Nutrigenetic testing for personalized nutrition – an evaluation of public perceptions, attitudes and concerns in a population of French Canadians

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2 **Background/aims:** This study aimed to evaluate attitudes, perceptions and concerns 3 about nutrigenetic testing for personalized nutrition in the general population of the province of Quebec, in Canada. 4 5 **Methods:** A total of 1425 individuals from the province of Quebec fully completed a 37question online survey on nutrigenetics and were included in analyses. Chi-square tests 6 7 were used to test for associations between categorical variables. 8 **Results:** The majority of participants (93.3%) considered dietitians as the best professionals to give personalized dietary advice based on nutrigenetic testing. The 9 main reported advantage for nutrigenetic testing was "health" (23.5%), followed by 10 11 "disease prevention" (22.2%). Among disadvantages, "no disadvantage" (24.4%), followed by "diet restriction" (12.9%) were mostly reported. The two major concerns 12 raised were the accessibility to genetic testing by telemarketing companies and 13 spammers (51.8%), and solicitation by companies using the personal genetic data to sell 14 products (48.6%). 15

Conclusions: French Canadians generally have a positive attitude towards
 nutrigenetics and find many benefits to its use. They rose up possible confidentiality
 issues associated with the management or property of genetic test results. However
 education about confidentiality issues is still considerably needed. These findings overall
 suggest that the population is interested by a more extensive use of nutrigenetics in
 health management.

23 Introduction

Nutrigenetics and nutrigenomics explore the interactions between food and genes, and 24 how these interactions can influence one's health and risk to develop chronic nutrition-25 related diseases [1-3]. Despite that the science of nutrigenetics/nutrigenomics has 26 27 greatly evolved since its emergence in the late 90's, and has now sufficiently progressed to bring a wide variety of genetic tests to predict the individual response to nutrients 28 and/or nutritional interventions, nutrigenetic technologies have still rarely been used in 29 health care practice [4-6]. Besides their recent commercialization by companies 30 specialized in nutrigenetic tests, sometimes in collaboration with registered dietitians, a 31 very small proportion of registered dietitians actually use nutrigenetics in their practice to 32 provide personalized nutritional recommendations to their patients, and often do not 33 consider themselves sufficiently trained to adequately use it [4,5]. Despite the infrequent 34 use of nutrigenetic testing by registered dietitians, many companies offer genetic tests 35 directly to consumers, thus making the technology very accessible, and the genetic 36 testing market as a whole has been steadily increasing in recent years [6,7]. 37 Nutrigenetic technologies appear to be well accepted in European and North-American 38 39 countries, including Canada [8-11]. Nielsen et al. studied public perceptions of personalized nutrition based on genetic testing among Canadians and observed that 40 41 participants' interest in nutrigenetics increased when participants received dietary advice 42 based on their genetic profile in comparison with participants who received dietary advice without genetic information [12,13]. Attitudes of Canadian consumers towards 43 nutrigenomics 44

were also studied by Morin *et al.* in focus groups in five Canadian cities, namely Halifax,
Montreal, Toronto, Edmonton, and Vancouver, and concluded that consumers perceived
benefits of nutrigenomics outweighed the risks [14].

However, cultural differences between populations might affect the way people perceive 48 nutrigenetics. Hence, our research group recently surveyed a population of French 49 Canadians living in the province of Quebec to assess their current knowledge and level 50 of interest in nutrigenetics. In order to bridge the substantial gap between research and 51 52 clinical practice regarding nutrigenetics, and to facilitate its integration in professional practice, attitudes, beliefs, perceptions and fears of consumers towards nutrigenetics 53 must be comprehensively assessed. We therefore aimed, in the present study, to draw a 54 55 global portrait of the current situation of nutrigenetics in Quebec by evaluating apprehensions, perceptions and attitudes of nutrigenetic testing for personalized 56 nutrition of the population of Quebecers. 57

59 Methods

60 *Recruitment*

61 A total of 2238 individuals aged of 18 years old or older living in the province of Quebec, 62 in Canada, were recruited via Facebook and the Laval University list of employees and 63 students and surveyed from March 10, 2015 to April 28, 2015. Participants had to have 64 access to a computer with an Internet connection and to be able to answer the 65 questionnaire written in French. To reduce the risk that someone completes the survey 66 more than once, the IP address of the computer used to complete the survey was checked. A total of 1535 individuals completed the survey, from which 110 were 67 thereafter excluded for missing information. A total of 1425 participants, including 252 68 69 men and 1173 women were kept for statistical analysis. The Ethics Committee on Research Involving Human Subjects of Laval University approved this project. 70

71 Questionnaire development

SurveyMonkey Gold with enhanced security (http://www.surveymonkey.com), an online 72 survey development cloud-based software, was used to build the questionnaire. Twenty 73 74 unrelated individuals pre-tested the questionnaire to estimate the necessary time to complete it, to verify the clarity of the questions and to evaluate the relevance of the 75 proposed answers. The survey comprised a total of 37 questions. Thirty-three of them 76 were closed-ended and four were open-ended. Most of the closed-ended questions 77 were multichotomic with one or multiple possible answers, so that the respondent could 78 79 choose more than one answer.

A brief definition of nutrigenetics was given at the beginning of the survey. A total of 14 80 questions for quota sampling were found at the beginning (ex. citizenship, age, etc.). 81 and at the end of the questionnaire (ex. personal and familial health history, gender, 82 ethnicity, etc.). Questions about citizenship, province/territory and age were 83 discriminatory to ensure that respondents were Canadian citizens living in the province 84 of Quebec, and were 18 years old or older. Seven items evaluated perceptions, attitudes 85 86 and concerns of participants, which were used to address the objective of the present study. Five items evaluated genetic literacy and knowledge of participants on 87 nutrigenetics, six evaluated participants' interest and willingness to undergo nutrigenetic 88 89 testing, and five evaluated intentions to follow dietary advice based on genetic testing. These last 16 items were mainly addressed in another paper by our research group [15]. 90 Statistical analysis. 91 92 Results were exported from SurveyMonkey into Microsoft Excel (Microsoft, Redmonds, CA, USA) to be converted into calculation sheets, before being imported into SAS, v9.4 93 (SAS Institute, Cary, NC, USA). In open-ended questions, common themes were 94 identified using NVivo software v10.2.0. Results were analyzed as categorical variables. 95 Chi-square tests were used to test for associations between categorical variables. 96 Statistical significance was set at p<0.05. 97

99 Results

100 Study population

101 Characteristics of subjects are presented in **Table 1**. Participants had a mean age of

102 38.3±14.9 years. A proportion of 49.4% of participants had completed undergraduate or

103 graduate university studies, and 14.6% had a college degree. A total of 25.2% of

104 participants had an annual household income equal or superior to \$100 000/year. The

vast majority were Caucasians (96.7%) and were not familiar with the term

¹⁰⁶ "nutrigenetics" (82.7%). Five participants had already undergone genetic testing.

107 Preference for Health Care Professional

When asked to which health care professional(s) should be referred an individual wishing to receive nutritional recommendations adapted to his genetic profile, 93.3% of participants identified registered dietitian as a good choice. Doctor/family physicians

were identified by 39.7% of participants, followed by geneticists (39.2%) and genetic

112 counsellors (28.6%). Naturopaths, nurses and pharmacists were identified by 11.9%,

113 10.3% and 8.2% of participants, respectively.

114 Perceived Advantages and Disadvantages of Nutrigenetic Testing

Table 2 shows the principal advantages and disadvantages given by study participants from receiving personalized dietary advices based on genetic makeup. Briefly, when asked about the perceived advantages of receiving DNA-based dietary advice, "health" was the most frequently reported theme (23.5%), followed by "disease prevention" (22.2%), "personalized dietary advice based on genetic makeup" (22.0%), "improving diet" (9.1%), "food classified as being good or bad" (7.7%), "weight control" (6.9%), and "feeling better" (5.4%). Additionally, 24.4% of respondents perceived no disadvantage
for receiving DNA-based dietary advice. The item "diet-related restrictions" was the most
frequently mentioned disadvantage (12.9%) followed by "worry/fear/anxiety" (8.1%), "the
loss of pleasurable eating practices" (5.5%), and "the risk to develop food obsession"
(5.0%).

A proportion of 90.7% (n=1292) of participants reported to be ready to follow a 126 personalized diet based on the results of a nutrigenetic test, as reported in a previous 127 paper [15]. The remaining 9.3% (n=133) were guestioned about the reasons for not 128 being inclined to follow personalized dietary advice based on genetic makeup. 129 Restrictions associated with the diet (25.6%) (e.g. "I do not like having restrictions."), the 130 131 fact that they do not want to follow any diet (12.8%) (e.g. "I do not like diets [...] Having a food structure bores me and I will not follow a diet for the rest of my life."), that they 132 already have a suitable diet (9.8%) (e.g. "I already have a balanced diet"), the pleasure 133 134 of eating (10.5%) (e.g. "It could take away the pleasure of eating."), the absence of health problems and illness (8.3%) (e.g. "I do not have any particular disease. I do not 135 think I need to follow a special diet."), the complexity to follow a diet based on DNA 136 dietary advice (6.8%) (e.g. "It must be complicated to eat in restaurants."), the personal 137 food preferences (6.0%) (e.g. "The fear of having to cut my favourite food. I am very 138 picky on the food side, so it would be difficult for me to go on a diet."), and the negative 139 impact of diet on psychological aspects such as self-control and guilt (6.0%) (e.g. "I do 140 not want to have to personally control what I think [...] Knowing my genetic profile would 141 142 make me feel guilty if I do not follow the nutritional recommendations, and I would know

that I have a direct effect on my health. I just do not want to know.") were among the

answers most often quoted by the participants in qualitative analyses (data not shown).

145 General Concerns about Nutrigenetic Testing

146 As shown in **Figure 1**, the accessibility to personal genetic data by telemarketing companies and spammers, and the solicitation by companies using personal genetic 147 data to sell products/supplements adapted to the genetic profile of individuals being 148 tested were the two main concerns (51.8% and 48.6%, respectively; % of study 149 participants that answered, "Very concerned"). Participants were generally not 150 concerned about the scientific advancement in the field of nutrigenetics, the destruction 151 of their DNA samples by the genetic testing company once results are reported to the 152 customer, and the accessibility to personal genetic data by the genetic testing company. 153 154 The price and the high cost of the technology were not among the major concerns with regard to the limits most commonly reported. A proportion of 55.8% of participants were 155 ready to pay less than \$100 CAD, 22.46% of the participants were ready to pay between 156 \$100-199 CAD, and 4.6% were ready to pay between \$200-299 CAD to obtain DNA-157 based dietary advice. In an ordinal model for multinomial data adjusted for sex, annual 158 income was significantly associated with willingness to pay for DNA-based personalized 159 nutrition (p<0.0001), where individuals with an income \geq \$80 000/year were more likely to 160 be willing to pay \$200 or more ($p \le 0.015$) for nutrigenetic testing. 161

When asked if they would share their nutrigenetic test results, 82.0% declared that they will share them with their life partner, but only 51.4% intended to share the results with their children. With regard to other relatives, most people were ready to share their results with parents or with their brothers and sisters (68.4% and 68.1%, respectively). 166 Percentages were higher with health care providers; 87.3% of participants intended to

share their nutrigenetic test results with a family physician and 88.1% with a registered

168 dietitian.

170 **Discussion**

This survey aimed to assess public perceptions and general concerns regarding
nutrigenetic testing for personalized nutrition in a population of French Canadians from
the province of Quebec, in Canada. In this study, advantages and disadvantages of
nutrigenetic testing were documented as well.

175 Study Population

The study sample was mainly composed of Caucasian women, often presenting high socioeconomic status and level of education. The majority was under 40 years of age, and all were French Canadians living in the province of Quebec. Because of the homogeneity of the study sample, generalizability of the results could be limited. Part of this homogeneity can be explained by the recruitment methods. Participants were partly recruited via the Laval University list of employees and students, explaining high levels of education, and it is likely that more women returned the guestionnaire than men..

183 Preference for Health Care Professional

Almost all participants preferred dietitians for providing DNA-based personalized dietary 184 185 advice. This observation is rather consistent with other studies on the subject. In a 186 Canadian study by Nielsen DE et al., 56% of participants answered "registered dietitian" when asked which health care professional, including registered dietitians, medical 187 doctors, registered nurses, naturopaths or other, they felt would offer them the best 188 personalized nutrition recommendation [12]. Similarly to the present study, medical 189 190 doctor was reported as the second-best source (27%) for personalized nutrition recommendation [12]. However, in that study, health care professionals were not 191

perceived as being the best source for personal genetic information [12]. A total of 47% 192 193 of participants reported "university research lab" as the best source, followed by "health care professional" (41%), and finally "direct-to-consumer genetic testing company" 194 (12%) [12]. Conversely, Poinhos R et al. documented, in a large survey of 9381 195 individuals across nine European countries, that family doctors/general practitioners 196 were deemed the best service providers for personalized nutrition in all countries except 197 in Poland, where registered dietitians were preferred [16]. Family doctors were also the 198 most trusted providers for personalized nutrition information in all nine countries studied 199 [16]. In Norway and Poland, trust in registered dietitians for providing personalized 200 201 nutrition information did not significantly differ from family doctors [16]. It should be mentioned that, in France and Germany, the minimum level of training to become a 202 registered dietitian requires less than a bachelor's degree unlike in Canada, the United 203 States and several other European countries [17]. These differences in educational 204 levels may partly explain the discordances of public opinions between different countries 205 and studies. These observations demonstrate that registered dietitians and physicians 206 are generally well trusted for giving personalized nutritional recommendations from 207 genetic testing, including in Quebec. Nonetheless, this high level of trust from the public 208 209 towards family doctors is rather surprising considering that dietitians receive much more nutritional training during undergraduate studies than family doctors, and actually have a 210 much higher level of expertise in nutritional counselling [18-21]. 211

212 Perceived Advantages and Disadvantages of Nutrigenetic Testing

Health benefits were reportedly the most frequent perceived advantage in the present
study. Consistently, our group previously observed that participants with personal and/or

familial health issues history were more willing to undergo a genetic testing [15]. These 215 216 results are consistent with the work of Rankin et al., who showed that "health benefits" 217 was positively associated with attitude towards and intention to adopt personalized nutrition [22]. In the same study, they demonstrated that attitude towards and intention to 218 219 adopt personalized nutrition were positively influenced by several other determinants of food choice, including "weight control", "ethical concern" and "mood" [22]. Unexpectedly, 220 "weight control" was among the less reported advantages for receiving personalized 221 dietary advice in the present study. Similar findings were reported in a study by Morin et 222 al., in which participants indicated, among others, "better diet, disease prevention and 223 224 overall healthier habits" as benefits of nutrigenomics testing [14]. Participants generally deemed that benefits of nutrigenomics outweighed risks, as opposed to health care 225 professionals, who had a more conservative thinking [14]. 226

227 General Concerns about Nutrigenetic Testing

Morin et al., also reported several risks perceived by the public regarding nutrigenomic 228 229 testing. Insufficient scientific evidence to support nutrigenomics testing, misinterpretation of the results by the public, psychological risks, confidentiality aspects, and high costs 230 were raised [14]. Rankin et al. reported "price" as negatively associated with attitude 231 towards and intention to adopt personalized nutrition [22]. In the present study, most of 232 233 participants would pay less than \$100 for dietary recommendations based on their genetic profile. These results show that, in this population, price also appears to be a 234 limiting factor. A substantial proportion of participants had a high socio-economic status. 235 Considering that annual income was significantly associated with willingness to pay for 236 237 personalized dietary recommendations based on genetic profile, price would probably

have constituted an even more important barrier to genetic testing and personalized 238 nutrition if the survey was conducted in a population with lower incomes. Fisher et al. 239 reported that about 30% of participants, particularly men with high incomes, would be 240 willing to pay more for personalized dietary advice than non-personalized dietary advice 241 [23]. Participants were, on average, willing to pay 150% of the standard price for non-242 personalized nutrition advice [23]. Henneman et al. showed that men were more prone 243 244 to genetic testing as well [24]. In the present study, willingness to pay for DNA-based personalized nutrition was not different between men and women. 245

Accessibility to genetic information was reported as an important preoccupation in some 246 cases. Similar concerns were widely reported in other studies. It was documented that 247 248 privacy risk was an important determinant of consumers' intention to use recommendation systems to obtain personalized nutrition advice [25]. Apprehensions 249 250 about genetic risk profiling were reported in about half of participants (all physicians) of a 251 recent study by Haga et al., where 50% of participants expressed concerns about health insurance discrimination and 43% about confidentiality regarding genetic testing [26]. 252 Authors also found with participants from the public that agreed or strongly agreed with 253 the possibility that results of genetic tests could affect their capacity to get health 254 insurance (51.3%) or a job (15.7%) [27]. In other studies, employment and insurance 255 256 taking were matters of concerns for participants as well [9,27-29]. These observations clearly demonstrate a certain public's awareness of the ethical issue of confidentiality. 257 However, the majority of participants were comfortable with sharing nutrigenetics 258 information within the family. Similarly, it was previously observed that almost half of 259 260 participants (49%) of a study believed that the information from genetic tests belongs to

the whole family [30]. In a survey by Haga et al., 89.7% of participants agreed or 261 262 strongly agreed with the share of results of their genetic test with their family members, and only 22.7% agreed or strongly agreed that the family does not need to know the 263 results [27]. Similar findings were reported in another study, in which almost every 264 participant considered that genetic information was familial, not merely individual [31]. 265 Interestingly, Heaton TG et al. observed that individuals are more willing to give away 266 267 personal information from genetic testing to an at-risk relative of a disease when the disease is preventable (mostly) and serious [32]. Authors state that information about 268 genetic testing is very dependent on disease characteristics [32]. Moreover, Nielsen et 269 al. reported that participants who received personalized dietary advice based on 270 participants' genotype shared more their information with a family member compared to 271 the control group (dietary recommendations with no genetic information) [12]. 272 Participants were also little concerned by the accessibility and destruction of DNA 273 274 samples by the genetic testing company, and the regulation of the industry of genetic testing. There is currently very little legislation surrounding the provision of evidence-275 based nutrition information and nutrigenetic testing, and customers may not be aware of 276 it [33,34]. Also, there are still some debates on the strength of scientific evidence 277

supporting the marketing of nutrigenetics and its use in health care practice [33,35].

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282 Conclusion

Overall, the present study showed that individuals perceive many advantages from nutrigenetic testing, mainly for health, and are comfortable with the disclosure of genetic information with relatives. They, however, remain generally aware of the potential privacy issues of nutrigenetic testing, although they do not seem to fully understand the risks associated with ownership of personal genetic information. These findings further support that the population is generally optimistic regarding the use of nutrigenetics in health care practice via registered dietitians.

291 **Declarations and special requirements**

292 Investigations Involving Human Subjects

293 Written informed consent was obtained from all subjects for the publication of this report.

294 The Ethics Committee on Research Involving Human Subjects of Laval University

approved this project (2014-292 / 24-02-2015). Authors' signatures:

296

297 Statement for Authors Submitting Original Research or Case Reports

The enclosed manuscript "Nutrigenetic testing for personalized nutrition – an evaluation 298 of public perceptions, attitudes and concerns in a population of French Canadians" has 299 300 been approved by me as well as by the responsible authorities at the institute where the work has been carried out. I certify that none of the material in this manuscript has been 301 302 published previously in any form and that none of this material is currently under 303 consideration for publication elsewhere. This includes symposia and proceedings of 304 meetings and preliminary publications of any kind except an abstract of 400 words or less. Authors' signatures: 305

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309 **Declarations**

- 310 Competing interests
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	Men*	Women*	Total*
Gender	252 (17.7)	1173 (82.3)	1425 (100.0)
Age (years)**			
18-29	60 (23.9)	477 (40.7)	537 (37.7)
30-39	34 (13.6)	283 (24.1)	317 (22.3)
40-49	47 (18.7)	150 (12.8)	197 (13.8)
50-59	52 (20.7)	143 (12.2)	195 (13.7)
60 and up	58 (23.1)	120 (10.2)	178 (12.5)
Matrimonial status			
Single (including divorced,	89 (6.3)	506 (30.0)	595 (41.8)
separated and widowed)			
Married or Common law	162 (11.4)	651 (45.7)	813 (57.1)
No answer	1 (0.07)	16 (1.1)	17 (1.2)
Ethnicity			
Caucasian	244 (96.8)	1134 (96.7)	1378 (96.7)
Others	8 (3.2)	39 (3.3)	47 (3.3)
Level of education			
High School			
Not completed	3 (0.2)	12 (0.8)	15 (1.1)
Completed	2 (0.1)	25 (1.8)	27 (1.9)
Vocational training	11 (0.8)	63 (4.4)	74 (5.2)
College			
Not completed	6 (0.4)	43 (3.0)	49 (3.4)
Completed	29 (2.0)	179 (12.6)	208 (14.6)
University			
Not completed	46 (3.2)	302 (21.2)	348 (24.4)
Completed	155 (10.9)	549 (38.5)	704 (49.4)
Annual household income (\$			
CAD/year)			
≤ 39 999	35 (13.9)	243 (20.7)	278 (19.5)
40 000 - 59 999	26 (10.3)	185 (15.8)	211 (14.8)
60 000 - 79 999	33 (13.1)	140 (11.9)	173 (12.1)
80 000 - 99 999	30 (11.9)	168 (14.3)	198 (13.9)
100 000 and up	96 (38.1)	263 (22.4)	359 (25.2)
No answer	32 (12.7)	174 (14.8)	206 (14.5)
Geographical distribution			
Quebec City	187 (74.2)	594 (50.6)	781 (54.8)
Montreal	7 (2.3)	66 (5.6)	73 (5.1)
Elsewhere in the province of Quebec	58 (23.0)	513 (43.7)	571 (40.1)

Table 1. Characteristics of participants

*Number (%).

**One participant had missing data for age.

Table 2. Perceived advantages and disavantages for nutrigenetic testing

Advantages		Disadvantages		
Statement	%*	Statement	%*	
Health	23.5	No disadvantage	24.4	
Disease prevention	22.2	Diet restrictions	12.9	
Personalized dietary advices based on genetic makeup	22.0	Worry/Fear/Anxiety	8.1	
Improving diet	9.1	Loss of pleasure of eating	5.5	
Dichotomy between good and bad food	7.7	To develop food obsession	5.0	
Weight control	6.9	No knowledge about potential disadvantages	4.8	
Feeling better	5.4	Changes in food habits	4.7	
To understand the impact of food on health	4.1	Food intake complexity	3.9	
Awareness of current health status	3.8	Costs	3.9	
Awareness of own situation	3.5	Awareness of current health status	3.8	
Having better results (glycæmic controls, physical activity, weight loss, etc.)	3.0	To only rely on the nutrigenetic test results	3.8	
Motivation	1.4	Guilt	3.2	
Allergies/Intolerances	1.3	The diet does not necessary apply to all people or family members	2.9	
Avoiding bad behaviours that could increase the risk	1.1	Unestablished relevance of dietary advices based on genetic makeup	2.0	
Better digestive health	1.1	The predictive value of nutrigenetic testing is unknown	1.9	
Promote personalized healthy lifestyle habits	1.1	Difficulty/Inability to follow the dietary advices	1.6	
Informed decision	1.1	Higher risks of nutritional deficiencies	1.6	
Reliable source of information	0.8	Feeling obligated	1.6	
Self-confidence	0.8	Population misunderstanding	1.5	
Does not know	0.8	Insurability	1.4	

Data are from qualitative analyses. Common themes were identified using NVivo software v10.2.0. *Percentage of participants who reported this advantage and/or disadvantage



Figure 1. Level of concern in regard to principal limits commonly reported in the field of nutrigenetics