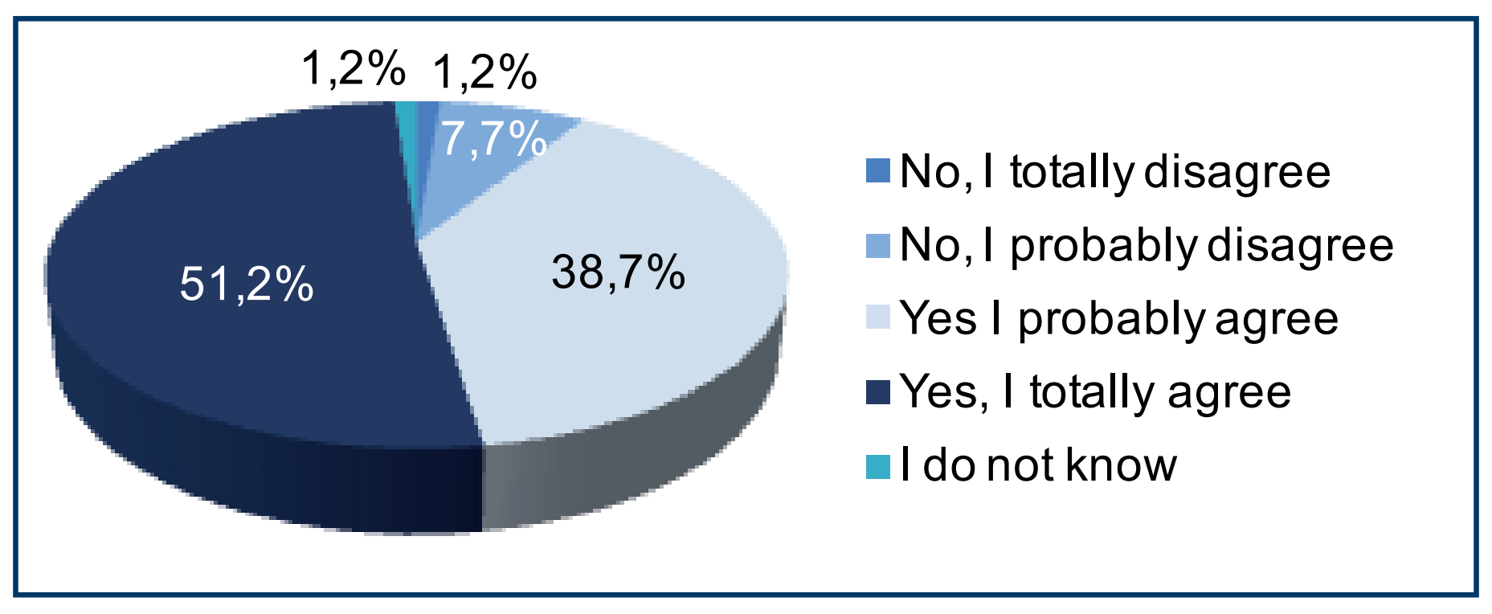


Part 2: General questions

Here we ask general questions to determine the attitudes of the several subjects.

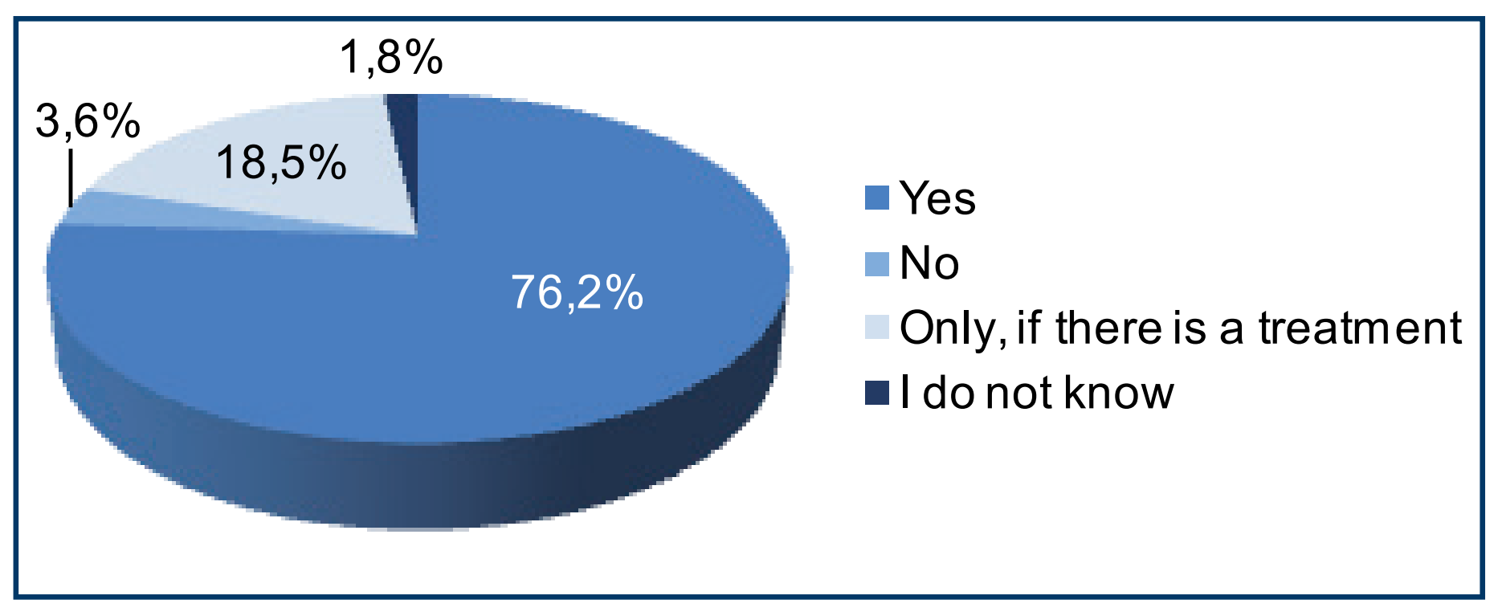
Example for question:

Everyone has the right to know everything about his outfit or genetic risk for genetic diseases.

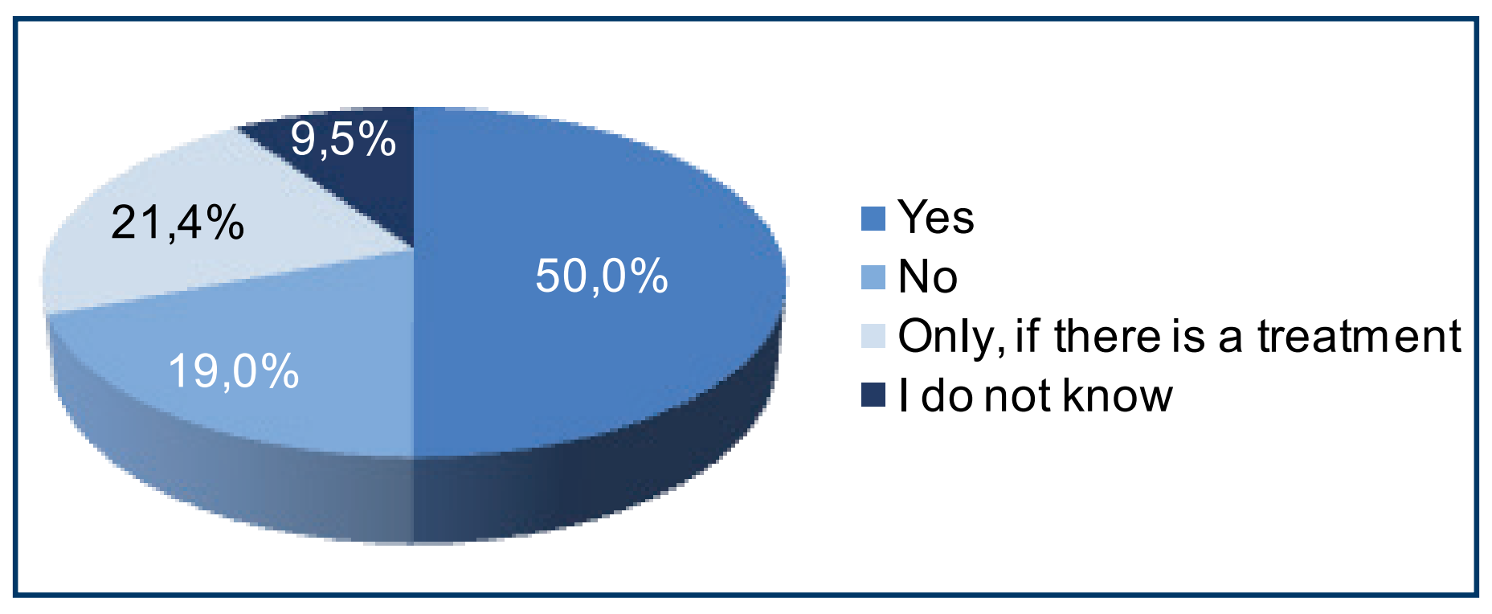


Part 3: Attitude towards wanting to know - or not

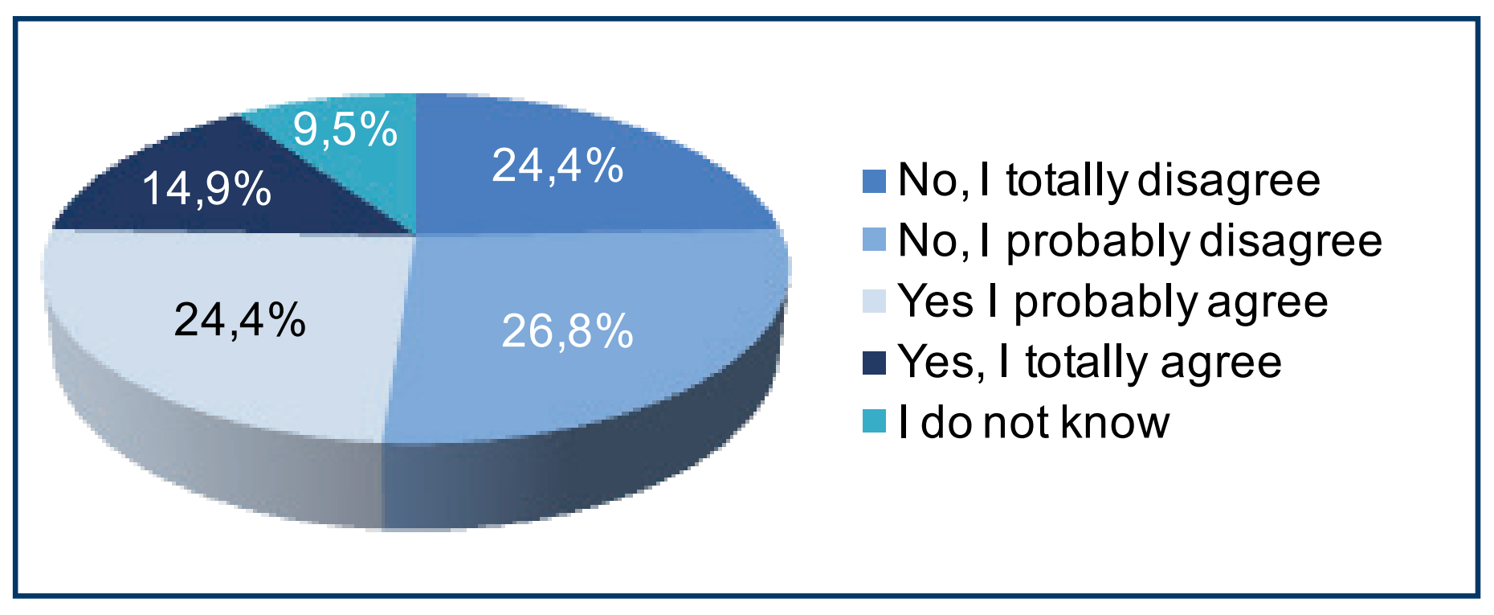
I want to know each randomly discovered disease that I have (n=168).



I want to know each randomly discovered risk that I have (n=168).



There is an easy and inexpensive way to have the risk for more than 250 genetic diseases tested. Would you agree to make the test?



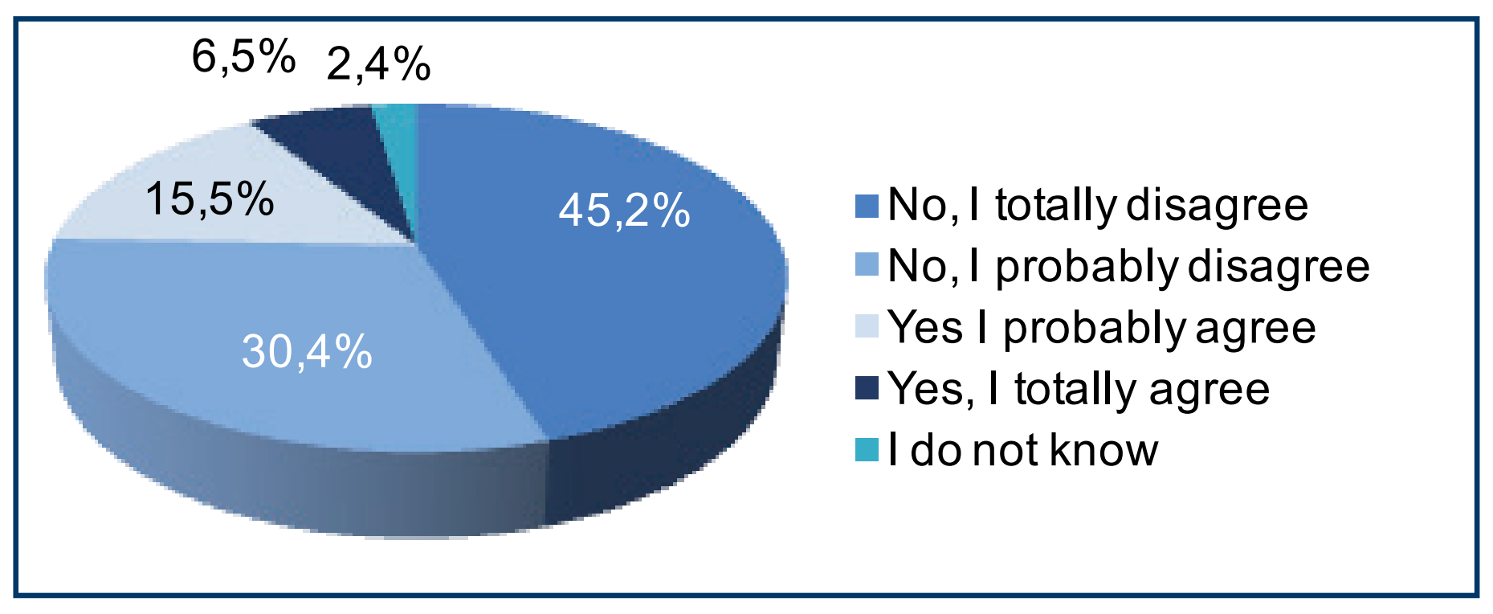
Interpretation of the first results

- More concrete questions are able to create a wider spectrum of answers between the subjects
- Professional background seems to influence the answer behavior
- As far as personal rights are touched, protection seems to be very important
- If there might be a life changing event (for example cancer diagnosis) medical support and expert knowledge/guidance are getting more important than pure information dropping
- It is possible to distinguish between a risk and a disease
- Most people want to be in control of their own results
- The “right to know” seems to be stronger than the “right not to know”

Part 4: Medical care or your right to self-determination

Example for question:

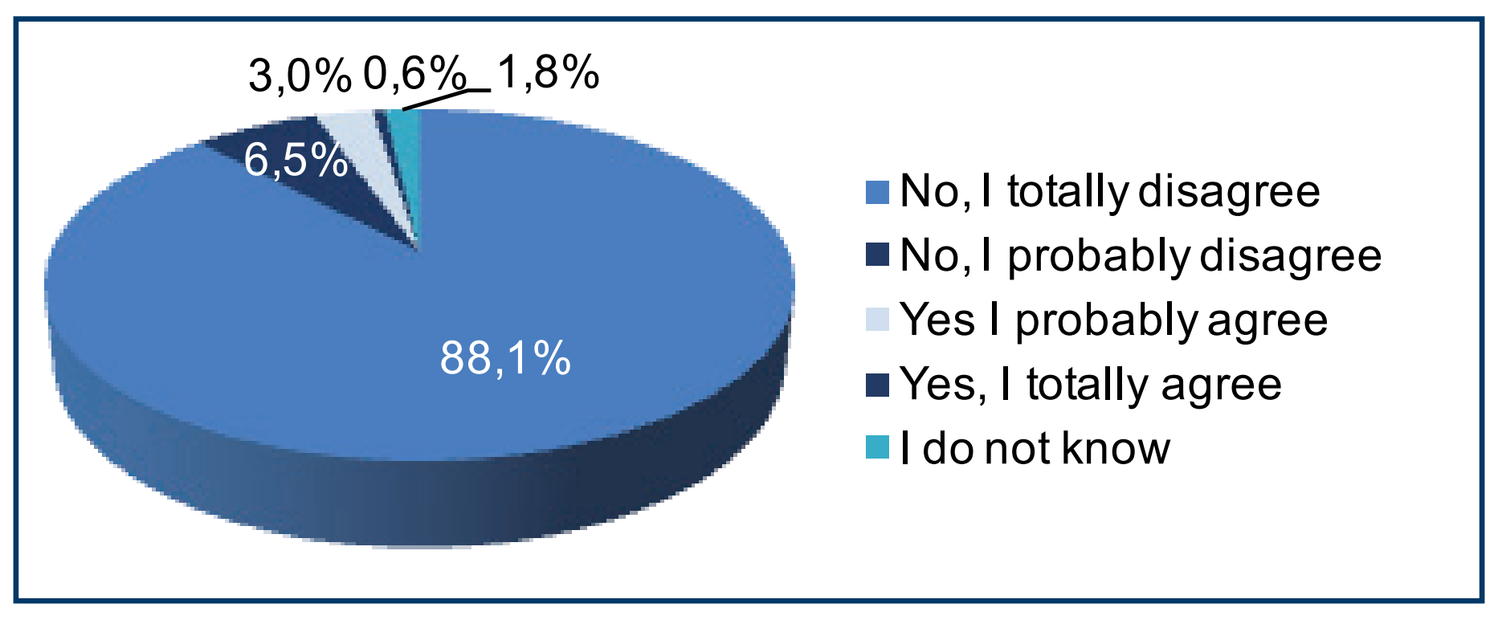
My doctor should know all my genetic findings and decide based on his expert knowledge, which of the results he tells me and which not.



Part 5: Information disclosure to third parties

Example for question:

Should it be legal, that various types of insurance (life insurance, disability insurance, etc.) have the right to investigate the genetic risk of their applicants / members in order to adjust the amount of the contribution depending on the risk that has been identified?



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