Awareness, attitudes and perspectives of direct-to-consumer genetic testing in Greece: a survey of potential consumers

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Direct-to-consumer genetic testing (DTCGT) is now offered by numerous companies. The present survey aimed to explore awareness, interest, reasons to take and refuse DTCGT, and understanding of results amongst 725 higher education students in Greece. A third of the responders were aware of DTCGT and interest was dependent on cost. More than 60% of the participants would undergo DTCGT to learn more about their health, to warn their children, so that their doctor can monitor their health and change their lifestyle. Nevertheless, they would prefer to consult their doctor first and expressed concerned about their personal data. After receiving results from a hypothetical DTC genetic test predicting higher risk for colon cancer, 59.5% of the responders thought that they could understand the results but 46.1% believed that the results have diagnostic value. In total, 83.6% of the participants would ask their doctor to explain the results and 70.4% would discuss results with their family. In conclusion, the majority of higher education students in Greece appreciate the benefits of genetic testing but with the involvement of their doctor. A physician's participation in the process and informing the public about the true value of genetic testing, are crucial to avoid misinterpretation of DTCGT results.

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INTRODUCTION

The impact of genetic information on disease diagnosis and prevention, the promises of personalized medicine, the public's increasing interest in genetic information, along with the increasing number of companies offering genetic services and the promotion and marketing campaigns, are some of the main reasons that lead to the advent of direct-to-consumer genetic testing (DTCGT).¹ During the last decade, the market of DTCGT has been growing¹, although some studies suggest that the market specifically for DTC genetic susceptibility tests for complex diseases is much smaller than previously suggested.² However, the number of private companies offering DTCGT increases, with a wide variation in the provided tests including genome-wide analysis, single-gene disorders, predisposition to complex diseases, paternity tests, pharmacogenomics, nutrigenomics and genealogy tests, which are all purchased directly by the consumer through the internet.³ As the cost of genetic testing decreases, the cost of DTCGT is expected to fall dramatically and therefore, become more accessible to consumers.

At the advent of DTCGT services, the main difference between conventional genetic testing and DTCGT was that the latter was offered without prior or subsequent involvement of a healthcare professional. More recently, and only after great legal battles, the biggest companies offering DTCGT services in the USA adhered to the requirement to have a physician involved in the process of ordering a test for health-related purposes.⁴ In 2013, the US Food and Drug Administration (FDA) sent a letter to 23andMe (Mountain View, CA, USA), one of the biggest companies offering DTCGT services, ordering the company to discontinue marketing of the Personal Genome Service until it receives FDA marketing authorization for the device.⁵ The FDA's warning further contributed to the discussion about whether DTCGT can be used without professional supervision. However, this is not the case for companies offering DTCGT outside the USA borders, such as Europe, and especially for smaller companies offering these services.

Regulation of DTCGT services received attention in the USA since 2010, but only four European countries (France, Germany, Portugal and Switzerland) have specific legislation that requires a medical doctor to carry out genetic tests and two countries (Belgium and UK) allow DTCGT.⁶ The rapid growth of the DTCGT market⁷ triggered increasing attention from the scientific community, Ethics Committees or Advisory Boards from European countries including Greece⁸, Italy⁹, Portugal¹⁰, Belgium¹¹, Austria¹², Denmark¹³, Finland¹⁴, the Netherlands¹⁵, UK¹⁶, as well as non-European such as Australia,¹⁷ by issuing opinions or position papers that emphasized the ethical issues raised by DTCGT and suggested a closer regulatory oversight.

According to a 2012 Report for the Hellenic National Bioethics Commission, 15 private companies offered DTCGT services in Greece, which is a relatively small country with a population of 11 million.¹⁸

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These were private companies with Greek websites offering genetic services via a kit for sample collection by the consumer. The services included tests for paternity, kinship, predisposition to complex diseases, pharmacogenetics, athletic performance, predisposition to single-gene diseases, nutritional or metabolic tests, anti-ageing tests, genealogy tests and whole-genome analysis. Only 26.6% of these companies had laboratories accredited according to international standards.¹⁸ According to their websites, the companies that were included in the Report did not have a physician or healthcare professional involved in the process of ordering a test for health-related purposes. To address the above issues, the Hellenic National Bioethics Commission issued a Statement of Opinion on DTCGT emphasizing the fact that there is no involvement of a healthcare provider before or after undertaking the test, which may lead to unnecessary testing and misinterpretation of the results.⁸

Yet to date, there is limited information on the awareness and interest of consumers in DTCGT in Greece and generally in European countries.¹⁹ As the process of consultation and possible regulation of DTCGT evolves, it is vital to record awareness, interest and understanding of DTCGT results in European countries. To our knowledge, this is the first survey in Greece that specifically investigates awareness, interest, motivations and understanding of DTCGT. The present study also aimed to compare the results from Greece with similar studies in other European and non-European studies.

Higher education students have been previously used as the study population to examine attitudes to DTCGT.^{20,21} Higher educational level, internet use and young age have been previously determined as demographic characteristics which are likely to be shared by prospective users of DTCGT services.^{21,22} Therefore, we chose higher education students (university and college students) as the study population for the following reasons: (i) because of their young age, students are familiar with using internet services and platforms used by the DTCGT companies, and therefore they are potential consumers of DTCGT, (ii) comparison of DTCGT interest and understanding of results between students from biomedical and non-biomedical sciences would allow to draw interesting conclusions on the value of genetics knowledge.

MATERIALS AND METHODS Participants

In total, 725 undergraduate, postgraduate and doctoral students from various disciplines completed a printed or an online version of the questionnaire, between January and July 2014. The questionnaires were completed voluntarily and anonymously by the study participants.

Two versions of the questionnaire were developed. As a part of their BSc project, a printed version of the questionnaire was distributed by the authors V. Mavroidopoulou and E. Xera and was completed by 402 students at various university/college sites. Subsequently, an online version of the questionnaire was developed using Google docs, which was sent by the authors to student mailing lists asking them to complete and forward the questionnaire to other students at their discretion. The online version of the questionnaire was completed by 323 students. Student participation in the study was not in any way linked to the completion or grade in any class/course.

Questionnaire

The questionnaire is presented in Supplementary Material 1. The questions were carefully chosen after a review of the relevant literature. Initially, the questionnaire requested demographic characteristics of the participants. After a brief introduction on DTCGT the participants were asked to complete 24 closed-ended questions, including Likert, dichotomous and buying propensity questions. The first 11 questions assessed awareness, interest and reasons to take and refuse DTCGT. A hypothetical scenario was then presented to the

participants summarized as follows: 'Imagine that you see an advertisement on the internet about a genetic test that predicts risk to colon cancer. The test includes a kit with a swab to collect a biological sample from the inside of the cheek, which is then sent back to the company by post. The company will study whether there are genetic defects that confer an increased risk to develop colon cancer. Along with the biological sample, the company required that you completed a short questionnaire about your lifestyle and family history. Imagine that you already know that one of your close relatives developed colon cancer, and you take the decision to do the genetic test. One week later you receive the genetic results by e-mail, according to which you have a twofold increased risk to develop colon cancer compared to the general population'. The last 13 questions assessed understanding of the DTCGT results and their impact on psychology and future actions of the participants. Some questions remained the same prior to- and following the hypothetical scenario to explore whether their views changed in the context of having a high risk for a serious disease, such as colon cancer. Approximately 7 min were needed to complete the questionnaire.

Statistical analysis

Statistical analysis was performed using the SPSS software (v17.0) (IBM, Armonk, NY, USA). Descriptive statistics were calculated to summarize the characteristics and the answers of the responders. The Pearson's χ^2 test was used to compare differences between answers at $P \leq 0.05$ level of significance. To facilitate comparisons, for the Pearson's χ^2 in the Likert questions the response category 'Very likely' was merged with 'Fairly likely' and the response category 'Not very likely' was merged with 'Unlikely'. Similarly, the response category 'Strongly agree' was merged with 'Agree' and the response category 'Disagree' was merged with 'Strongly disagree'.

RESULTS

Demographic characteristics of participants

The demographic characteristics of the responders are shown in Table 1. Most of the students were of Greek origin, <25 years of age, females, not married, without children and in their undergraduate studies. The participants' disciplines were divided in two categories: healthcare/biomedical sciences and non-biomedical sciences with comparable number of students in each category (Supplementary Material 2).

Awareness and interest in DTCGT

The level of awareness of DTCGT was relatively good with 30.1% having heard of the services (Table 2). Only 3.4% of the responders had ever done a DTC genetic test. Students from healthcare/ biomedical sciences who were during their postgraduate or doctoral studies were more likely to have heard of DTCGT. Interest in taking a DTC genetic test was dependent on cost with only 9.7% answering 'very/fairly likely' to order a DTC genetic test if the cost is 500€ and 51.6% if the test was free (Table 2). Most participants expressed an interest in ordering a DTC genetic test for a serious disease such as cancer (54.9%) or a test for metabolism or genealogy (50.2%) but they would prefer to consult their doctor first (76%). A higher percentage of responders would agree to take the test after a briefing (61.3%), with undergraduate students being more interested than postgraduate and doctoral students (Table 2).

Perceived knowledge of genetics and reasons to take and refuse DTCGT

In total, 43.7% of the responders ('disagree/strongly disagree') had a self-perception that they lacked basic knowledge of genetics as opposed to 34.5% who believed that they had basic knowledge of genetics ('strongly agree/agree') (Figure 1). Older students who were from healthcare/biomedical sciences and at postgraduate or doctoral level were more confident that they had basic genetics knowledge

Table 1 Demographic characteristics of participants

Characteristic	n <i>(%)</i>
Ethnic origin	
Greece	665 (91.7)
Albania	51 (7.0)
Romania	3 (0.4)
Other	6 (0.9)
Educational level	
Undergraduate	590 (81.4)
Postgraduate	103 (14.2)
Doctoral	32 (4.4)
Age (years)	
≼25	521 (71.9)
26–30	146 (20.1)
>30	58 (8.0)
Gender	
Male	231 (31.9)
Female	494 (68.1)
Marital status	
Married	42 (5.8)
Single/never married	683 (94.2)
Children	
Yes	38 (5.2)
No	687 (94.8)
Smoking	
Smoker	333 (45.9)
Non-smoker	392 (54.1)

(Figure 1). Responses to seven possible reasons to take DTCGT showed that >60% of the participants would take DTCGT in order to learn more about their health, so that they can warn their children, so that their doctor can monitor their health and they could change their lifestyle. On the contrary, it was less probable that they would order a DTC genetic test out of curiosity or owing to scientific research or even for fun. Responses to four possible reasons for refusing to take a DTC genetic test indicated that participants thought that the results are unreliable (46.9%). However, only 27.7% agreed that the information is not useful (Figure 2). A total of 55.7% agreed that they would wish to know their risk for certain diseases but they would be concerned about their personal data by 47.8%. Concern about personal data increased with age and level of studies (Figure 2).

Understanding and consequences of the results

After the hypothetical scenario was given to the participants, the questionnaire aimed to examine their understanding of the results and their possible future actions. Most of the responders (59.5%) thought that they could understand the results, especially older students and those at their doctoral studies (Figure 3). A total of 54.8% of the participants would take the results seriously but students from non-biomedical sciences who were during their undergraduate studies were more likely to take the results seriously. However, 46.1% of the responders believed that the results had diagnostic value, which was more likely in students from non-biomedical sciences. Most of them

were undecided about whether the results are unreliable (41.8%). A total of 45.2% of the responders were concerned about their personal data, which increased with age, and the vast majority would ask their doctor (83.6%) or a geneticist (71%) to explain the results (Figure 3).

Regarding the consequences of the DTCGT results and future actions, the vast majority of the responders would change their lifestyle (67.5%) and this was more probable for women than men (Figure 4). The vast majority of the responders would discuss the results with their family (70.4%). The results would cause temporary stress to 73.2% of the participants, as opposed to long-term stress (41%). Women were more likely to have temporary stress after receiving the results, and those who had a perception that they lack basic genetic knowledge would be more likely to suffer from long-term stress. The participants' answers were divided concerning whether the results would be reassuring by offering the option for regular checkups, but those who thought that they lacked basic genetic knowledge were less probable to consider the results as reassuring (Figure 4).

In the final question whether genetic services should only be provided via genetic centers or laboratories (not through the internet) 57.2% of the responders agreed, 22.5% were undecided and 20.3% disagreed. Older students who were during their postgraduate or doctoral studies were more likely to believe that genetic tests should be offered through genetic centers only (Figure 4).

DISCUSSION

Approximately one-third of students, who are young individuals, familiar with the internet and media platforms frequently used to promote DTCGT services, were aware of DTCGT. This probably means that awareness of DTCGT is lower in the general population and especially in older groups. Interest in DTCGT was dependent on cost and increased if the test was for free, and this may reflect the fact that students generally do not have permanent jobs and income. As the cost of DNA sequencing decreases,²³ whole-exome and even whole-genome sequencing services that are offered directly to consumers will become cheaper and this may increase interest in such DTCGT services in the future.

Although some studies support that interest in DTCGT for susceptibility tests for complex diseases is much smaller than previously suggested,² the results of our survey showed that there was no difference between predisposition tests for serious diseases (for example, cancer) and tests for less serious genetic traits (for example, metabolism or genealogy), suggesting that consumers are unable to distinguish between different types of genetic tests and their varying impact on their lifetime decisions and lifestyle changes. In addition, our study illustrated that even a pseudo-real, hypothetical scenario concerning one's health affects the consumer's perception on the validity of the results, and individuals who lack basic genetic knowledge are more probable to suffer from long-term stress after receiving the results. All the above raise the need to inform consumers about the different types of DTCGT and their risks and benefits, by formulating position statements and recommendations to raise awareness.²⁴

According to our study, most of the responders thought that they could understand the results but they also believed that the results have diagnostic value. However, this was not the case as the hypothetical scenario offered a test that predicted risk to colon cancer and did not offer diagnosis for colon cancer, pointing out that more information is needed for the consumer to understand the true value of the results (for example, risk prediction vs diagnosis) and make informed choices before a test. Indeed, this raises the ethical issue of informing the consumers inadequately through the promotion and advertisements of DTCGT.⁸

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Table 2 Awareness and interest in DTCGT

	<i>Total (</i> n = 725)	Age (years)			Gender		Science		Educational level		
		≤25	26–30	> 30	Female	Male	Non-biomedical	Healthcare/ biomedical	Undergraduate	Postgraduate	Doctora
Do you know or h	ave you heard of ge	enetic test	s that are p	rovided dii	rectly to co	nsumers	via the internet?				
Yes	30.1	28.0	35.6	34.5	30.4	29.4	22.4ª	39.0	28.1ª	35.0	50.0
No	69.9	72.0	64.4	65.5	69.6	70.6	77.6	61.0	71.9	65.0	50.0
Have you ever do	ne a genetic test wl	nich is pro	wided direc	tly to cons	umers via t	he intern	et?				
Yes	3.4	4.4	1.4	0	3.2	3.9	1.3ª	6.0	4.2	0	0
No	96.6	95.6	98.6	100.0	96.8	96.1	98.7	94.0	95.8	100.0	100.0
How likely would	it be to order such	a test if it	was for fre	e?							
Very likely	28.9 ^a	29.6	27.6	25.9	29.6	27.3	24.2	34.3	29.9 ^a	28.2	12.5
Fairly likely	22.7	25.0	16.6	17.2	21.3	25.5	25.2	19.7	23.9	19.4	9.4
Undecided	16.9	19.4	11.0	8.6	17.2	16.0	17.5	16.1	18.2	10.7	12.5
Not very likely	18.2	15.5	25.5	24.1	18.9	16.9	19.3	17.0	16.0	25.2	37.5
Unlikely	13.4	10.6	19.3	24.1	13.0	14.3	13.9	12.8	12.1	16.5	28.1
How likely would	it be to order such	a test at a	a cost of 50	00 €?							
Very likely	2.8ª	2.3	4.8	1.7	2.6ª	3.0	2.1ª	3.6	3.2ª	0	3.1
Fairly likely	6.9	8.3	4.1	1.7	5.9	9.1	4.1	10.1	8.0	2.9	0
Undecided	9.5	11.1	6.8	1.7	9.7	9.1	7.7	11.6	10.7	4.9	3.1
Not very likely	23.7	24.2	20.5	27.6	25.1	25.1	23.4	24.1	22.7	33.0	12.5
Unlikely	57.1	54.1	63.7	67.2	56.7	58.0	62.7	50.6	55.4	59.2	81.3
How likelv would	it be to order such	a test for	a serious d	isease e.g.	cancer or	cardiovas	cular diseases?				
Very likely	27.2 ^a	28.4ª	23.3	25.9	27.1	27.3	27.0 ^a	27.4	28.0ª	27.2	12.5
Fairly likely	27.7	29.8	19.9	29.3	26.1	31.2	31.4	23.5	28.5	29.1	9.4
Undecided	18.3	18.0	19.9	17.2	16.6	22.1	19.3	17.3	18.3	19.4	15.6
Not very likely	14.1	13.4	17.8	10.3	16.2	9.5	11.3	17.3	14.2	9.7	25.0
Unlikely	12.7	10.4	19.2	17.2	14.0	10.0	11.1	14.6	11.0	14.6	37.5
If you answered '	Very likely' or 'Fairly	/ likely' in	the previou	is question	n, would you	u prefer t	o consult your docto	or before doing a	the genetic test?		
Yes	76.0	78.1	71.9	66.7	77.1	74.0	76.2	75.8	76.7	72.9	71.4
No	24.0	21.9	28.1	33.3	22.9	26.0	23.8	24.2	23.3	27.1	28.6
How likely would	it be to order such	a test tha	t assesses y	our metab	olism or de	efines you	r genealogy origin?				
Very likely	20.8	20.3	19.2	29.3	21.1	20.3	20.8	20.8	21.9 ^a	19.4	6.3
Fairly likely	29.4	31.9	24.7	19.0	28.9	30.3	27.8	31.3	30.7	27.2	12.5
Undecided	18.9	19.2	19.9	13.8	18.6	19.5	20.3	17.3	19.5	17.5	12.5
Not very likely	19.0	18.2	21.2	20.7	18.2	20.8	19.5	18.5	18.0	20.4	34.4
Unlikely	11.9	10.4	15.1	17.2	13.2	9.1	11.6	12.2	10.0	15.5	34.4
After a briefing al	bout genetic tests th	nat are pro	wided direc	tly to cons	sumers via t	the intern	net, would you accep	ot to do the test	?		
Yes	61.3ª	64.9	51.4	53.4	60.4	63.0	60.7	61.9	63.2	58.4	34.4ª

Abbreviation: DTCGT, direct-to-consumer genetic testing.

Values are in percentage. Percentages may not add up to 100% owing to rounding.

aindicates P<0.05 between answers.

The vast majority of study participants would ask their doctor to explain the results to them, depicting the usual absence of a healthcare professional either before or after the test, highlighting the possibility of increased physician utilization after receiving positive results.²⁵ The fact that most of the responders would discuss the results with their family is not surprising for the Greek family, which has always been characterized by strong bonds between its members, but this means that DTCGT results may lead to unnecessary health tests not only for the consumer him/herself but also for his/her family members, leading to an overconsumption of limited healthcare resources.

Comparison with other studies in other countries should be treated with caution for various reasons, such as population-specific characteristics that may affect attitudes (for example, culture and religion), differences in sample size and demographics (for example, specific groups or unselected participants), and differences in campaigns for promoting DTCGT or informing the public about DTCGT between countries. Nevertheless, such comparisons may offer a perspective on the awareness and attitudes on DTCGT at a European and US level.

Although not specific to DTCGT, a previous study in Greece examined the public's awareness on the trends and potential pitfalls

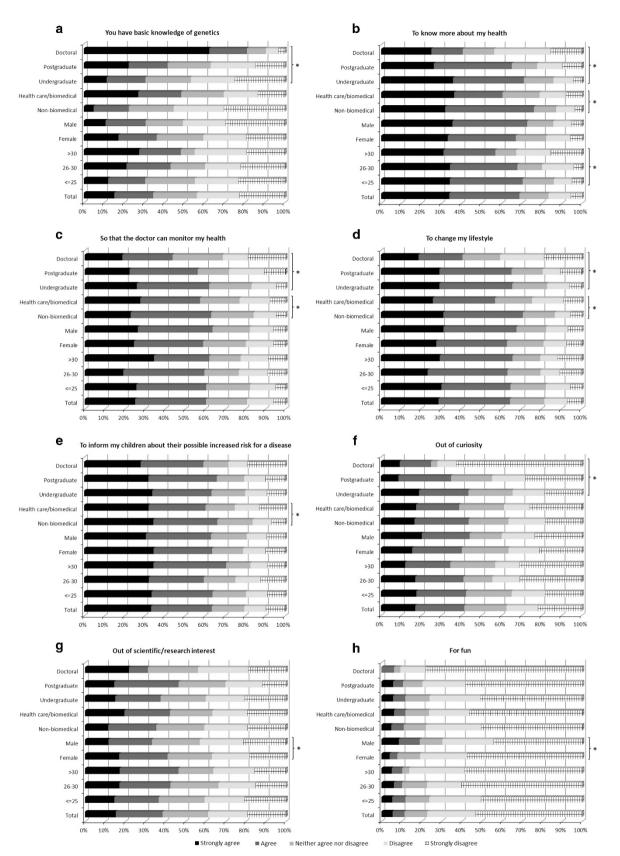


Figure 1 Reasons to take DTCGT. A 5-point Likert scale ('Strongly agree', 'Agree', 'Neither agree nor disagree', 'Disagree' and 'Strongly disagree') was used to record the responders' self-perception of genetics knowledge (a) and their motivations to take a DTCGT (b-h). *Indicates P < 0.05 between answers.

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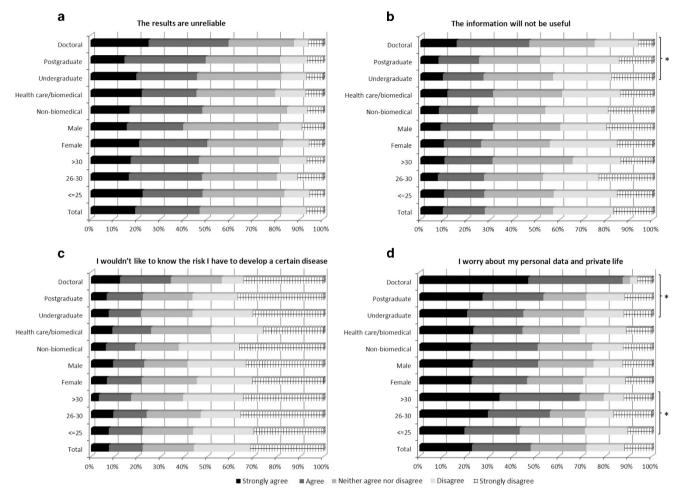


Figure 2 Reasons to refuse DTCGT. A 5-point Likert scale ('Strongly agree', 'Agree', 'Neither agree nor disagree', 'Disagree' and 'Strongly disagree') was used to record the responders' reasons to refuse a DTCGT (a-d). *Indicates P<0.05 between answers.

of genetic testing.²⁶ The survey included a single question about 'direct-access genetic testing' and found that the vast majority of the general public (82.1%) strongly opposes to it and most participants would prefer referral from a physician than from a pharmacist,²⁶ showing similar trends to our study.

A similar study in university students assessing attitudes to DTCGT in Switzerland found that approximately two-thirds of the respondents were aware of internet-based DTC genomics and the reasons to do a test were to contribute to scientific research and find out their disease risk, indicating a strong interest in genetic research participation.²¹ In contrast, our study among higher education students in Greece indicated that approximately one-third of the participants were aware of DTCGT and the most common motivations to do a DTC genetic test were to learn more about their health, to warn their children and so that the doctor can monitor their health.

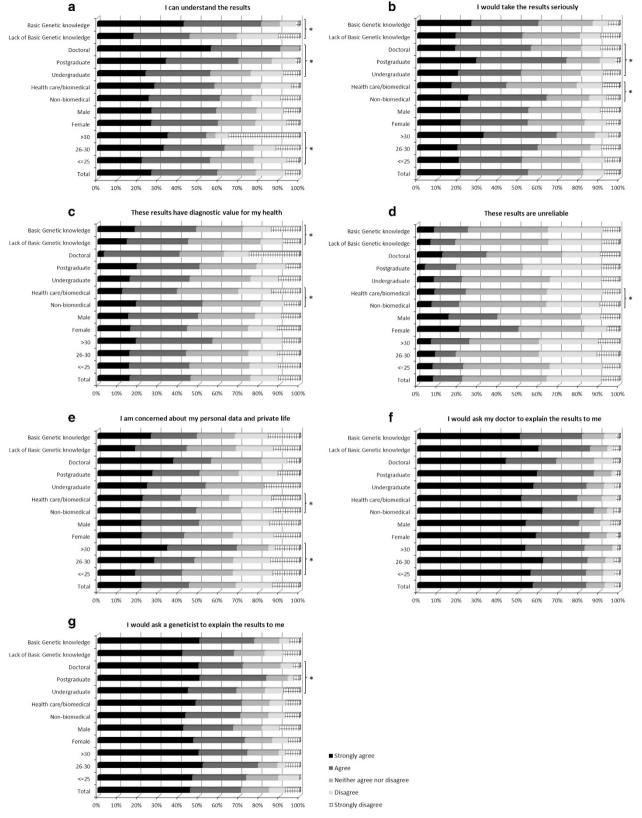
Awareness in DTCGT differed vastly in a UK study (13%), which was conducted in >4000 unselected adult volunteers with a mean age of 50 years,²⁷ clearly owing to the difference in the demographics of the study populations (unselected adults vs students). The UK survey also identified that the level of interest in taking a DTC genetic test was clearly dependent on cost and concluded that the decreasing cost of genetic testing services may lead to an increased uptake of DTCGT, and consequently have implications for the burden on physicians and the cost on the National Health Care System. However, the reasons to

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take the test were 'it would encourage me to adopt a healthier lifestyle' (96%), to 'learn more about myself' (86%), to 'convey genetic risk information to my children' (80%) and so that the 'doctor can monitor my health more closely' (79%),²⁷ whereas the current study found lower percentages for the same reasons, that is, 64, 69, 63 and 60%, respectively.

Numerous studies concerning DTCGT are also available from the USA³ but we chose to compare our results with USA studies that investigated DTCGT awareness and perceptions with methods which are similar to the present study, that is, with questionnaires and hypothetical scenarios directed to certain population groups. Gollust *et al.*²⁸ investigated motivation and perceptions of individuals who registered to an event in the USA and found that over 50% of participants wanted to ascertain their risk for a particular condition (vs 55.7% in our sample), and over 90% would share the results with their doctor (vs 83.6% in our study).

Bloss *et al.*²⁹ investigated consumer perceptions on DTCGT and found that over 82% of the responders would want to know the risk for a disease. According to our survey in Greece, over 55% of participants wanted to know whether they have an increased risk for a disease and over 68% would want to know more about their health. Bloss *et al.*²⁹ also found that 36% of the participants were concerned about privacy issues which is comparable to our study.



I can understand the results

Figure 3 Understanding of DTCGT results. A 5-point Likert scale ('Strongly agree', 'Agree', 'Neither agree nor disagree', 'Disagree' and 'Strongly disagree') was used to record the responders' understanding of the hypothetical DTCGT (a-g). *Indicates P<0.05 between answers.

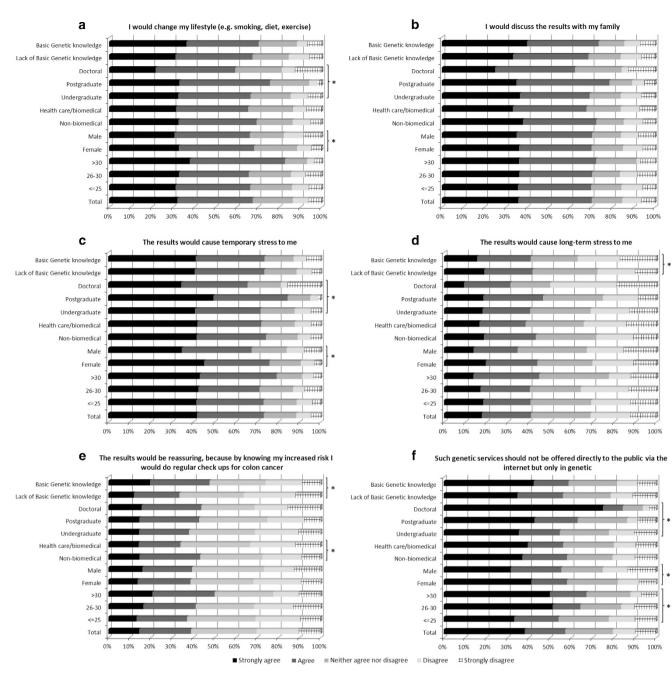


Figure 4 Consequences of DTCGT and future actions. A 5-point Likert scale ('Strongly agree', 'Agree', 'Neither agree nor disagree', 'Disagree' and 'Strongly disagree') was used to record the consequences of the DTCGT and the responders' future actions after receiving the results (a-f). *Indicates P < 0.05 between answers.

Ormond *et al.*²⁰ examined the attitudes toward personal genomics in medical students and graduates after providing two hypothetical scenarios. There was similar interest in personal genomics (57% in Ormond *et al.*²⁰ vs 61.3% in our sample) and concern about privacy (58% in Ormond *et al.*²⁰ vs 47.8% in our sample). However, curiosity was the most common reason (96%) to undertake genetic testing in Ormond *et al.*²⁰ as opposed to 41.5% in our survey and only a small proportion of the sample believed that the results are not reliable (16% in Ormond *et al.*²⁰ vs 46.9% in our sample). Similarly to our study, Ormond *et al.*²⁰ also identified that there was a concern about the cost of genetic testing (42%).

Study limitations

There are two limitations in the current study: (i) The participants were all students from universities and colleges and therefore, there is a selection bias to young, educated and computer-literate individuals, without a permanent job or income of their own. Under no circumstances the study population was representative of the general population. However, the way that DTCGT is promoted requires computer-literate individuals who are usually young individuals. (ii) The participants were not 'real' consumers but 'potential' consumers who were given a hypothetical scenario to assess understanding and impact of DTCGT. Hypothetical interest in DTCGT and its impact may differ from actual choices. Nonetheless, to our knowledge, the actual use of DTCGT has not been explored in Greece and therefore assessment of awareness, interest and understanding of the results in potential consumers is an important first stage of research.

CONCLUSION

Students of higher education in Greece, who are potential consumers of DTCGT, may present an increased interest in DTCGT as the cost decreases. Despite one's self-perception that he/she can understand the results, there is a strong likelihood for misinterpretation of the results. This highlights the importance that a physician or generally an expert is involved in the process and that companies offering such services need to inform the consumers adequately about the true value (prognostic or diagnostic) of the tests. Educating and informing the consumers about the usefulness of genetic testing is crucial in order to make informed choices. The ACCE Model Process, which takes into account the four main criteria: analytic validity, clinical validity, clinical utility and associated ethical, legal and social implications for evaluating genetic tests,³⁰ may be a valuable framework both for the public and policy makers, in order to elucidate the usefulness of certain genetic tests offered directly to consumers. Preliminary findings such as these from the present study can help to assess the future demand for DTCGT in Greece among young individuals who are potential users of the service and identify potential problems that need to be resolved.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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