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Public interest and expectations concerning commercial genotyping and genetic risk assessment

In contrast to the modest progress made in the interpretation and clinical application of genomic data, genotyping technologies have experienced great progress. Genotyping costs are progressively decreasing making individual genotyping more commonly available. Financial availability of individual genome analysis and the strong desire of many people to know about their individual genomic characteristics, promotes the marketing of genetic tests of variable predictive value directly to the public. A survey of 2000 Russian respondents revealed very positive attitudes and beliefs towards these genetic developments: 85% of surveyed individuals would like to have their genetic risk for avoidable diseases estimated, and 89% responded stating that they would try to change their lifestyle by giving up bad habits, following a recommended diet or taking medications if a high risk of disease was identified. It is believed that with time, validated genetic information will find its rightful place in medicine, by supplementing phenotypic clinical data with validated genetic interpretations.

KEYWORDS: common diseases ■ genetic risk assessment ■ genetic testing ■ genomic medicine ■ lifestyle ■ predictive diagnostics ■ public attitude ■ survey

Expectations concerning genetic testing for disease predisposition have changed substantially over time. When the Human Genome Project was launched, it was anticipated that there would soon be a time when everyone could own a CD containing their individual genetic information, along with accurately defined predictions concerning one's own health and suggestions for important medical and nonmedical decisions based on personal genetic status. However, the more that is learned about the human genome, the more complexity is discovered, and there are now many concerns regarding the usefulness of genetic tests for common diseases [1,2]. In contrast to the modest progress made in the interpretation and clinical application of genomic data, genotyping technologies have experienced great progress in technology development. Genotyping costs are progressively decreasing, making individual genotyping more commonly available. Technical and financial availability of individual genome analysis and the strong desire of many people to know about their individual genomic characteristics, promote the marketing of variable analyses of individuals' DNA sequences for medical and nonmedical purposes directly to the public. Consumers of genetic diagnostics are becoming a major inducement, promoting forthcoming applications of genomic data into all spheres of life. Thus, for many reasons, it is essential to be aware of public attitudes

towards genetic testing for common diseases and the population's desire to estimate their own genetic risks.

A number of studies have been conducted so far, and all have revealed a high interest in people for genetic testing, including testing for multifactorial diseases [3,4]. Different questions were asked in different studies, but usually, more than 50% reported that they would like to undergo genetic testing; for example:

- A total of 69% of the British population expressed their interest in being tested for genetic susceptibility to heart disease, and 64% to cancer [4];
- A total of 61% in a Dutch population agreed that genetic testing should be available for those who want to use it [3], and 52% would want to know what their risk is if they could prevent disease;
- A total of 81% of women in the USA agreed that testing for breast cancer should be offered to everyone [5].

It can be difficult to make comparisons between different countries regarding the general public attitude towards genetic testing developments owing to social, historical and cultural differences. The Russian population has not been studied in this respect before, and their opinions can differ considerably when compared with even very closely culturally related

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European populations, owing to their unique historical, social and political background. In this report, we would like to present some of our findings concerning public attitudes towards various aspects of genetic testing, which are mainly derived from a survey of 2000 Russian respondents, and discuss the future perspectives of genomic diagnostics developments in the sphere of genetic testing to predict common diseases. In our view, the success of genomic diagnostics basically depends on the accuracy of the technology and the reliability of data interpretation. In addition, usage also depends on several social issues:

- The level of public interest in genetic testing;
- Regulation in this industry, especially involving ethical and confidentiality issues accompanying predictive data;
- Patients' expectations of the received information based on their variable medical and genetic knowledge;
- Careful evaluation of the short- and long-term effects of providing personal genetic information;
- The ability to change an individual's lifestyle and healthcare management in response to defined genetic risks.

To address some of the issues from this list, we developed a questionnaire that consisted of approximately 30 items that were asked to a socially active, working Russian city population.

Materials & methods

■ Participants & procedure

Survey participants (n = 2000) were all residing in Tomsk, a city of 516,100 people in West Siberia, Russia. The city is known as an academic and educational center in Russia and is home to the first university west of the Ural Mountains, having a high proportion of students and academic employees. Survey participants' enrollment was organized by the Institute of Medical Genetics of the Siberian Branch of the Russian Academy of Medical Sciences (SB RAMS [Tomsk, Russia]). Potential participants were reached through several contact strategies: most of the responders were contacted at their work places, and usually, an employer was asked to distribute the questionnaires among their colleagues and collect them (individuals from approximately 15 large and small organizations participated); a smaller portion of respondents were enrolled through social/hobby associations;

and approximately 10% of participants were contacted during their annual preventive medical examination at two medical centers. The sample was specially enriched with people of older age by contacting them during their visits to polyclinic medical centers. Approximately 100 students were additionally identified in two different universities. A total of 10% of questionnaires were completed on the internet as the questionnaire was posted for a short time on the institute's website and on one of the city's popular web-portals. Two questions were added to the internet forms to verify that people were Tomsk residents and have had no special medical education. Questionnaires obtained through the internet were compared with the forms collected in the usual way and did not differ in the frequency of completion. Owing to the active enrollment procedure, nonresponse rate was very low and did not exceed 7–10%. No payment was provided for the study participants.

The demographics of the study participants are presented in TABLE 1. A total of 69% of respondents were women, 27% were in the age group under 24 years, 43% were in the age range between 25–39 years old, 28% were in the age category of 40–64 years of age and approximately 2% were 65 years and older. Most of the people were employed in state (40%) or by commercial organizations (34%) and approximately 50% of survey participants had higher education.

■ Questionnaire

The questionnaire items were developed through several stages. The first stage consisted of interrogating a group of ten medical genetics specialists working in academic research centers. These specialists were asked to express their opinions regarding the most important issues they would like to know about concerning public attitudes towards genetic testing developments. Several questions were adapted for the Russian language from previous studies, such as those by Henneman *et al.* and Toiviainen *et al.* [3,6]. A number of questions and proposed answers were formulated and tested on 50 individuals. Every person from each tested group was asked how they understood the meaning and exact wording of the questions, and special consideration was given to ensure that people understood that the survey focused on common diseases rather than rare monogenic traits. The questionnaire consisted of two parts printed on both sides of one page, and took approximately 5 min to complete. The first part contained the

Table 1. Respondent's characteristics.

Characteristics	Proportion of respondents (%), n = 2000
Age groups (in years)	
<24	27.4
25–39	43.2
40–64	27.9
≥65	1.5
Education	
Incomplete secondary education	1.5
Secondary education	6.3
Specialized secondary education	22.4
Incomplete higher education	20.0
Higher education	46.2
Academic degree	3.6
Gender	
Male	30.6
Female	69.4
Occupation	
Work in a state institution	39.4
Work in a commercial organization	33.7
Student	17.2
Individual entrepreneur	3.6
Retired	3.6
Unemployed	1.1
Housewife	1.4

most important questions concerning attitudes towards disease-predisposition genetic testing and the reasons contributing to an individual's decisions and attitudes, and there was a list of common conditions of interest. Demographic information, such as gender, age group, occupation, level of education, health status self-assessment and some other characteristics (marital status, number of family members, mean income and so on) was assembled. The second part of the questionnaire contained a number of statements concerning genetic research and diagnostic developments and people were asked to respond on a two-point scale (agree or disagree).

■ Data analysis

Differences between groups were analyzed using the Pearson χ^2 test. Multiple regression analysis was executed to study public attitudes towards predictive genetic testing, and lifestyle changes in response to genetic test results were used as the dependant variable while gender, age groups, level of education and self-assessed health status were the independent variables. The analyses were carried out using the Statistical Package for Social Sciences (SPSS [IL, USA]).

Results

■ The desire to estimate personal genetic risk for common diseases

One of the main issues investigated was the assessment of public attitudes towards predictive genetic testing for common diseases. Two questions were included in the respondents' assessment: "would you like to know about probable future diseases?" and, "would you like to estimate the genetic risk for diseases which are avoidable by means of prophylaxis?" (TABLE 2). The question regarding prophylaxis added an additional nuance, that a disease might be avoided, and added approximately 18% of positive answers to the 68% of respondents who answered that they would like to know about future diseases. A total of 85% of respondents would like to estimate their genetic risks if disease could be avoided. Further analyses revealed that a significantly higher proportion of women expressed positive attitudes for predictive genetic testing. Younger age groups were also more likely to consider being tested (FIGURE 1). A total of 69% of the survey participants agreed with the statement that genetic tests should be extensively promoted and 86% believe that it is essential to assign more money

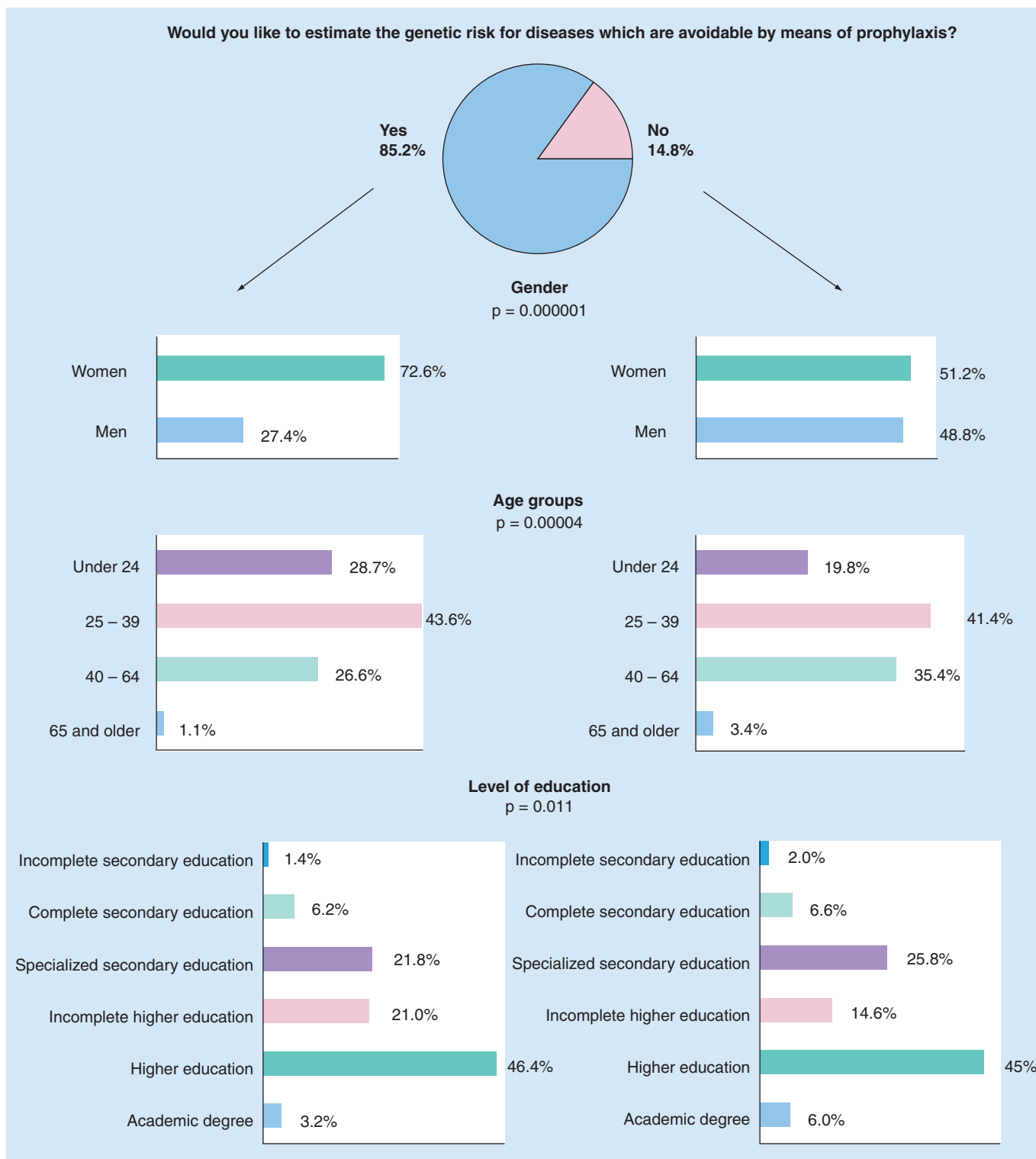


Figure 1. Characteristics of the groups of respondents with different attitudes to personal genetic risk assessment for avoidable diseases with respect to gender, age group and level of education. Two groups differed in indicated parameters. The significance of differences was calculated using the Pearson χ^2 test.

for genetic developments. A total of 81% agreed that, “knowing the genetic mechanisms of diseases will help people to live longer”, and the same proportion of respondents thought that knowing their own genetic variants would

allow them to control their lifestyle more easily. Approximately half of the respondents believed that genetic testing results, if they became publicly available, could result in increased discrimination of tested individuals (TABLE 2).

Table 2. Attitudes towards personal genetic risk assessment, benefits and dangers of genetic testing and test availability.

Items	Agreed (%)	Disagreed (%)	Not responded (%)
I would like to know about probable future diseases	68.3	31.0	0.7
Would you like to estimate the genetic risk for diseases that are avoidable by means of prophylaxis?	85.2	14.8	0
Would you try to change your lifestyle by giving up bad habits and following a recommended diet or taking medications if a high risk of disease was identified?	88.5	11.5	0
Knowing genetic mechanisms of diseases will help people to live longer	81.3	16.8	1.9
Knowing their own genetic variants allows individuals to control their lifestyle more easily	81.4	17.2	1.4
I believe that if genetic testing results become publicly available, they could result in the discrimination of tested people	48.0	49.8	2.2
Genetic tests should be promoted extensively	68.6	28.2	3.2
I believe it is essential to assign more money to genetic developments	85.9	10.9	3.2

Multiple regression analysis revealed that gender is an independent factor influencing the desire to estimate genetic risks for diseases that can be controlled. Women opted more for predictive genetic testing than men. More positive attitudes are typical of younger people, while older age groups tend to refuse predictive testing (TABLE 3). The likelihood of respondents saying “yes” to the question about predictive genetic testing was higher for those with a lower self-assessed health status; thus, individuals with good health are less interested in predictive diagnostics. Level of education had little influence on the attitudes towards predictive testing (TABLE 3).

To address the motives that can influence decisions as to whether or not to undergo genetic testing, respondents were asked to select from a list of possible reasons that might influence them to be tested, and reasons that would influence them not

to be tested (FIGURE 2). The main reason for people being interested in undergoing genetic testing for disease predisposition is their anxiety about their own health (38% of respondents). Physician’s recommendations can play a large part in their decision making (23%). A need for more detailed information and curiosity were mentioned by 18 and 17% of respondents, while family members’ or friends’ advice influenced only 4%.

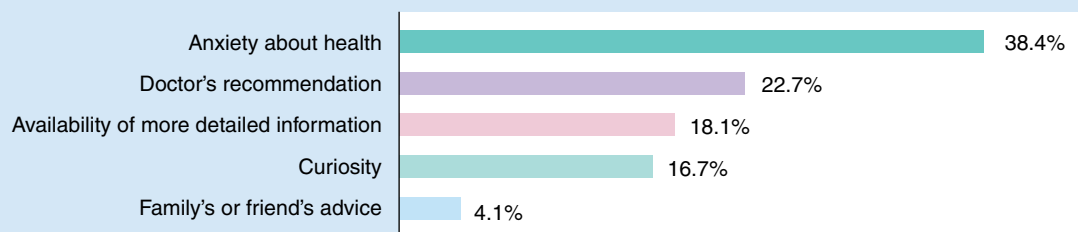
Among the reasons preventing the decision to undergo genetic testing are, “a lack of money for testing and possible treatments” (41%) and, “a lack of time” (20%) (FIGURE 2). At the same time, 18% of respondents said that nothing would stop them from being tested. Fear of discovering a disposition to a disease was a reason to reject testing for 14% of respondents. Very few respondents noted that the fear of possible treatment (4%) was a reason for not being tested and only 3% of respondents thought that testing, “is useless”.

Table 3. Linear regression analysis predicting attitude to personal genetic risk assessment for avoidable diseases.

Variable	Standardized regression coefficient	
	β	p-value
Health status	-0.091	0.000
Gender	-0.162	0.000
Age	0.138	0.000
Level of education	-0.041	0.065

*The negative coefficient for gender means that women are more likely to say “yes” than men; the positive coefficient for age yields a higher likelihood of saying yes to testing for younger people; the negative coefficient for self-evaluated health status means that people with lower health status are more likely to say “yes” than people with good self-reported health status; influence of the level of education was very low.
 β : Standardized coefficient.*

What can force you to undergo genetic testing?



What can prevent you from undergoing genetic testing?

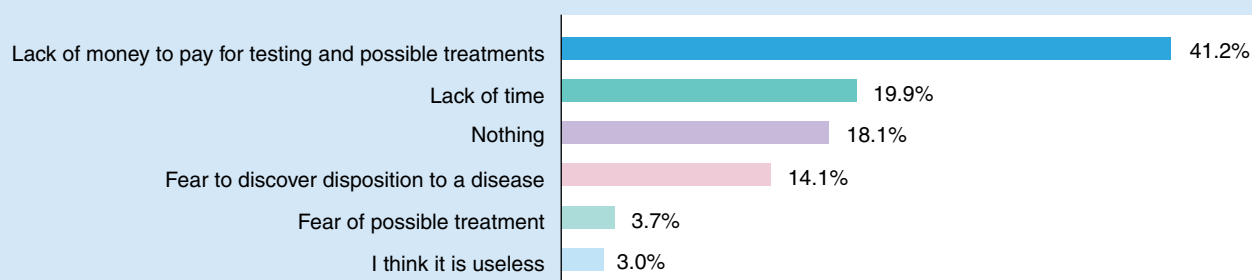


Figure 2. Respondent's answers to questions about reasons contributing to their decision to take a genetic test and those that can prevent them from wanting testing. Answers are ranged according to their weight (percentage of respondents selected them from the list).

FIGURE 3 presents the distribution of answers to the question concerning motives that can affect people's decisions to take a genetic test between different groups of respondents (men compared with women, different ages, health status and education). It was repeatedly discovered that women are more anxious about their health than men, and this can urge them to consider genetic testing ($p < 0.0001$ for the frequency comparison of this answer between men and women). In all ages, the main reason leading to the decision to be tested was anxiety about health, except for in the oldest age group where a doctor's recommendation was the most frequent answer and was twice as common compared with other age groups (52 vs 21–23% in all other ages; $p = 0.046$ for comparison between groups). Curiosity being an incentive to order a test decreased with age and was mentioned in 20, 16, 14 and 13% of respondents depending on their age group (<24, 25–39, 40–64, ≥65 years of age). When analyzing education

level with respect to different reasons for wanting to be tested, it was found that, for individuals with the lowest level of education, curiosity was the most common reason for wanting testing while, for other educational groups, anxiety about health was the most influential factor. Anxiety about health as a reason to take a test had greater value for individuals with a lower self-reported health status.

Considering the reasons that prevent individuals from being tested (FIGURE 4) revealed that a lack of money is a more common reason for women declining testing compared with men and more men tend to think that genetic testing “is useless” than women ($p = 0.043$). The answer “genetic testing is useless” was significantly more common in the oldest age group (23% in individuals who are ≥65 years old vs 1.7% in those who are <24; 2.8% in 25–39 year olds; and 3.7% in the age group of 40–64 years of age). Level of education had no significant influence on how people answered this question.

Table 4. A list of diseases were proposed for respondents to rank according to the advisability of genetic testing developments.

Disorders for which predictive genetic testing is mainly advisable	Ranked by respondents (%)
Oncological diseases	16.5
Cardiovascular (hypertension, myocardial infraction, brain stroke, atherosclerosis)	15.8
Diabetes mellitus	11.0
Pregnancy complications	8.3
Alcoholism	7.9
Neurodegenerative diseases (Parkinson's disease, Alzheimer's disease)	7.7
Gynecological diseases	7.3
Eye diseases	5.7
Musculoskeletal system disorders	5.6
Bronchial asthma	5.3
Drugs ineffectiveness and side effects	5.2
Hormonal contraception side effects	3.7

We asked survey participants to select the diseases they deemed to be most valuable for genetic diagnostics (TABLE 4). The disease rating (how many people 'vote' for a disease) reflected traditionally high levels of interest in oncological and cardiovascular diseases [4] which accounted for 17 and 16% of respondents. Diabetes mellitus, pregnancy complications, alcoholism, neurodegenerative disorders and gynecological diseases accounted from 7 to 11% of answers, and eye diseases, musculoskeletal system disorders, bronchial asthma, drug ineffectiveness and side effects and hormonal contraception side effects accounted from 4 to 6% of answers (TABLE 4).

■ Will genetic data change people's habits?

One of the most important issues in the use of predictive genetic testing is whether the personal genetic information is of significant value to an individual to convince them to make lifestyle changes in order to prevent disease. We asked

participants of our survey if they would try to change their lifestyle by giving up bad habits, following a recommended diet or taking medications if a high risk of disease was identified. As many as 88.5% replied affirmatively (TABLE 2).

We found that in those who reported they would change their lifestyle, 90% would want to take a genetic test for disease predisposition (FIGURE 5). For those who would not change their habits, only 48% would take a genetic test. Men were more skeptical about the idea of lifestyle changes compared with women, and similarly, when comparing older age groups with younger ones. Positive attitudes towards changing lifestyles did not depend on an individual's health status and had subtle connections with their levels of education. Multiple regression analysis demonstrated that gender and age were independent factors that influenced answers to this question. Women were more positive about possible behavior changes in response to genetic test results. Consensus in the older age group

Table 5. Linear regression analysis predicting response to a question about lifestyle changes if a high disease risk was discovered.

Variable	Standardized regression coefficient	
	β	p-value
Health status	-0.032	0.181
Gender	-0.158	0.000
Age	0.057	0.015
Level of education	-0.018	0.411

The most important factors influencing peoples response to the question about lifestyle changes in order to decrease the risk of possible disease were gender and age: women were more opt for changing their habits in order to reduce the risk; the older their age, the less people believe they will change their lifestyle.
 β : Standardized coefficient.

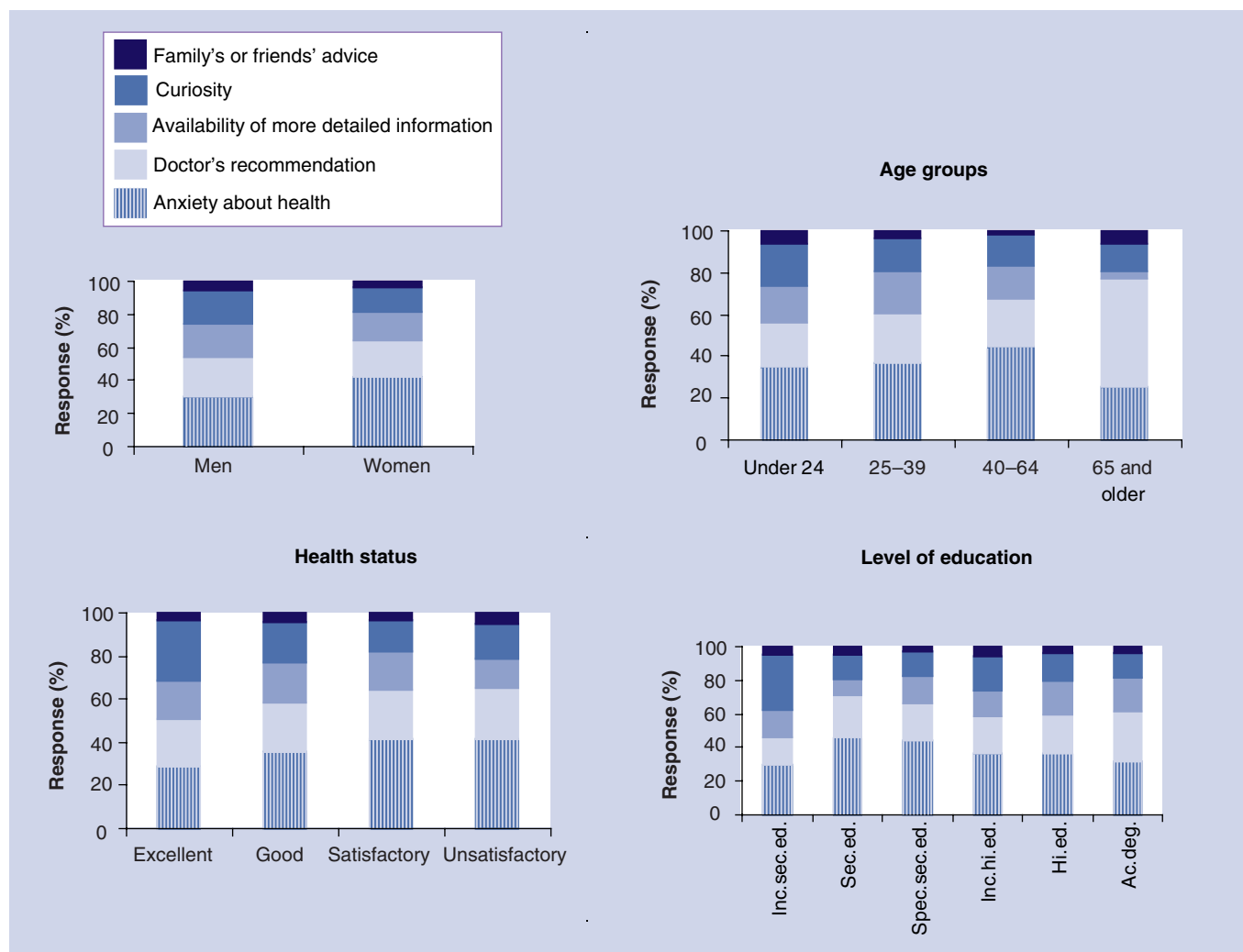


Figure 3. Motives that can influence peoples' decisions to undergo genetic testing (analysis in different age groups, health status and level of education).

Ac.: Academic; deg.: Degree; ed.: Education; Hi.: Higher; Inc.: Incomplete; Sec.: Secondary; Spec.: Specialized.

was that people did not believe they would change their lifestyle in order to lessen disease risk (TABLE 5).

Discussion

Several previous studies investigated the public's attitude towards genetic testing for common disorders; most of them detected a high level of personal interest in genetic diagnostics [3,4,6,7-11]. Our results indicate that a very positive attitude exists in a Russian population. However, there was a considerable proportion of individuals who were also worried about discrimination based on genetic testing becoming a problem.

It is usually difficult to make comparisons between countries, since different attitudes can be explained by different traditions, reliance on medical specialists and a lack of critical debate within a society [6]. For example, in the Finnish population, women had a more critical attitude

towards genetic tests compared with men [6]. In this study of a Russian population, women had more positive attitudes. Henneman *et al.* assessed public attitudes towards the availability and use of genetic tests in a Dutch population [3]. They used a different scale of answers, but apparently found much less support for the benefits of genetic testing than in this research. In Tomsk, 81% believed that knowing genetic variants allows individuals to control their lifestyle more easily, while only 24% of the Dutch respondents completely agreed with the statement that, "they would be able to control their own lives more if they knew their risk of developing a serious disease". A total of 44% "completely disagreed" with the statement. This difference might reflect different attitudes, but may also be due to stylistic nuances of the two languages. Only 10% of the Dutch disagreed and 52% completely agreed that "more money should be

available for the development of genetic testing”, which is a very similar result to estimates measured in response to the equivalent item in our survey. In the Dutch study, 61% completely agreed that genetic tests should be available for those who want to use them. A high proportion of respondents (52%) favored knowing their own risks of developing certain diseases in order to participate in prevention, and only 21% answered “completely disagree”. These estimates were also very similar to those in the Russian population studied.

There is a growing interest in, and high expectations regarding, the potential of genetic tests for ‘multifactorial’ common diseases. Accurate testing for disease predisposition may motivate risk-reducing behavior. DNA-based risk information may be viewed by patients as more personal and relevant compared with the other risk evaluation approaches, such as family history or conventional risk factor estimation [12].

Currently, in the scientific community, there is little agreement concerning the utility of predictive genetic testing for common diseases [1,2,13–15]. However, genetic testing is already being commercialized by a number of companies, many of them providing direct-to-consumer genetic diagnostics [101–105]. More permissive societal attitudes towards different aspects of genetic diagnostics can encourage the development of genetic testing as well as influencing and raising the visibility of diagnostic companies, regulatory healthcare agencies and applied genetic research. In our survey, we found a very high level of interest in genetic developments, with many people being interested in learning about their individual genetics. Most individuals would agree to undergoing genetic testing for common disease susceptibility. Therefore, companies providing direct-to-consumer genetic services could find a sizable market for their services. According to the

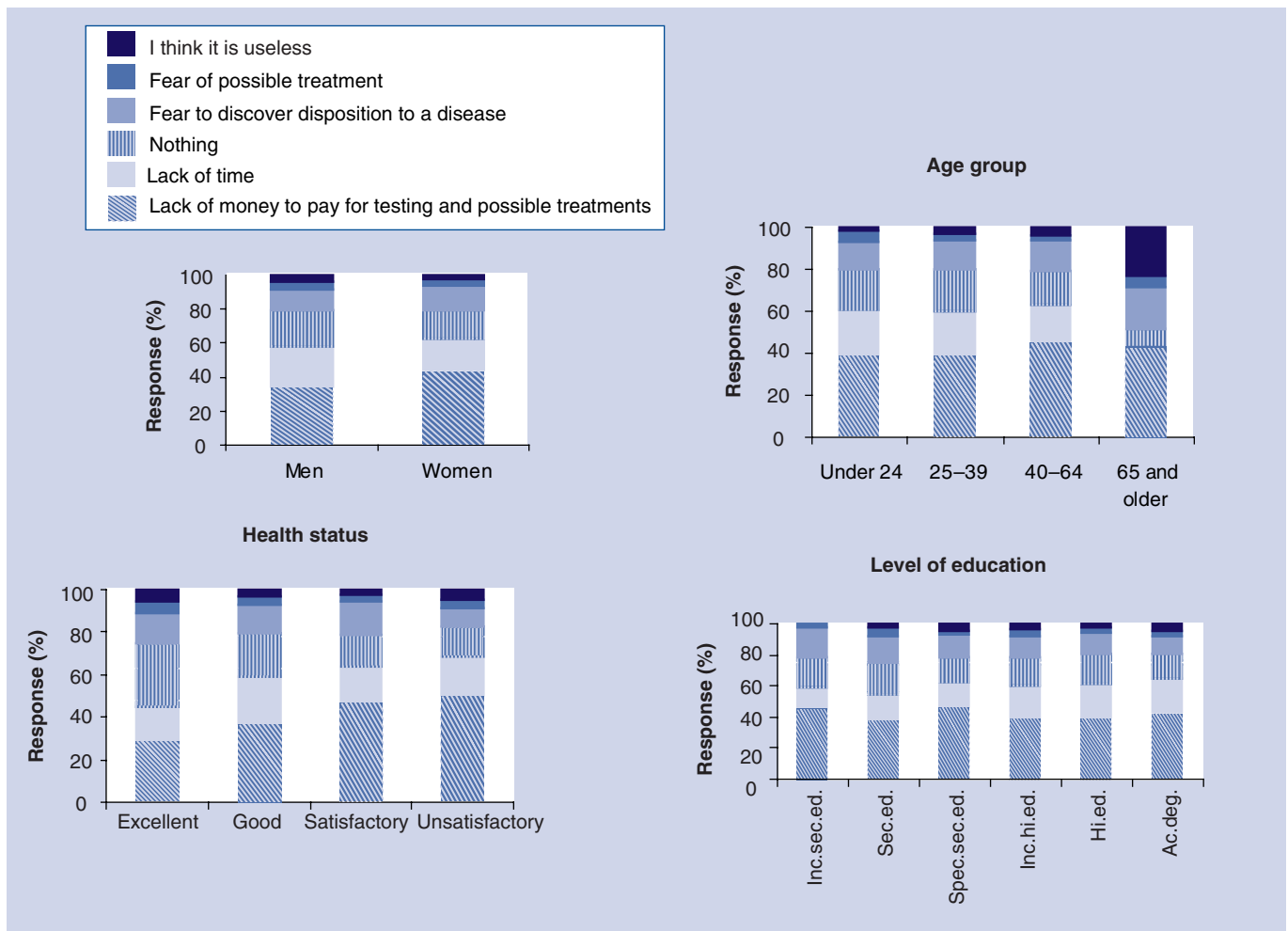
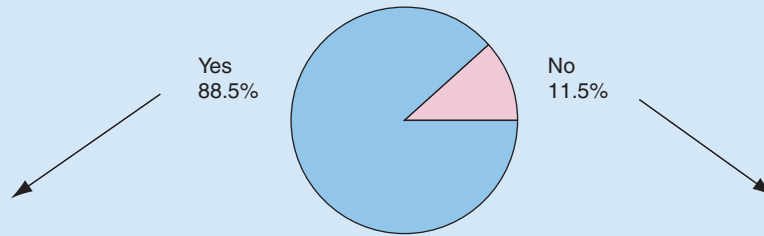


Figure 4. Reasons preventing a decision to undergo genetic testing (analysis in different age groups, health status and level of education).

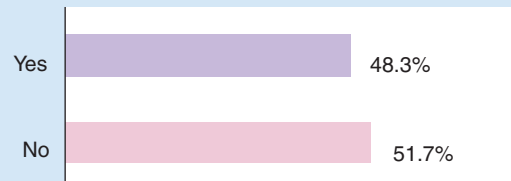
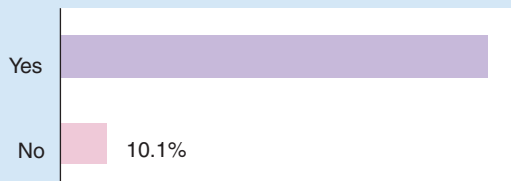
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Would you try to change your lifestyle by giving up bad habits and following a recommended diet or taking medications if a high risk of disease were identified?



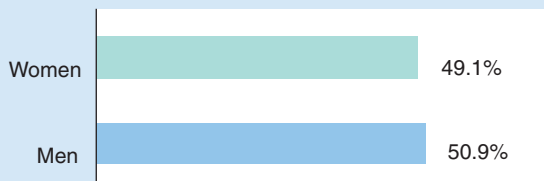
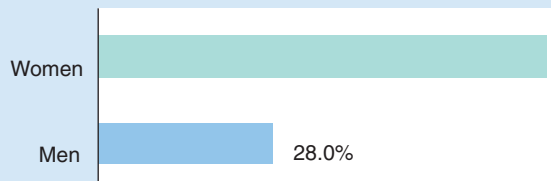
Would you like to estimate the genetic risk for diseases which are avoidable by means of prophylaxis?

p < 0.00001



Gender

p < 0.000001



Level of education

p = 0.02

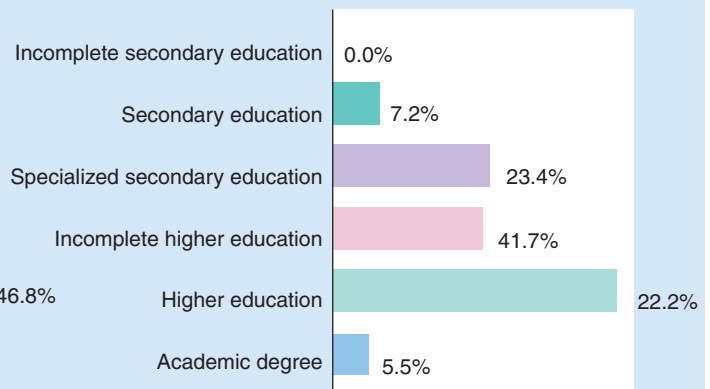
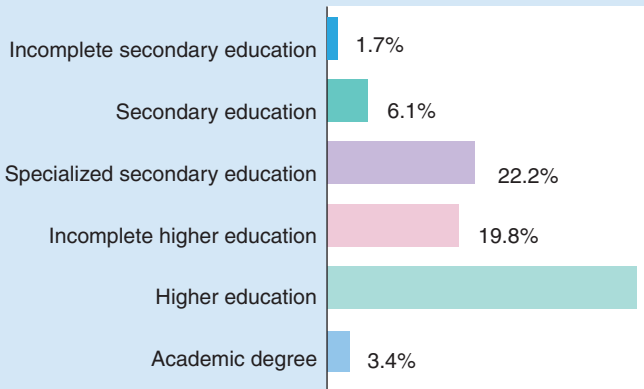


Figure 5. Results of comparison tests from the groups who gave opposite answers to the question about lifestyle changes if a high risk of a disease was identified by genetic testing with respect to the participant's gender, level of education, health status and desire to estimate genetic risks for diseases. The significance of differences was calculated using the Pearson χ^2 test.

results of our survey, companies could appeal to the high level of anxiety that became apparent concerning individual's health, which is more commonly observed in women than men. Curiosity is a stronger component in men, but

decreases with increasing age. However, older people tend to trust their physicians' instructions more than younger people. A major factor for individuals is their ability to pay for testing. Thus, decreasing genotyping costs will result in

the more active growth of the genetic diagnostics market. In general, only elderly people have the opinion that testing is useless for them. The most interested age group is the 25–39 year olds.

The public currently have highly overestimated expectations regarding genetic testing for disease predisposition. This could make it difficult for diagnostic companies in finding acceptance of their services. Customers may generally be unsatisfied with estimates of probability rather than receiving definitive answers about the risks of possible disease. Informed genetic counselors may be helpful to many individuals until validated, accurate and specific genetic tests are available for common diseases, thus working through the traditional medical models may be more acceptable.

At present, both the lay public as well as physicians have generally inadequate knowledge regarding susceptibility testing. Some years ago, we performed a pilot study that surveyed 100 primary care doctors regarding their attitudes towards emerging genetic technologies (MARKOVA *ET AL.*, RESEARCH INSTITUTE OF MEDICAL GENETICS SB RAMS, UNPUBLISHED DATA), and it was surprising to discover that 93% of interrogated specialists considered it reasonable to order genetic tests for common diseases for their patients, and 95% believed that the results of genetic testing could help them in diagnostic procedures and patient management. A total of 95% of doctors were certain that genetic test results could help them to convince their patients to correct their lifestyles and to undergo necessary treatment or prophylaxis. Such expectations are unrealistic, since the use of genetic markers in risk assessment models have little impact (approximately several %) on the enhancement of risk algorithms based on conventional risk factors [16]. Overestimated expectations by both consumers and doctors (who are intermediate consumers themselves) can have negative consequences by decreasing the level of confidence in genetic tests in general. Therefore, education in this area for both the public and healthcare providers is of exceptional importance for marketing genetic tests. The need for education for healthcare providers has been repeatedly emphasized in many publications [4,17].

An absolute majority of respondents in our survey stated they would change their lifestyles in order to avoid a disease if there was a high risk (88.5%). Surveys can only outline the general perception of society's behavior, they do not address more specific and complicated questions regarding how these perceptions are addressed on an everyday basis. The problem

with many studies concerning risk-reducing behavior changes is that, owing to the low diagnostic predictive value of most genetic tests for complex diseases at present, much of the existing evidence of the psychological impact of genetic tests comes from studies of hypothetical testing situations. Few studies address the effect of genetic testing prospectively with individuals who receive testing and counseling [18–20].

There is a growing interest in studies that test whether results regarding individual disease susceptibility will influence risk-reduction behaviors. Health-behavior studies are limited to date because of the lack of confidence in the predictive value of most gene–disease association studies. In this sense, the behavioral effects of personal genetic testing project of the Scripps Translational Science Institute (CA, USA) and Navigenics (CA, USA) (together with Affymetrix [CA, USA] and Microsoft [WA, USA]) [106], in which participants' lifestyle changes after undergoing personal genetic tests will be assessed, may become valuable.

Several studies that examined smoking cessation as a result of genetic risk assessment demonstrated contradictory results [18–24]. McBride *et al.* showed that more smokers quit at 6-month follow-up than controls after receiving genetic risk information concerning lung cancer susceptibility, but there was no difference between smokers receiving results indicating a higher risk versus a lower risk [23]. The higher motivation to stop smoking was reported in the genetic test group (lung cancer susceptibility was assessed) compared with the control group at 1-year follow-up in the study by Lerman *et al.* [24]. Wright *et al.* examined the consequences of informing smokers that they had a genetic predisposition to nicotine dependence [20]. Results of their study suggest that learning of a genetic predisposition to nicotine addiction makes smokers more likely to choose a genotype-matched pharmacological treatment but they are less likely to use their own willpower to quit. In some studies, it was demonstrated that using genetic tests to estimate risks for common complex conditions did not motivate behavioral changes, at least beyond the impact of the other risk estimates [21].

Conclusion

Heated debates regarding the perspectives of genetic testing for common diseases have found their place into the scientific literature during the last decade. In spite of the huge progress in basic research, there is still no common agreement concerning the current usefulness of genomic testing. Commercial genotyping is becoming more and

more available, and if current interest persists, it will be difficult to stop a wave of genetics commercialization, even if it does not offer adequate medical responsibility for its ultimate effects and consequences. A number of private for-profit companies are marketing different types of tests, providing whole-genome SNP analysis or sequencing directly to the public. Although there can be harmful effects, such companies provide an opportunity for society to accumulate needed experience. We hope that with time, genetic information will find its rightful place in medicine, not by replacement, but by supplementing phenotypic clinical data for diagnostics and clinical management.

Future perspective

The high level of public interest in personal genetic testing is promoting genetics commercialization and direct-to-consumer genotyping services. Such companies are providing an opportunity for society to learn 'how to deal with' genetic information. With time, validated genetic information will find its rightful place in medicine, by supplementing phenotypic clinical data with validated genetic interpretations.

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Executive summary

- Currently, in the scientific community, there is no agreement regarding the utility of predictive genetic testing for common diseases.
- In contrast to the modest progress in interpretation and clinical application of genomic data, genotyping technologies have experienced huge progress in technology development. Genotyping costs are progressively decreasing, making individual genotyping more commonly available.
- Financial availability of individual genome analysis and the strong desire of many individuals to know about their individual genomic characteristics promotes the marketing of genetic tests, that are of variable predictive value, directly to the public.
- Consumers of genetic diagnostics are becoming a major inducement in promoting future applications of genomic data into all spheres of life.
- The success of genomic diagnostics depends on the accuracy of technology and the reliability of data interpretation.
- Usage of genetic tests also depends on several social issues:
 - The level of public interest in genetic testing;
 - Regulation in this industry;
 - Patients' expectations of the received information;
 - Careful evaluation of the short- and long-term effects of providing personal genetic information;
 - The ability to change an individual's lifestyle and healthcare management in response to defined genetic risks.
- A very positive attitude and belief towards genetic developments prevails in a Russian population:
 - A total of 85% of respondents would like to have their genetic risk estimated for avoidable diseases;
 - A total of 89% answered that they would try to change their lifestyle by giving up bad habits, following a recommended diet or taking medications if a high risk of disease was identified.
- The main reason that people are interested in undergoing genetic testing for disease predisposition is their anxiety about their own health and recommendation by their physician.
- Among the reasons preventing the decision to undergo genetic testing are having a lack of money for testing and possible treatments, and a lack of time.

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