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Final Report

Exploring How Canadians Understand Nutrigenomics

Results of Focus Groups with Members of General Public and Health Care Professionals

Prepared for the Public Health Agency of Canada

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EXECUTIVE SUMMARY

Phoenix SPI was commissioned to undertake research for the Public Health Agency of Canada (PHAC) related to nutrigenomics. The overall objective of this research was to investigate how Canadians perceive genomics and to establish a basic understanding of "genomic literacy" and "nutrigenomic literacy" among Canadians. The target audience for this research included members of the Canadian general public and health professionals.

A mixed-method approach was undertaken that includes both qualitative and quantitative research. This report presents the findings from the qualitative phase of the research – a set of focus groups – conducted November 22-29 2007. A total of 12 focus groups were held with members of the general public in five cities, with two groups in each of Toronto, Halifax, Edmonton, and Vancouver, and four groups in Montreal (French). Four focus groups were conducted with health care professionals, with two groups in each of Toronto and Vancouver. One group in each city was conducted with doctors and pharmacists, and the other with naturopaths, dieticians, and nutritionists.

The following definition of nutrigenomics was read to the general public participants:

> Nutrigenomics is about how our genetic makeup affects how we respond to what we eat and drink, and how we can change our diet to help promote health and reduce our genetic risks of disease. For instance, because of differences in their genetic makeup, some people respond differently to caffeine. Recent clinical research has identified a range of health effects associated with the consumption of caffeine. For example, three people that drink two cups of coffee every day can experience three distinct health effects because of their genetic make-up:
>
> - One person may not be affected at all
> - Another person may be at greater risk for heart disease, and
> - The third person may reduce their risk of heart disease.

This research was qualitative in nature, not quantitative. As such, the results provide an indication of participants' views about the issues explored, but cannot be generalized to the full population of any of the audiences included in this research.

General Public

Awareness and Initial Perceptions of Nutrigenomics

Prior to their participation in the study, most participants had never heard the term 'nutrigenomics'. This was confirmed through the questionnaire they completed prior to the group discussion in which they were asked to explain what the term means to them. Approximately one-third were unable to provide any meaningful feedback, and among those who did most did not capture its correct meaning. It was most likely to be described as the study or science of nutrition, nutrients, or food in general. Only a relatively small number provided interpretations that touched on the actual subject matter of nutrigenomics and these were most likely to describe it generally as the study of nutrition and genetics. Lack of awareness of nutrigenomics was also underscored by the fact that none of the participants have seen or heard about any nutrigenomic services available to Canadians.

Many participants hesitated when asked where they would go for information about how their unique genetic make-up affects their personal nutrition and health. Most identified the Internet (typically using a search engine), health care professionals, or both. Health care professionals identified most often included geneticists, family physicians, pharmacists, dieticians, and nutritionists. Many participants also said they would consult family members, especially older ones, to ask about their family's medical history.

Review of Media Article and Mock-up of Nutrigenomics Website

Most participants reacted with interest, curiosity, and often surprise to the media article on nutrigenomics they were given to read. While the article did not significantly alter participants' thinking regarding the role genes play in their health and making them who they are, most said that it did provide perspective, clarify things, or give them more to think about. Most participants felt that genetics can have a significant impact and the article tended to confirm the importance of genes. However, it also clarified the extent to which diet can influence their impact.

Many were clearly positive about what they read, describing it as good or even great news. Those who reacted positively usually said that the article made them think about advances in medicine and health care, and that this technique seemed to reduce the guesswork in the field. Related to this, many said that nutrigenomics seemed to represent an approach to health care that was personalized or adapted to the individual.

While no one reacted negatively to the article in general, a number of participants did react with scepticism or at least caution to what they read. Some detected a commercial or marketing aspect to nutrigenomics that made them uncomfortable or uneasy. To some others, the idea of basing dietary advice on genetic testing was taking a preoccupation with health to an extreme. The price of the test identified in the article – under $100 – made some think about how accessible this was, and were inclined to check it out, while it made others think that it could not be very useful or powerful as a tool for a price that is that low.

Although the topic of nutrigenomics was new to participants and the media article they read was their first exposure or introduction to the topic, they had no difficulty identifying what they perceived to be potential benefits and risks associated with nutrigenomic testing. Moreover, participants in each group tended to identify the same benefits and drawbacks, and most identified both perceived benefits and perceived risks or drawbacks. Indeed, very few participants felt that there were only benefits or drawbacks to nutrigenomic testing.

The perceived benefits associated with nutrigenomics testing had to do with the possibility of improving one's health, and in this sense they were all related to one another. Leading the way was the possibility of a tailored approach to health care, including the possibility of reducing guesswork when it comes to prescribing a diet for individuals. Other perceived benefits routinely identified included the ability to detect or diagnose predispositions and preventative treatment, increased understanding of the link between one's genes and one's health, increased interest in changing one's diet to improve health, greater interest in health in general, and the possibility of reducing health care costs for society as a whole.

The potential risk identified most often was the possibility of a misdiagnosis or a mix-up of test results leading to a faulty or mistaken prescription that could adversely affect someone. Other perceived risks or drawbacks regularly identified included regarding nutrigenomics as the answer to all health problems, becoming rigidly fixated on a prescribed program or diet, the possible fraudulent activities on the part of companies (i.e. phony test results, not carrying out tests, prescribing unnecessary supplements), breaches of confidentiality/not ensuring privacy of information, and anxiety/preoccupations over test results.

Based on the information they read, most felt that the potential benefits of nutrigenomics testing outweigh the possible risks or harms. That said, many were uncertain, and some felt that the risks outweighed the benefits because the science is still in its infancy.

Nearly all participants said the article encourages or motivates them to look for more information about nutrigenomics. The Internet and health care professionals were the two most-frequently-identified sources for more information, but Health Canada, public health authorities, government in general, universities, libraries, and medical journals were also regularly identified. Many also said they would consult companies offering these services for more information.

Most participants became more critical or sceptical of nutrigenomics after reviewing a mock-up of a website modelled on those of firms that offer nutrigenomic services. Critical reaction was based primarily on what was described as its marketing or commercial aspect. There was a widespread sense that companies selling nutrigenomics products and services might be more interested in a money-making venture than in promoting health. Many focused specifically on the marketing of nutritional supplements. In addition to the marketing or commercial aspect, a number of participants reacted negatively to the Internet-based dimension of nutrigenomics. Many volunteered that they would prefer to be tested in an actual physical establishment like a clinic or a laboratory. Underlying critical reaction to buying tests like these over the Internet, as well as mailing-in one's sample, was a widespread impression that this is too important an issue to be handled in this way.

Review of Information Document on Nutrigenomics

Overall reaction to a short information document on nutrigenomics prepared specifically for these focus groups was positive. Participants routinely described it as a good overview, clear, and balanced in its perspective. The latter was what was most likely to stand out and catch participants' attention – specifically the section providing an overview of the pros and cons of nutrigenomics. Many also liked the fact that the document raises or addresses issues or points they themselves raised.

The key outstanding or remaining questions participants had about nutrigenomics, after everything they looked at and read, included proof that nutrigenomics works/is effective, whether the government will get involved in regulating/overseeing nutrigenomics, Health Canada's stand on nutrigenomics, and whether the medical community will get involved in nutrigenomics and/or whether will nutrigenomics will become part of the health care system. While most remain uninterested in taking a nutrigenomics test without first getting further information, some participants said they were prepared to take such a test.

Related Communications Issues

Participants identified various types of information that they felt were important for Canadians to know in order to make an informed decision about nutrigenomics and whether it is something for them or their family. Leading the way was information about the 'pros and cons' of nutrigenomics. There was a virtual consensus that this was important information. Specific information routinely identified as important included the following:

- Proof/hard evidence about the success of nutrigenomics.
- Who, if anyone endorses, nutrigenomics.
- Reliability of home tests that form the basis for the evaluation.
- Who does the testing and /where.
- Conditions that can be tested for.
- Possible public oversight/regulation of nutrigenomics.
- Maintenance/assurance of confidentiality/privacy of information.
- Costs of testing and possible coverage under public health care.

Participants identified a variety of ways to inform Canadians about nutrigenomics, but the most frequently-suggested means was to place pamphlets or brochures in doctors' offices/clinics and health care facilities. Organizations regularly identified as credible or trustworthy sources of up-to-date, accurate information on nutrigenomic testing included Health Canada, Public Health Agencies, the U.S. Food and Drug Administration, government in general, organizations representing health care professionals, universities/academic institutions, and scientific/medical journals. While many identified family physicians, dieticians, and nutritionists as credible and trustworthy, some felt that these health care professionals might not yet be up-to-speed on nutrigenomics (especially family physicians) because of the relative newness of the field.

Health Care Professionals

Awareness and Perceptions of Nutrigenomics

Prior to their participation in the study, most health care professionals had never heard the term 'nutrigenomics'. Those who had were all dieticians, nutritionists, and naturopaths. Despite the relatively limited familiarity with nutrigenomics, most health care professionals intuited that it refers to a link between diet or nutrition and genetics. This was evident through the definitions of nutrigenomics provided by participants in the questionnaire they completed prior to the group discussion.

Health care professionals identified various sources they would turn to for information about nutrigenomics. The source identified most often, and usually the first one mentioned, was the Internet. Many said they would go to special sites, including Medline, Pub Med, Pharmacy Links, and the International Journal of Pharmaceutical Compounding. In addition to the Internet, participants routinely identified colleagues and professional literature as sources they would consult, as well as companies offering these services.

Information related to the claims made by companies offering nutrigenomics services and the nature of the tests were most often identified as the most important types of information needed in order to counsel patients properly. This included information about

what the companies test for, the range of tests available, clinical practice guidelines, the degree of reliability of tests, case-study-based evidence of success and success rates, the nature of prescriptive treatments and whether companies help clients interpret results. Other key information included the cost of tests, privacy/confidentiality guidelines, and the extensiveness of testing (e.g. how many people have taken such tests?).

Geneticists, nutritionists, and dieticians were the most frequently-identified health care professionals to whom participants would refer a patient or client for further information about nutrigenomics. Some said they would refer their patients to researchers or professors at universities or medical schools, and a few said they might recommend a naturopath.

Review of Website

Most health care professionals reacted with a certain amount of scepticism to the mock-up of a website modelled on those of firms that offer nutrigenomic services, with physicians and pharmacists more likely to express strong scepticism. This was based on lack of proof/evidence for the effectiveness of these services, the sense that testing is limited (i.e. 19 genes for five possible conditions), lack of regulation/oversight of these services, the impersonal nature of the service, marketing of nutritional supplements and possible conflict of interest (i.e. carrying out tests and selling supplements), and a sense that if this is effective treatment they would have heard of it before. Some reacted more positively, describing the information as intriguing and suggesting that such services could potentially be very beneficial. Despite the widespread scepticism, all health care professionals expressed interest in this information, and many described this as important for them to know about as health care professionals.

All the health care professionals felt that these services need to be mediated by qualified health care professionals or, at the very least, that there needs to be some kind of oversight or regulation on the part of Health Canada or government. Reasons included the belief that patients are going to be visiting their health care providers with questions about such tests and therefore the latter should be involved in the process, the belief that health care providers may have to deal with negative fall-out or consequences resulting from these tests, the belief that health care professionals are in a position to ask pertinent questions about these services that their patients may not think of asking, and the belief that there should be some way to guarantee the legitimacy of these tests and the claims being made about nutrigenomics.

Despite their concerns or reservations, all health care professionals were able to identify perceived benefits associated with nutrigenomic testing. The benefits identified most often were a proactive approach to health care through preventative measures, and greater interest in healthy eating in general. Many also suggested that nutrigenomics could potentially be very useful in targeted treatment of specific conditions or predispositions to them. When it came to perceived risks or potential harms, health care professionals were most likely to raise concerns about the accuracy or validity of results. Related to this were the possible health-related consequences of a misdiagnosis or inaccurate results.

Review of Information Document on Nutrigenomics

The reaction of health care professionals to this document was very similar to that of members of the general public. There was widespread agreement that it provides a good overview of the topic and helps clarify the issues by providing balanced coverage of the 'pros and cons' of nutrigenomics. Like members of the general public, health care professionals were most likely to react positively to information in the section titled 'Nutrigenomics: Some Issues'. Many said that this section made them think (or reinforced their belief) that there is much left to learn regarding the link between nutrition and genetics in particular, or genes and environmental factors in general. The document elicited relatively little in terms of negative or critical reaction. Small numbers reacted critically to each of the following: the lack of certainty regarding the possible benefits of nutrigenomics, the example of lactose intolerance because there is no need for a gene test to diagnose this condition, the definition of nutrigenomics because it suggests a reductionist view of what affects health, and the examples of how food intake can affect health because these were described as providing nothing new in terms of information.

The most frequently-identified outstanding question about nutrigenomics identified by health care professionals related to its potential regulation and/or oversight. This included the claims nutrigenomics firms can make about their products and services, the types of supplements they can provide or market, standards governing testing and safety, regulation of home test kits, standards governing the interpretation of results, and standards governing confidentiality and privacy of information. Many also re-iterated that they would like to see proof or evidence of the effectiveness of nutrigenomic testing.

Related Communications Issues

Health care professionals believe that numerous actors have a supporting role to play in helping them provide information about nutrigenomic testing. These include Health Canada, the community of professionals involved in providing health care, associations representing health care professionals, university researchers and medical schools, and regulatory bodies responsible for creating guidelines governing health-related practices.

Health care professionals identified various types of information they felt were important for Canadians to know so that they can make an informed decision about nutrigenomics. However, identified most often was information on the 'pros and cons' of nutrigenomics. They also identified a variety of ways to inform Canadians about this. The most frequently-suggested means was through health care professionals (i.e. family physicians, dieticians, nutritionists, naturopaths, pharmacists), as well as pamphlets, brochures, and posters in their facilities/offices. Placing information on specific websites was also routinely identified. These included YouTube, Health Canada, and sites of associations of health care professionals. Infomercials and television ads were also identified.

Finally, there was unanimity that nutrigenomics testing should not be left exclusively to the marketplace, and widespread support for the following: Health Canada informing consumers about the benefits and harms of this kind of testing, regulations affecting what companies can claim about the testing products they sell, and health professional associations (licensing bodies, etc.) creating guidelines for the appropriate counselling of

patients on nutrigenomic issues. Some felt that the latter measure was not appropriate because it implied a certain amount of paternalism (i.e. it implied that certain professionals in the field of health care are qualified to comment on another field). Moreover, it was also suggested that professional associations would probably be reluctant to do this, especially if nutrigenomics began to prove its worth based on scientific evidence.

More Information:

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SOMMAIRE

L'Agence de la santé publique du Canada (ASPC) a retenu les services de Phoenix SPI pour réaliser une étude sur la nutrigénomique. L'objectif général du projet était d'examiner ce que pensent les Canadiens et les Canadiennes de la génomique et d'évaluer la connaissance qu'ils ont de celle-ci et de la nutrigénomique. L'étude avait pour groupes cibles les membres du grand public et les professionnels de la santé du Canada.

Il s'agissait d'une recherche à méthodes mixtes, utilisant à la fois des méthodes qualitatives et quantitatives. Ce rapport présente les résultats de la recherche qualitative dans le cadre de laquelle ont eu lieu des rencontres de discussion du 22 au 29 novembre 2007. En tout, 12 rencontres de discussion, regroupant des membres du grand public, ont eu lieu dans cinq villes : deux rencontres se sont tenues à Toronto, à Halifax, à Edmonton et à Vancouver, et quatre autres à Montréal (en français). Quatre rencontres de discussion réunissant des professionnels de la santé ont été organisées à Toronto et à Vancouver (deux dans chaque ville). Une de ces rencontres, dans chacune des villes, réunissait des médecins et des pharmaciens et l'autre, des naturopathes, des diététistes et des nutritionnistes.

Nous avons lu la définition suivante aux membres du grand public :

> « La nutrigénomique s'intéresse à l'influence de notre patrimoine génétique sur la façon dont notre corps réagit à ce que nous consommons et aux changements que nous pouvons apporter à notre alimentation pour améliorer notre santé et réduire le risque de maladie héréditaire. Par exemple, en raison d'un patrimoine génétique différent, certaines personnes réagissent différemment à la caféine. Des recherches cliniques récentes ont identifié une gamme d'effets sur la santé associés à la consommation de caféine. Par exemple, trois personnes qui consomment deux tasses de café par jour peuvent faire l'expérience de trois effets distincts sur la santé à cause de leur patrimoine génétique :
>
> - une personne pourrait ne pas être affectée du tout;
> - une autre personne pourrait accroître son risque de maladie du cœur;
> - la troisième personne pourrait réduire son risque de maladie du cœur. »

Cette recherche était de nature qualitative et non quantitative. Par conséquent, les résultats représentent les opinions des participants sur les questions traitées et ne peuvent être généralisés à l'ensemble des personnes composant les groupes cibles de cette étude.

Grand public

Connaissance de la nutrigénomique et opinions initiales sur le sujet

Avant de participer à cette étude, la plupart des participants n'avaient jamais entendu le terme « nutrigénomique ». Leurs réponses au questionnaire qu'ils ont rempli avant la rencontre, leur demandant entre autres d'expliquer en quoi consiste la nutrigénomique, ont confirmé ce fait. Environ le tiers des participants étaient incapables de donner une définition précise et ceux qui l'ont fait étaient, pour la plupart, dans l'erreur. Les participants ont généralement décrit la nutrigénomique comme étant l'étude ou la science de la nutrition, des nutriments ou des aliments en général. Seuls quelques participants ont

offert une définition se rapprochant de son sens exact, décrivant la nutrigénomique comme l'étude du lien entre la nutrition et la génétique. Enfin, aucun des participants n'était au courant ou n'avait entendu parler de services d'analyse nutrigénomique offerts aux Canadiens.

Plusieurs participants ont hésité quand nous leur avons demandé où ils s'adresseraient pour obtenir des renseignements sur la façon dont leur propre patrimoine génétique influence leur nutrition ou leur santé. La plupart se tourneraient vers Internet (ils utiliseraient, généralement, un moteur de recherche) ou les professionnels de la santé, ou les deux. Parlant des professionnels de la santé, les participants ont surtout mentionné les généticiens, les médecins de famille, les pharmaciens, les diététistes et les nutritionnistes. Plusieurs participants ont aussi indiqué qu'ils consulteraient des membres de leur famille, en particulier les plus âgés, afin de se renseigner sur les antécédents médicaux de la famille.

Opinions sur l'article médiatique et la maquette du site Web sur la nutrigénomique

Nous avons demandé aux participants de lire un article médiatique sur la nutrigénomique. Celui-ci a suscité, chez la plupart des participants, de l'intérêt, de la curiosité et de l'étonnement. Bien que cet article n'ait pas changé leur perception du rôle que jouent les gènes dans leur santé et leur individualité, la plupart des participants ont indiqué que cet article avait néanmoins mis les choses en perspective, clarifié certains points ou leur avait donné matière à réflexion. La plupart des participants étaient d'avis que la génétique peut influencer considérablement la santé et l'article est venu confirmer l'importance des gènes à ce chapitre. Toutefois, ce dernier leur a aussi permis de mieux comprendre l'influence que peut avoir l'alimentation sur le comportement de ces gènes.

Plusieurs ont réagi très favorablement à cet article, voyant là une bonne nouvelle ou même, une excellente nouvelle. Ces participants ont indiqué, d'une part, que l'article les avait amenés à réfléchir aux progrès de la médecine et à ceux dans le domaine des soins de santé et, d'autre part, que cette technique semblait éliminer une partie de l'incertitude dans la gestion de la santé d'un individu. D'autres ont dit que la nutrigénomique semble offrir, dans le domaine des soins de santé, une approche personnalisée ou adaptée à l'individu.

Bien qu'aucun participant n'ait mal réagi à cet article, certains participants se sont montrés sceptiques, ou à tout le moins prudents, devant son contenu. Quelques-uns ont dit avoir éprouvé un certain malaise à la lecture de cet article, décelant dans celui-ci un aspect commercial à la nutrigénomique. D'autres étaient d'avis que, bien qu'il soit important de se préoccuper de sa santé, l'établissement d'un régime alimentaire en fonction des résultats d'une analyse génétique poussait cette préoccupation à l'extrême. Le coût d'une analyse, indiqué dans l'article (moins de 100 $), rendait celle-ci accessible, selon certains, et leur donnait le goût d'examiner la question de plus près. Par contre, le faible coût d'une telle analyse en a amené d'autres à douter de l'utilité ou de l'efficacité de cet outil.

Même si les participants n'avaient encore jamais entendu parler de la nutrigénomique et que l'article médiatique que nous leur avions présenté constituait leur premier contact avec la question ou leur avait servi d'entrée en matière, ceux-ci n'ont eu aucune difficulté à imaginer les avantages et les risques possibles de l'analyse nutrigénomique. Qui plus est,

les participants à chacune des rencontres ont généralement parlé des mêmes risques et avantages et la plupart pouvaient imaginer autant les avantages que les risques ou les inconvénients d'une telle analyse. En effet, très peu de participants se sont montrés entièrement optimistes ou pessimistes, y voyant uniquement des avantages ou des inconvénients.

Les avantages de l'analyse nutrigénomique, que pouvaient imaginer les participants, se résumaient essentiellement à une chose : la possibilité d'améliorer la santé de l'individu. Le principal avantage perçu était la possibilité d'adopter une approche plus personnalisée, dans le domaine des soins de santé, permettant de réduire l'incertitude dans la prescription d'un régime alimentaire donné. Parmi les autres avantages décrits le plus souvent, mentionnons les suivants : la possibilité de dépister ou de diagnostiquer une prédisposition et d'établir un traitement préventif, l'amélioration de notre compréhension du lien existant entre les gènes d'un individu et sa santé, une motivation accrue à modifier son régime alimentaire en vue d'améliorer sa santé, un intérêt accru dans la santé de façon générale et enfin, la possibilité de réduire les coûts des soins de santé, pour l'ensemble de la société.

Pour ce qui est des risques, les participants craignaient surtout les erreurs de diagnostic ou la confusion dans les résultats (confondre les résultats d'un individu avec ceux d'un autre) pouvant donner lieu à des prescriptions qui nuiraient à la santé de l'individu en question. Les autres risques ou inconvénients cités le plus souvent étaient les suivants : considérer la nutrigénomique comme une panacée, s'en tenir de façon trop rigide au programme ou au régime prescrit, être victime de fraude de la part des entreprises offrant de tels services (p. ex., faux résultats, analyses non réalisées, prescription de suppléments inutiles), être victime d'une violation de la confidentialité ou de lacunes dans la protection des renseignements personnels et enfin, éprouver de l'anxiété ou de l'inquiétude à l'égard des résultats de l'analyse.

Après avoir lu cet article, la plupart des participants étaient d'avis que l'analyse nutrigénomique présente plus d'avantages que de risques. Par contre, plusieurs se sont dits incertains à ce chapitre et quelques-uns étaient d'avis que les risques que présente l'analyse nutrigénomique l'emportent sur les avantages qu'elle comporte étant donné que cette science n'en est encore qu'à ses débuts.

Presque tous les participants ont dit que l'article les encourageait ou les motivait à se renseigner davantage sur la nutrigénomique. Pour obtenir ces renseignements, les participants se tourneraient principalement vers Internet et les professionnels de la santé. La plupart consulteraient aussi Santé Canada, les autorités de santé publique, le gouvernement (en général), les universités, les bibliothèques et les revues médicales. Plusieurs chercheraient aussi à se renseigner auprès des entreprises offrant ce genre d'analyse.

La plupart des participants sont devenus plus critiques ou sceptiques à l'égard de la nutrigénomique après avoir étudié la maquette du site Web modelé sur ceux d'entreprises offrant des services d'analyse nutrigénomique. Les critiques concernaient principalement l'aspect commercial ou vendeur du site Web. De façon générale, les participants croyaient qu'il était possible que les entreprises dans ce domaine souhaitaient davantage s'enrichir

que promouvoir la santé. Plusieurs ont commenté la commercialisation de suppléments alimentaires. D'autres participants voyaient aussi d'un mauvais œil le fait que les services en matière de nutrigénomique ne soient offerts que par le biais d'Internet. Certains ont ajouté qu'ils préféreraient passer une telle analyse dans un établissement ayant pignon sur rue, comme une clinique ou un laboratoire. Les participants ont critiqué le fait qu'on doive commander ces analyses par Internet pour ensuite envoyer son échantillon par la poste, cette intervention et ses conséquences étant trop importantes pour procéder ainsi.

Réactions au document explicatif sur la nutrigénomique

Les participants ont généralement bien réagi au contenu du court document sur la nutrigénomique préparé pour ces rencontres de discussion. La plupart étaient d'avis qu'il donnait un bon aperçu de la question, qu'il était clair et qu'il offrait une perspective équilibrée. Ce dernier point est celui qui est ressorti le plus souvent : la section présentant les avantages et les inconvénients de la nutrigénomique a particulièrement capté l'attention des participants. Plusieurs ont aussi aimé le fait que ce document abordait les points qu'ils avaient eux-mêmes soulevés.

Après avoir lu les documents et étudié les renseignements que nous leur avions présentés, les participants s'interrogeaient encore sur certains points. Généralement, ils se demandaient s'il existe des preuves de l'efficacité de la nutrigénomique, si le gouvernement participera à la réglementation ou à la surveillance des activités dans ce domaine, si Santé Canada avait adopté une position sur la question, si le milieu médical s'intéressera à la nutrigénomique ou si cette science sera un jour intégrée au système de soins de santé. Si la plupart des participants n'étaient pas intéressés à demander une analyse nutrigénomique avant d'en savoir plus sur le sujet, certains se sont néanmoins dit prêts à se livrer à une telle analyse.

Autres questions relatives aux communications

Nous avons demandé aux participants d'énumérer les genres de renseignements qui devraient être communiqués aux Canadiens et aux Canadiennes en vue de leur permettre de prendre des décisions éclairées en matière de nutrigénomique et de déterminer si une telle analyse leur conviendrait ou serait souhaitable pour leur famille. Les participants ont mentionné divers genres de renseignements. En tête de liste : les avantages et les inconvénients de la nutrigénomique. Pratiquement tous les participants étaient d'avis qu'il s'agissait là de renseignements importants. La plupart considéraient également important de communiquer les renseignements suivants :

- Les preuves de l'efficacité de la nutrigénomique
- Les organisations et les professionnels qui appuient la nutrigénomique
- La fiabilité du test à domicile utilisé pour l'analyse
- Les responsables de l'analyse et le lieu où celle-ci est réalisée
- Les problèmes de santé pouvant être dépistés
- La surveillance ou la réglementation possible de la nutrigénomique par le secteur public
- La protection des renseignements personnels / l'assurance de confidentialité

- Le coût de l'analyse et l'acquittement des frais par le système de soins de santé public

Les participants ont proposé divers moyens pour renseigner la population sur la nutrigénomique, mais recommandaient, pour la plupart, de déposer des dépliants ou des brochures dans les bureaux de médecins ou les cliniques médicales et dans les établissements de santé. Les sources de renseignements sur l'analyse nutrigénomique jugées les plus crédibles et fiables étaient les suivantes : Santé Canada, les organismes de santé publique, la Food and Drug Administration des États-Unis, le gouvernement (en général), les organismes représentant les professionnels de la santé, les universités ou les établissements universitaires et enfin, les revues scientifiques ou médicales. Si plusieurs considéraient les médecins de famille, les diététistes et les nutritionnistes comme étant des sources crédibles et fiables, certains craignaient toutefois que ces professionnels de la santé ne soient pas encore suffisamment renseignés sur la nutrigénomique (surtout les médecins de famille) en raison de la nouveauté relative de cette science.

Professionnels de la santé

Connaissance de la nutrigénomique et opinions sur le sujet

Avant de participer à cette étude, la plupart des professionnels de la santé n'avaient jamais entendu le terme « nutrigénomique ». Ceux qui le connaissaient étaient tous diététistes, nutritionnistes ou naturopathes. Même si les participants connaissaient peu la question, la plupart devinaient intuitivement que la nutrigénomique s'intéressait au lien entre le régime alimentaire et la génétique. Cette définition est ressortie clairement des réponses fournies par les participants au questionnaire que nous leur avions demandé de remplir avant la rencontre.

Les professionnels de la santé ont mentionné diverses sources quand nous leur avons demandé où ils s'adresseraient pour obtenir des renseignements sur la nutrigénomique. Celle mentionnée le plus souvent, et généralement d'entrée de jeu, était Internet. Plusieurs consulteraient des sites spécialisés comme les bases de données Medline, PubMed ou PharmacyLinks et le *International Journal of Pharmaceutical Compounding*. En plus de consulter Internet, les participants se tourneraient vers leurs collègues, la littérature professionnelle et les entreprises offrant de tels services.

Nous avons demandé aux professionnels de la santé d'énumérer les genres de renseignements qui leur seraient nécessaires pour bien conseiller leurs patients à ce chapitre. La plupart ont indiqué qu'il serait important pour eux de connaître les déclarations ou les prétentions des entreprises offrant de tels services ainsi que la nature des tests en question. On voudrait notamment savoir ce que dépistent les tests, les types de tests offerts, les lignes directrices de pratique clinique, le degré de fiabilité des tests, l'efficacité de ces tests (démontrée par des études de cas) et les taux de réussite, la nature des traitements prescrits et si l'entreprise aide ses clients à interpréter les résultats obtenus. Parmi les autres renseignements jugés importants, mentionnons les suivants : le coût des tests, les politiques en matière de vie privée et de confidentialité, ainsi que le nombre d'analyses réalisées (p. ex., le nombre de personnes ayant subi une telle analyse).

Devant un patient ou un client souhaitant obtenir davantage de renseignements sur la nutrigénomique, les professionnels de la santé recommanderaient généralement la consultation d'un généticien, d'un nutritionniste ou d'un diététiste. Certains ont indiqué qu'ils suggéreraient à ce patient de consulter un chercheur ou un professeur d'université ou d'une faculté de médecine. Enfin, quelques-uns recommanderaient possiblement la consultation d'un naturopathe.

Opinions sur le site Web

La plupart des professionnels de la santé se sont montrés un peu sceptiques à l'égard de la maquette du site Web modélisé à partir de sites d'entreprises offrant des services d'analyse nutrigénomique; les médecins et les pharmaciens ont, pour la plupart, exprimé un grand scepticisme. Leurs réticences provenaient de l'absence de preuves de l'efficacité de ce genre de service, du caractère apparemment limité de l'analyse (19 gènes pour dépister cinq maladies), de l'absence de réglementation ou de surveillance de ces services, de la nature impersonnelle de ceux-ci, de la commercialisation de suppléments alimentaires, du conflit d'intérêts possible (réalisation d'analyses et vente de suppléments) et du fait qu'ils n'avaient jamais entendu parler de ce genre de service (d'où le doute quant à son efficacité). Certains ont réagi plus favorablement, disant que son contenu avait piqué leur curiosité et jugeant les services très prometteurs. Malgré le scepticisme général, tous les professionnels de la santé se sont montrés intéressés par le contenu présenté et plusieurs voyaient là des renseignements importants pour eux à titre de professionnels de la santé.

Selon tous les participants, il serait nécessaire que des professionnels de la santé qualifiés servent d'intermédiaires dans la prestation de ce genre de services ou, à tout le moins, que Santé Canada ou le gouvernement mette en place une certaine réglementation ou des mécanismes de contrôle. Pour expliquer leur point de vue, les participants ont présenté les raisons suivantes : d'abord, étant donné que les patients consulteront les professionnels de la santé pour obtenir des renseignements sur ce genre d'analyse, ces derniers devraient participer au processus. Deuxièmement, les professionnels de la santé pourraient se trouver confrontés aux retombées ou aux conséquences négatives de ce genre d'analyse. Troisièmement, ils seraient en mesure de poser des questions pertinentes sur ces services, questions auxquelles leurs patients n'auraient peut-être pas pensé. Enfin, la participation des professionnels de la santé conférerait une légitimité aux analyses et aux déclarations visant la nutrigénomique.

Malgré leurs inquiétudes ou leurs réserves, tous les professionnels de la santé ont pu trouver des avantages à l'analyse nutrigénomique. Les avantages mentionnés le plus souvent concernaient, d'une part, la possibilité d'adopter une approche proactive en matière de santé grâce aux mesures préventives proposées et, d'autre part, la possibilité de susciter un plus grand intérêt quant à une saine alimentation. Plusieurs ont aussi suggéré que la nutrigénomique pourrait être très utile dans le traitement ciblé de certaines maladies ou prédispositions. En ce qui concerne les risques que présente l'analyse nutrigénomique, les professionnels de la santé ont surtout parlé de leurs craintes à l'égard de la justesse ou de la validité des résultats et des conséquences possibles sur la santé d'une erreur de diagnostic ou de résultats erronés.

Réactions au document explicatif sur la nutrigénomique

La réaction des professionnels de la santé à ce document était très semblable à celle des membres du grand public. La plupart étaient d'avis que, par sa présentation équilibrée des avantages et des inconvénients de la nutrigénomique, ce document offrait un bon aperçu de la question et permettait de clarifier les choses. À l'instar du grand public, les professionnels de la santé ont particulièrement aimé la section intitulée *La nutrigénomique : quelques points à considérer*. À sa lecture, plusieurs ont compris (ou ont vu leur opinion confirmée) que le lien entre la nutrition et la génétique, en particulier, ou celui entre les gènes et les facteurs environnementaux, en général, était encore nébuleux. Le document a suscité relativement peu de réactions défavorables ou de critiques. Quelques participants ont critiqué ce qui suit : l'incertitude entourant les avantages possibles de la nutrigénomique, l'exemple de l'intolérance au lactose (nul besoin d'une analyse génétique pour établir un tel diagnostic), la définition de la nutrigénomique offrant une vision réductrice des facteurs qui influencent la santé et enfin, les exemples illustrant l'incidence de l'alimentation sur la santé, exemples n'apportant, semble-t-il, rien de nouveau.

Les principales questions que se posaient toujours les professionnels de la santé après la lecture du document portaient sur la surveillance ou la réglementation éventuelle de la nutrigénomique et, plus particulièrement, sur la réglementation des aspects suivants : les prétentions ou les déclarations que peuvent faire les entreprises offrant des produits et services dans ce domaine, les types de suppléments que celles-ci peuvent fournir ou commercialiser et les tests à domicile. Ils se questionnaient aussi sur la normalisation éventuelle des aspects suivants : les analyses, l'innocuité, l'interprétation des résultats, la confidentialité et la protection des renseignements personnels. Plusieurs ont enfin répété qu'ils aimeraient obtenir des preuves de l'efficacité de l'analyse nutrigénomique.

Autres questions relatives aux communications

Les professionnels de la santé ont dit avoir besoin du soutien de divers intervenants pour bien renseigner la population sur l'analyse nutrigénomique. Ils ont notamment parlé de Santé Canada, des professionnels participant aux soins de santé, des associations représentant les professionnels de la santé, des chercheurs universitaires et des facultés de médecine et enfin, des organismes de réglementation responsables d'établir les lignes directrices concernant les pratiques dans le domaine de la santé.

Nous avons demandé aux professionnels de la santé d'énumérer les genres de renseignements qui devraient être communiqués aux Canadiens et aux Canadiennes pour leur permettre de prendre des décisions éclairées en matière de nutrigénomique. Les participants ont mentionné divers genres de renseignements, mais ont insisté sur l'importance de communiquer les avantages et les inconvénients de la nutrigénomique. Ils ont aussi proposé divers moyens pour communiquer ces renseignements à la population : l'intervention des professionnels de la santé (médecins de famille, diététistes, nutritionnistes, naturopathes, pharmaciens), ainsi que la présence de dépliants, de brochures et d'affiches dans leur cabinet seraient, semble-t-il, des plus souhaitables. Plusieurs participants ont aussi proposé d'inclure des renseignements sur la question dans certains sites Web comme YouTube, le site de Santé Canada et ceux des associations des

professionnels de la santé. Certains ont aussi suggéré le recours aux publireportages et aux publicités télévisées.

Enfin, tous les professionnels de la santé s'entendaient pour dire que les services d'analyse nutrigénomique ne devraient pas être régis exclusivement par le marché. La plupart souhaitaient aussi que Santé Canada renseigne les consommateurs sur les avantages et les risques que comporte ce genre d'analyse, qu'une réglementation soit mise en place afin de contrôler les déclarations des entreprises concernant leurs produits et services d'analyse et que les associations des professionnels de la santé (organismes de réglementation, etc.) établissent des lignes directrices sur les conseils à donner aux patients en matière de nutrigénomique. Certains se sont opposés à cette dernière mesure, lui reprochant son côté paternaliste (laissant sous-entendre que certains professionnels de la santé auraient les qualifications nécessaires pour se prononcer sur les activités d'un autre domaine). De plus, certains ont indiqué que les associations professionnelles seraient probablement peu disposées à intervenir ainsi, surtout si des preuves scientifiques venaient démontrer l'utilité de la nutrigénomique.

Pour de plus amples renseignements :

Nom du fournisseur : Phoenix Strategic Perspectives Inc.
Numéro du contrat de TPSGC : HT344-070003-001/CY
Date d'attribution du contrat : Le 17 septembre 2007

Pour obtenir plus de renseignements sur cette étude, veuillez écrire à por-rop@hc-sc.gc.ca.

INTRODUCTION

Phoenix Strategic Perspectives was commissioned by Health Canada to undertake research for the Public Health Agency of Canada (PHAC) related to nutrigenomics.

Background and Objectives

Nutrigenomics is an emerging field of research that offers innovative approaches to addressing the aetiology and progression of complex chronic diseases by investigating how genes and nutrition interact to affect human health. A joint effort to engage the Canadian public about nutrigenomics is being undertaken by researchers in the Network of Centres of Excellence for Advanced Foods and Materials Network (AFMNet) based at the University of Ottawa and the University of Alberta and the Biotechnology, Genomics and Population Health group within the Public Health Agency of Canada.

Nutritional genomics has already 'gone public' in the sense that there are commercial providers of nutrigenomic services and associated products operating chiefly via the Internet in the United States. In the U.S., concern has been raised by the Government Accountability Office regarding the extent to which nutrigenomics is, or ought to be, regulated. These concerns have put pressure on the Food and Drug Administration (FDA) to not only examine more thoroughly the composition of the genetic tests that are being distributed direct-to-consumer (DTC), but also to study the validity of so-called *in vitro* multivariate diagnostic index assays (IVDMIAs) – the principal form of test offered DTC. As the FDA shores up its regulation of supplement health claims, the effect on the early nutrigenomics market might be decisive: some companies will make it over the regulatory bar and may end up with approved tests and claims while others might not.

There are four research themes in the AFMNet-supported project, *Social Issues in Nutritional Genomics: The Design of Appropriate Regulatory Systems and Issues of Public Representations and Understanding*. These themes are: 1) media portrayal; 2) public understanding and acceptance; 3) regulation; and 4) professional development. The two streams of AFMNet-funded research relevant to the collaboration with the PHAC concern public understanding and the regulation of nutrigenomics.

AFMNet researchers are conducting an international comparative legal analysis of the regulations that apply to nutrigenomics. Canadian regulations will be compared with those in other jurisdictions, including the U.S., in order to understand the extent to which Canadian consumers and patients have regulated access to nutrigenomics products and services. In research on the public understanding and acceptance of nutritional genomics, the issue is how the public perceives nutrigenomics from the standpoint of assessing how media representations of nutrigenomics are interpreted. Equally, public understanding and acceptance of nutrigenomics will stimulate change in the education of health care professionals who must communicate with the public about nutritional genomics. For example, research on the impact of nutrigenomics for dieticians in Canada is underway.

Given the rapidity with which the science of nutrigenomics is making advances and gaining a foothold, and given that commercial applications exist in several jurisdictions, it

is time to consider how these developments will affect Canadian consumers, patients, and the public more generally. Important questions include whether Canadians have any knowledge of nutrigenomics, and if so, what is their level of knowledge, what are their perceptions regarding the relevance of nutrigenomics to them, and what risks and benefits do they consider.

In what is termed "the Information Age", it is not surprising that people want as much information as possible about risks to their health. The desire to be informed about disease prevention, control and treatment options, and the risks associated with each is great. No matter what course of action a person may embark upon – with or without the guidance of a health professional – results will be sub-optimal if the available information is difficult to interpret/understand, biased, misleading or simply incorrect. The concept of easy-to-understand, complete and useful layperson's communications materials about health and various risk management options is not a novel one. However, the area of nutrigenomics is so new that work has not yet been undertaken on risk communications in this field.

The overall objective of this research was to investigate how Canadians perceive genomics and to establish a basic understanding of "genomic literacy" and "nutrigenomic literacy" among Canadians. The findings from this research will inform future efforts to raise awareness and understanding of nutrigenomic research among Canadians, and support related health promotion and disease prevention communications tailored to meet the varying needs of Canadians.

More specifically, this research had the following objectives:

- To investigate previous knowledge or exposure to information on nutrigenomics and how this affects understanding of the subject.
- To understand how people respond to terms and concepts related to this topic (e.g. 'predisposition', 'genetic make-up', 'personalized nutrition').
- To understand specific barriers to understanding key concepts of nutrigenomics and how these barriers could be overcome.
- To explore different means of raising the awareness of Canadians and educating them on this topic.
- To solicit information on current gaps in health professionals' capacity — knowledge, skills, resources, political will, etc.
- To test potential communications material that may be used to raise awareness of this issue.
- To provide baseline information on the general population's knowledge of, attitudes towards, and interest in this subject.

Research Design

To address the research objectives, a mixed-method approach using both qualitative and quantitative research was undertaken. This report presents the findings from the qualitative phase of the research – a set of focus groups – conducted November 22-29 2007. The findings from the quantitative phase – a telephone survey of the general public – will be presented in a separate report following completion of that phase of the research.

Target Audiences

The target audiences for this research included members of the Canadian general public and health professionals. The qualitative phase of the research included focus groups with members of each of these target audiences. The specifications applying to the focus groups with each of these audiences are described in detail below.

Focus Groups – General Public

The following specifications applied to the focus groups with members of the general public:

- A total of 12 focus groups were conducted in five cities, with two groups in each of Toronto, Halifax, Edmonton, and Vancouver, and four groups in Montreal (French).
- One group in each of Toronto, Halifax, Edmonton, and Vancouver was conducted with participants who have a high school education or less, and the other was conducted with participants who have at least some post-secondary education. In Montreal, two groups were conducted with each of these audiences. The research in Montreal took place over a two-day period (i.e. two groups each night).
- At least half of the participants in each group had the following characteristics:
  - They have children in the home.
  - They are consumers of natural health products.
  - They have used the Internet to look for health-related information.
- All participants were between the ages of 18 and 70.
- All groups included a mix of participants by gender, age (within the parameters identified above), income, marital status, and ethnicity.
- 12 participants were recruited for 7-8 to show per group. Turnout was excellent, with between 7-9 participants in each group.
- Participants were paid $60 to participate.
- The groups lasted two hours and were held in regular focus group facilities.
- The moderator's guide was developed in close consultation with PHAC officials and designed to address the research objectives identified above.
- Participants were asked to arrive 20 minutes early to complete a mini-questionnaire prior to the focus group. The questionnaire was designed to gauge their awareness, understanding, and behaviour regarding issues related to the topic of the study.

- In order to better explore issues related to nutrigenomics during the groups, participants were asked to read and react to a media article on the topic, as well as a short information document prepared specifically for these focus groups by PHAC officials and members of the research team led by the University of Ottawa. Participants also reviewed a mock-up of a website modelled on those of firms that offer nutrigenomic services.
- Sponsorship of the study was revealed (i.e. PHAC/Government of Canada), as well as the involvement of researchers at the University of Ottawa and the University of Alberta.

Focus Groups – Health Professionals

The following specifications applied to the focus groups with health care professionals:

- Four focus groups were conducted, with two in each of Toronto and Vancouver.
- One group in each city was conducted with doctors and pharmacists, and the other with naturopaths, dieticians, and nutritionists.
- The groups with doctors and pharmacists included a mix of doctors by type of practice (e.g. family doctors, private clinics, community/public health, acute vs. long-term care), and pharmacists by practice setting.
- The groups with naturopaths, dieticians, and nutritionists included a mix by type of practitioner and type of practice.
- Efforts were made to include a mix of participants by age and gender.
- 8 participants were recruited for 5-6 to show per group. Turnout was excellent, with between 5-7 participants in each group.
- Doctors and pharmacists were paid $200 to participate, and naturopaths, dieticians and nutritionists received $100.
- The groups lasted two hours and were held in regular focus group facilities.
- The areas of investigation in the moderator's guide overlapped to a great extent with those explored with the general public, although different issues were also explored.
- Health care professionals were also asked to arrive 20 minutes early to complete a mini-questionnaire prior to the focus group. The questionnaire was similar but not identical to the one completed by members of the general public.
- In order to better explore issues related to the topic during the group discussion, health care professionals were asked to read and react to a definition of nutrigenomics (different from that used in the general public focus groups), as well as the short information document prepared specifically for these focus groups (same as that used for the general public). They also reviewed the mock-up of a website modelled on those of firms that offer nutrigenomic services (same as that used for the general public).

- Sponsorship of the study was revealed (i.e. PHAC/Government of Canada), as well as the involvement of researchers at the University of Ottawa and the University of Alberta.

This phase of the research was qualitative in nature, not quantitative. As such, the results provide an indication of participants' views about the issues explored, but cannot be generalized to the full population of any of the audiences included in this research.

Participants' comments are provided in quotation marks or italics, and are either actual verbatim comments or have been paraphrased to reflect the intent of the remark.

Structure of Report:

This report is divided into two parts: Part 1 presents the results of the focus groups with members of the general public, and Part 2 presents the results of the groups with health care professionals.

Overview of Findings:

Findings from this research tended to be consistent across locations, language groups, and within audiences (i.e. members of the general public on the one hand and health care professionals on the other). Differences among members of the general public were most likely to be based on education, while differences among health care professionals were most likely to distinguish physicians and pharmacists on the one hand from nutritionists and dieticians on the other. Having said that, differences within both audiences were more likely to relate to issues of awareness than to attitudes regarding nutrigenomics. Differences are identified at the appropriate places throughout the report.

The principal investigator for this study was Stephen Kiar. Stephen conducted the focus groups with members of the general public in Toronto, Edmonton, and Vancouver, as well as the focus groups with health care professionals in Vancouver. Philippe Azzie conducted the focus groups with members of the general public in Halifax and Montreal, as well as the groups with health care professionals in Toronto. Both contributed to the final report.

Appended to this report are the following in both official languages:

- Recruitment screeners
- Moderator's guides
- Mini-questionnaires
- Definition of nutrigenomics provided to health care professionals (English only)
- Media article used with members of the general public
- Information document on nutrigenomics
- Mock-up of sample nutrigenomics website.

GENERAL PUBLIC

CONTEXTUAL ISSUES

This section provides contextual information on participants' views and behaviour regarding personal health and nutrition. This includes feedback provided by participants during the focus group discussion, as well as feedback provided through the questionnaire they were asked to complete prior to the group discussion.

Diet & Exercise Top List of Factors Linked to Personal Health

Participants had no difficulty identifying what they perceive to be the most important factors related to personal health. Moreover, there was widespread agreement regarding these factors, with the same ones routinely identified in every group. Two factors, however, led the way in terms of perceived importance: diet/nutrition* and exercise. Both factors were identified by participants in all groups, often together, though diet was usually identified first. Once mentioned, there was widespread agreement with these factors among other participants.

A host of other factors were identified as important by participants in virtually every group. These included stress, general lifestyle (including a balance between work and leisure), attitude/emotional wellness, environmental factors (especially air and water quality), limiting risks (e.g. not smoking, not over drinking), sufficient sleep/rest, and family history/genetics. Regarding the latter, two observations are warranted. First, family history and genetics were not usually among the first factors identified, although they were generally acknowledged as being important when identified by a participant. In other words, while this was not usually among the initial top-of-mind factors, it was nevertheless seen to be important. Second, participants were much more likely to focus on or refer to 'family history' than 'genetics' per se. This is discussed in greater detail below.

Factors identified less often, although still mentioned in most groups, included socio-economic situation, hygiene, and regular medical check-ups. Some participants specified that an important element contributing to personal health is maintaining a balance between various factors. This included, for example, ensuring a balance between diet, exercise, and sleep.

Consensus That Diet Has Significant Impact on Health

In light of the fact that diet was the factor identified most often as contributing to personal health, it is not surprising that there was a consensus that it has a significant impact on a person's health. Participants routinely used expressions like 'crucial', 'major', 'considerable', and 'great' to describe the extent to which this factor affects health.

The contribution of diet to health seemed self-evident to participants and they routinely referred to the old adage "You are what you eat", or some variation on this theme, to explain its importance. A variation on this theme used the analogy of fuel in a car to

* In order to avoid confusion, it should be kept in mind that the term 'diet' refers to what a person eats in general, not the process of dieting in order to lose weight. It should also be kept in mind that 'nutrition' includes taking vitamins and supplements.

explain the importance of diet to the body. Diet provides the basic fuel or energy we need to live a healthy life, and just as poor fuel affects the performance of a car, a poor diet adversely affects a person's health. Some participants suggested that this can be experienced in a palpable way. Food that is high or rich in vitamins and/or minerals literally gives energy and makes one feel good, whereas food that lacks vitamins or minerals can make one feel lethargic.

There was also widespread agreement that proper diet can help avoid or decrease the risk of certain diseases or conditions, including, but not limited to, heart disease, cancer, diabetes, and osteoporosis. Conversely, a poor diet can increase the likelihood of sickness or disease.

In short, the link between nutrition and health was universally acknowledged and generally viewed as self-evident.

Widespread, Multi-Faceted Interest in Link Between Nutrition & Health

The importance attributed to diet was reflected in a widespread interest among participants in the link between personal nutrition and the health of both themselves and their families. Nearly everyone expressed at least some interest in this topic, and most expressed strong interest in it.

This was corroborated through the questionnaire participants were asked to complete prior to the group discussion. In it, participants were asked to use a 5-point scale (1 = not interested at all; 5 = very interested) to rate their level of interest in the link between personal nutrition and the health of themselves/their families. In response, most expressed at least moderate interest in this topic (i.e. scores of 4 or 5), and a majority expressed strong interest. Nearly all those who did not express clear interest provided scores at the mid-point of the scale (i.e. scores of 3) instead of negative scores. Indeed, only three participants expressed little or no interest in this topic. Participants who provided scores of three or less were most likely to have an education level of high school or less.

In addition to being widespread and relatively strong, interest in this topic was multi-faceted. Participants collectively identified a variety of issues that interest them in this area. Topics of interest identified most frequently included the following:

- Ingredients in food (e.g. salt, sugar, cholesterol, trans-fats)
- Maintaining a balanced diet
- Impact/effect of certain foods on reducing likelihood of diseases
- Foods that are good/best sources of various vitamins/nutrients
- Vitamins and supplements.

Topics of interest identified less often, although by a few participants in most groups included:

- Genetically modified foods
- Food additives
- Food allergies

- Health implications/effects of processed foods vs. natural foods
- Best foods/diet for certain conditions (e.g. diabetes)
- Food preparation/best way to prepare foods
- Impact/effect of various elements in food (e.g. Omega 3, red dye, anti-oxydants)
- High-fibre foods
- Use of steroids in animals
- Herbal remedies.

Topics of interest identified infrequently, by no more than a few participants, included:

- Possible over-compensation/over-reliance on vitamins/supplements
- Foods that neutralize each other or should not be served with each other
- Celiac disease/gluten free diet
- Unpasteurized juice
- Multigrain foods.

Some participants explained that their interest in the topics or issues they identified was often generated by something they had heard or read in the media. Examples included the possible link between hyperactivity and the use of red dye in foods, the health benefits of foods with Omega 3, and the use of steroids in animals.

Most Have Looked for Information Related to Personal Nutrition & Health

Most participants' interest in the link between personal nutrition and health has translated into searches for information in this area. Not surprisingly, participants typically looked for information related to the issues of interest to them listed above. Additional types of information sought included the following, though none was identified frequently:

- Healthy recipes/meals
- Possible effect of food/diet on attention deficit disorder and autism
- Best foods to consume during pregnancy
- Factors affecting digestion
- Foods to take/avoid with certain medications
- Proteins and carbohydrates
- Mercury levels in fish
- Sanitary conditions in food plants.

Information sought by participants was usually looked for, at least initially, through the Internet and primarily by using a search engine. The main exception was ingredients contained in foods, which participants usually sought simply by reading product labels. In many groups, virtually all of the participants said that they regularly read ingredient labels before buying food products they are not familiar with.

Other sources of information identified relatively frequently included health food stores, family physicians/doctors, and cook books. Sources identified infrequently included

pharmacies, the Mayo clinic, Health Canada, the World Health Organization, nutritionists, homeopaths, herbalists, and dieticians.

Virtually all participants said they have sought information during the past two years or so when the focus was broadened beyond the search for information about personal nutrition and health to health-related information in general. Participants were asked about this in the questionnaire they were asked to complete prior to the group discussion. Information sought often centered around specific conditions/illnesses. This included causes, symptoms, treatment, and preventative measures. Many also sought information on exercise programs, how to maintain a healthy lifestyle in general, and information related to a specific health issue they heard or read about in the media.

Most Take Measures to Improve Health Through Diet/Personal Nutrition

In addition to looking for information, nearly all participants indicated that they have taken action to improve the health of themselves and/or their family through personal nutrition or diet. The most frequently-identified measures taken include taking vitamins and/or supplements, ensuring a balanced diet, trying to exercise, and looking for foods with or without certain ingredients (e.g. multigrain bread, high-fibre foods, whole wheat pasta, low sugar content).

Participants also routinely identified activities such as reading product labels, avoiding certain foods (e.g. junk food), planning meals, buying nutritional drinks/juices, and buying specific types of meat (e.g. lean meat, grain fed chicken). Actions identified less often include looking for healthy recipes on the Internet, reading food guides, consulting dieticians, nutritionists, homeopaths, or naturopaths, and using alternative medicine. Despite the listing of these types of health care providers, relatively few individuals in the focus groups have gone to dieticians, nutritionists, homeopaths, or naturopaths.

The importance of taking vitamins and looking for foods with or without certain ingredients was confirmed through the questionnaire participants were asked to complete prior to the group discussion. Asked how regularly they use natural health products, including things like vitamins and minerals, but also herbal products, homeopathic medicines, traditional medicines, and things of this nature, well over half indicated that they do this regularly, with most of the rest doing so occasionally. As well, approximately two-thirds said they buy health supplements like vitamins and minerals, and buy foods with specific health properties because these are supposed to be beneficial.

Most Claim at Least Some Knowledge of Link Between Nutrition & Health

In the same pre-focus-group questionnaire, participants were asked how well informed they think they are about the link between nutrition and health. Using a 5-point scale (1 = not knowledgeable at all; 5 = very knowledgeable), approximately half the participants provided scores at the mid-point of the scale, suggesting at least some, albeit limited knowledge. Nearly all the rest considered themselves at least moderately knowledgeable (scores of 4 or 5), though relatively few considered themselves very knowledgeable. By contrast, very few considered themselves to have little or no knowledge in this area. There were no evident differences by education in responses to this question.

A certain amount of caution should be exercised in interpreting these results. Some participants may have exaggerated their level of knowledge in this area so as not to appear to be ignorant in an area they clearly regard as important and which concerns the well being of themselves and their families. Moreover, in this type of questions in general, respondents tend to inflate their levels of knowledge or understanding.

Consensus That Genetics Affects Health, But No Agreement on Extent of Influence

As noted earlier, genetics was generally acknowledged as being an important factor when participants were asked in an open-ended manner about the most important factors related to personal health. When asked specifically about the impact of a person's genetic make-up on their health, there was a consensus that it has an impact, although there was no agreement on the extent of influence. While most participants were of the opinion that genetics can have a significant impact, no one felt that it predetermines a certain outcome. Indeed, many suggested that environmental or historical factors can be as influential as genetic ones in affecting one's health, including dietary habits passed on from generation to generation.

General & Limited Understanding of *How* Genetic Make-up Affects Health

When it came to the *way* in which someone's genetic make-up affects their health or the nature of the link between genetics and health, participants were able to provide only limited and general feedback. Most referred to a 'predisposition' or used synonyms such as 'susceptibility', 'tendency', and 'inclination' to suggest that our genetic background marks us or conditions us in a certain way that can have an impact on our health. Some referred to genetic defects or mutations, or strong vs. weak genes, to explain how someone's genetic make-up affects their health, but they were unable to provide any more detail. Finally, some said they did not know how someone's genetic make-up affects their health even though they assume that it does.

In the questionnaire they were asked to complete prior to the group discussion, participants were asked about the meaning of the term 'predisposed'. Specifically, they were asked what it would mean to them if they were told they were 'predisposed' to getting a certain disease. Many responded by explaining how they would react to being given this information instead of explaining what the expression 'predisposed' means to them. However, in explaining their reaction, it was evident that they understood what the expression meant. For example, most said they would inquire about preventative measures that could help reduce the likelihood of contracting the disease. Others said that if they were told they were predisposed to getting a certain disease they would be worried that they would actually contract it.

Among those who did explain what the term meant to them, most focused on the *increased likelihood* of getting the disease in question. Representative responses in this regard included the following:

- *There's a chance I will get this disease.*
- *There's a greater likelihood of my getting this disease.*

- *There's a higher than normal chance I'll get this disease*.
- *I'm more likely than others to get this disease*.
- *J'ai plus de chance de contracter cette maladie*.

A few participants interpreted the meaning of 'predisposition' more strongly. They understood this to mean that they would, at some point in time, get the disease. In other words, it was *definite* as opposed to *possible* that they would get the disease.

Some participants focused on the *reasons* or *causes* as opposed to the likelihood of contracting the disease in their understanding of the term. Representative responses in this regard included:

- *There's a genetic basis for the disease.*
- *This disease is in my gene pool.*
- *I'm a carrier of the gene for this disease.*
- *The sickness is in the family.*
- *There's a family history of the disease.*
- *Certain factors favour the apparition of this disease*.
- *I'm more likely to get this disease because of certain hereditary or environmental factors that affect me*.
- *La maladie est héréditaire.*

A few participants thought that being predisposed meant that they had come into contact with someone who has the disease in question and were infected, while a few others thought it meant that they had the symptoms of the disease in question. Finally, a few indicated that they did not know what it would mean if they were told they were *predisposed* to getting a certain disease. Nearly all those who thought that being predisposed meant that they had come into contact with someone infected, had the symptoms of a disease, or did not know what it would mean had a high school education or less.

Most Link Genetic Make-up With Family History

As noted already, participants were generally unable to explain just *how* someone's genetic make-up affects their health. Moreover, when participants did discuss the way or how genetics affects health they tended to talk of it in terms of family history. Put differently, family history seems to provide the meaningful context or conceptual framework for understanding and discussing how one's genetic make-up, or the genetic make-up of family members, affects health.

Most participants thought they had a relatively good understanding of how genetics affects their health or the health of family members, and they did in the sense that they know, to varying degrees, about their family medical history. Many added that they talk about this

or are asked about it with some regularity by their family physician. Participants were also readily able to provide examples of how members of their family are predisposed to various conditions, such as weight gain, cancer, heart disease, arthritis, osteoporosis, diabetes, lactose intolerance, and high blood pressure.

This tendency to link genetic make-up to family history was evident to a certain extent through responses to a question in the questionnaire participants were asked to complete prior to the group discussion. Specifically, they were asked to write one or two sentences to explain what the expression 'a person's genetic make-up' means to them. In response, over half of them emphasized or alluded to the idea of *inheritance* in some form or another. The largest proportion, over one-third, suggested that a person's genetic make-up refers to what we inherit, what is hereditary, or what is passed on to us from our parents and ancestors. Smaller numbers went further down this path, suggesting that this refers to family background, family history, or predispositions.

By contrast, relatively few participants linked this expression to the basic elements of our being. Those who did provided the following explanations:

- *It means our DNA.*
- *Notre ADN.*
- *Most basic elements making us what we are.*
- *Biological determinants of who we are.*
- *Cells that make us what we are.*
- *Blood type.*
- *How genes affect us.*
- *Basic building blocks of who we are.*

In short, participants were more likely to understand genetics in historical and familial rather than biological terms. Put another way, when participants think about genetics, they are more likely to interpret it as genetic *background* than genetic *make-up* (though the latter is actually what they were asked about).

General Sense That Genetics Influences How Body Responds to Food

All participants were of the opinion that genetic make-up influences how their body and/or that of family members respond to food, though some added that they think environmental factors are as important or more important in this regard. This impression that genetic make-up influences how someone's body responds to food was usually based on personal experience, and participants were readily able to provide examples of what they meant. The tendency, however, was to focus on ways in which the body responds negatively to food. Examples provided included allergic reactions to certain foods, hyperactivity in reaction to sugar, weight gain, lactose intolerance, the effects of alcohol, celiac disease, reactions to caffeine, gas/flatulence, and problems with acid. A few participants said that their mood tends to be affected by the foods they eat – that is, they tend to feel more energetic or more lethargic based on what they eat.

Beyond providing examples, however, participants were unable to say how their genetic make-up, or that of family members, influences how their body responds to food except

through general references to metabolic rates and the speed with which the body processes foods. Moreover, the latter explanation tended to be used only to explain weight gain. In short, while participants evidently react to certain foods, there was no clear sense or understanding of how this was linked to their genetic make-up. This link was assumed rather than explained.

Widespread But General Interest in How Body Responds to Food

While there was widespread interest in knowing more about how one's genetic make-up influences how one's body responds to food, this interest tended to be general rather than specific. Most participants, for example, were unable to identify anything specific they wanted to know about. That said, many did identify specific things they would like to know. This included getting a better understanding of the impact of genetic vs. environmental factors in relation to health, identifying an ideal diet based on one's genetic make-up, identifying possible solutions to certain medical conditions, and engaging in preventative measures to deal with illnesses that are prevalent in their families.

AWARENESS & INITIAL PERCEPTIONS OF NUTRIGENOMICS

This section reports on participant awareness and understanding of nutrigenomics.

Nutrigenomics Previously Unknown to Virtually All Participants

Prior to their participation in the study, all but a small handful of participants said they had never heard the term 'nutrigenomics'. In other words, the term was previously unknown to virtually everyone. Moreover, among the few who said they had heard the term before, only a very few were certain that they had heard about it. Most of those who recall hearing about it think they came across it on the Internet, while one participant recalls attending a conference at which it was discussed.

Nutrigenomics Most Likely to be Viewed as 'Science of Nutrition'

Lack of familiarity with the expression nutrigenomics was confirmed through the questionnaire participants were asked to complete prior to the group discussion. Participants were asked to write one or two sentences to explain what the term 'nutrigenomics' means to them. In response, the largest proportion, approximately one-third, were unable to provide any meaningful feedback. They wrote nothing at all, indicated that the term meant nothing to them, or said they did not know what it meant.

Among those who did try to define or interpret the term, most did not capture its correct or proper meaning. It was most likely to be described as the study or science of nutrition, nutrients, or food in general. Some participants described it as the 'economics' or 'cost' of nutrition. Other interpretations were offered by no more than a few participants and included:

- *Person who deals with nutrition.*
- *Good foods.*
- *Nutritional value of certain foods.*
- *Nutrition engineering.*
- *Genetically modified foods.*
- *Natural foods.*
- *Nutrients necessary to health.*
- *Related to what we eat.*
- *The study of food and how it affects the body.*

Only a relatively small number of participants provided interpretations that were correct or touched on the actual subject matter of nutrigenomics. These participants were most likely to describe it generally as the study of nutrition and genetics. Other related interpretations were offered by individuals or no more than a couple of participants and included:

- *How certain nutrients affect our genes.*
- *How nutrition interacts with genetics to affect health.*
- *How nutrition plays a role in gene structure.*
- *How genes influence nutrition.*
- *Nutrition based on genetic background.*

- *How genes affect what we eat and drink.*

Some of those who provided correct interpretations or touched on the subject matter of nutrigenomics indicated in the discussion that followed that they were guessing at the meaning of the expression.

Focus of 'Personal Nutrition' on Personalized Plan

Before the group discussion, participants were also asked to write one or two sentences to explain what the term 'personalized nutrition' meant to them. Nearly all of them were able to provide an interpretation of this term and the core element of most interpretations was some kind of nutritional plan or regime adapted to or designed for an individual. The largest proportion of participants, approximately one-third, described it as a nutrition plan adapted to an individual's health needs. A smaller but still substantial number described it as a personalized diet. Other definitions or descriptions focusing on the same theme and identified by small numbers included:

- *A nutrition plan created for someone by a nutritionist or dietician.*
- *What is good for me personally.*
- *A nutrition plan based on an individual's characteristics, including age, sex, weight.*

Some participants focused on the theme of healthy eating without emphasizing the personalized dimension. This included the following interpretations:

- *Eating with a view to improving health.*
- *The need to eat healthily.*
- *Making choice regarding healthy foods.*

Only a relatively small number of participants provided interpretations that did <u>not</u> include a prescriptive dimension. These individuals focused exclusively on the idiosyncratic element in the expression. For example, some equated personalized nutrition with an individual's eating habits, while a few others described it as the way in which food affects us individually.

Participants React Mainly to Personal/Idiosyncratic Dimension of Nutrigenomics

After being asked about their prior awareness and understanding of nutrigenomics, participants were read the following definition of it:

> Nutrigenomics is about how our genetic makeup affects how we respond to what we eat and drink, and how we can change our diet to help promote health and reduce our genetic risks of disease. For instance, because of differences in their genetic makeup, some people respond differently to caffeine. Recent clinical research has identified a range of health effects associated with the consumption of caffeine. For example, three people that drink two cups of coffee every day can experience three distinct health effects because of their genetic make-up:
>
> - One person may not be affected at all
> - Another person may be at greater risk for heart disease, and
> - The third person may reduce their risk of heart disease.

Participants were then asked what this description makes them think of. Generally speaking, their reactions focused on the perceived personal or idiosyncratic dimension of nutrigenomics. In other words, the idea that no two people are the same or that we are all different is what resonated most.

For example, many participants responded positively or optimistically to this definition, adding that this is important information to know. This was based mainly on the assumption that one could tailor one's diet based on one's specific genetic make-up so as to act proactively to reduce the genetic risks of disease or deal with a specific condition one might already have (e.g. diabetes). On the other hand, some found the information about nutrigenomics unsettling because it seemed to imply that since we all react differently to food and drink, there is no way to speak generally about good food and bad food. In the words of one participant: "Does this mean that we should throw the food guide out the window?". Another felt that people might become slaves to a certain diet because they think it is tailor-made for them based on their specific genetic make-up.

In short, both positive and less-than-positive reactions were usually rooted in the perceived personal or idiosyncratic dimension of nutrigenomics. In the words of another participant: "It seems to usher out the 'one size fits all approach' to nutrition".

Other reactions to the definition included the following, each of which was articulated by at least a few participants in many groups:

- Genetics is clearly an important factor, but so is the environment and lifestyle.
- Nutrigenomics seems to be the next frontier of medicine.
- This could mean that diet will replace pills/medication in the treatment of certain conditions.
- How do they actually know how our genetic makeup affects how we respond to what we eat and drink? Is there a test?
- How can they be sure about the effects of caffeine (i.e. how do they know that what they are measuring is a reaction to caffeine?).

Responses to Food Vary – Most Frequent Interpretation of Nutrigenomics Definition

The perceived personal or idiosyncratic dimension of nutrigenomics was also evident when participants explained what it is in their own words. Most provided some variation on the notion that we all react differently to food based on our genetic make-up. It is worth adding that relatively few participants made any link between genetic make-up and group identities (i.e. races, ethnic groups, gender) when explaining nutrigenomics in their own words. The tendency was to link genetic make-up to the unique individual as opposed to groups.

Some participants described nutrigenomics as the way in which our genetic makeup affects our response to food, without adding that changing diet can reduce the genetic risk of disease. Some others, however, emphasized both dimensions.

Internet, Health Professionals – First Steps in Seeking Info on Genetics & Health

Many participants hesitated or remained silent for a short time when asked where they would go for information about how their unique genetic make-up affects their personal nutrition and health. In other words, it was not self-evident to many where they would go for such information, and some indicated that they did not know where they would go.

That said, most participants identified one or both of the following possible sources of information: the Internet and health care professionals. Most of those who identified the Internet specified that they would use a search engine, using combinations of terms such as 'nutrition', 'health' and 'genetics' or even 'nutrigenomics' now that they were familiar with the expression. Some said they would consult specific websites, including Health Canada, the World Health Organization, and the Mayo Clinic.

The health care professionals participants said they would consult routinely included the following, although the first five in the list were identified more often:

- Geneticists
- Family physicians
- Pharmacists
- Dieticians
- Nutritionists
- Homeopaths
- Herbalists
- Naturopaths.

While identified less often, many participants said they would consult family members, especially older ones, to ask about their family's medical history. Many participants who identified the Internet, health care professionals, or family members, specified that this would be their first or preliminary move if they were looking for such information. In the case of health care professionals, some added that if these individuals could not provide the information themselves they might be able to point one in the right direction. There was a sense among many participants, perhaps most, that health care providers in general, and doctors in particular, might not know very much about this subject given how new it is.

Sources identified less often, but by a few participants in most if not all groups, included universities, libraries, health food stores, and medical journals.

No Awareness of Companies Offering Nutrigenomics Services

Lack of awareness of nutrigenomics was also underscored by the fact that none of the participants have seen or heard about any 'nutrigenomic' services available to Canadians, know of any companies currently offering services in this area, or have heard of any tests being marketed on radio, TV or in print trying to get people to have their personal genetic make-up mapped out.

REVIEW OF MEDIA ARTICLE AND MOCK-UP OF NUTRIGENOMICS WEBSITE

This section reports on participants' impressions of nutrigenomics based on reading a media article on the topic and reviewing a mock-up of a website modelled on those of firms that offer nutrigenomic services.

Media Article

The article participants were asked to read appeared in the *Prince George Citizen*. It provided basic information about nutrigenomics using as background the story of a registered dietician who had her DNA tested by a company giving personalized nutrition advice based on genetic testing.

Media Article on Nutrigenomics Primarily Sparks Interest, Curiosity & Surprise

The media article elicited a variety of reactions from participants, and while reactions differed, no one was left indifferent by what they read. Most participants reacted with interest, curiosity, and often surprise to what they read, with many noting that this information was completely new to them. Many were clearly positive about what they had read, describing it as good or even great news, with some adding that they would like to get a similar test done on themselves.

Those who reacted positively or with interest usually said that the article made them think about advances in medicine and health care, and that this technique seemed to reduce the guesswork in the field. Related to this, many said that nutrigenomics seemed to represent an approach to health care that was personalized or adapted to the individual.

While no one reacted negatively to the article in general, a number of participants did react with scepticism or at least caution to what they read. Some detected a commercial or marketing aspect to nutrigenomics that made them uncomfortable or uneasy. While this was not the main thrust of the article, it is what resonated most with some participants. To some others, the idea of basing dietary advice on genetic testing was taking a preoccupation with health to an extreme. Related to this, some wondered if it was really necessary to take a test to determine what constitutes a healthy diet. The price of the test identified in the article – under $100 – made some think about how accessible this was, and were inclined to check it out, while it made others think that it could not be very useful or powerful as a tool for a price that is that low.

Finally, some participants described what they read as disturbing or disquieting, explaining that they would worry about what might be found or detected through such testing.

Variety of Issues Related to Nutrigenomics Stand-Out or Catch Attention

A number of specific things in the article stood out or caught the attention of participants. Moreover, the same types of things were identified in all groups.

- *Study/science of nutrigenomics is still in its infancy*: Most participants said this attracted their attention because it was mentioned or alluded to more than once in

the article and because it suggests that there is still uncertainty in this field and that more needs to be learned.

- *Replacing guesswork with accurate, personal, DNA-based dietary advice*: This attracted the attention of many participants, but for different reasons. Most said it drew their attention because, if it is true, it represents a major advance in health care. However, some said it attracted their attention because they do not think that decisions about what we should and shouldn't eat are simply guesswork.
- *Current testing focuses on 19 genes*: This attracted the attention of many because it struck participants as a small number. While no one knew the exact number of human genes, or even the approximate magnitude, participants were certain that it was much higher than 19. Some said that this grabbed their attention because it made them wonder about the accuracy of testing (i.e. if they only test 19 genes, how reliable are the results?)
- *Diet can influence the impact of genes*: This information stood out because it was new to many. Participants whose attention was drawn to this said they did not know that the impact of genes could be modified by what people eat.
- *Tests are available by mail order and on the Internet*: This surprised many participants who assumed that the testing would take place in a clinic.
- *Companies located in United States*: Many were curious as to why this type of testing only seems to be available in the United States.
- *Cost of DNA test kit*: Many said the cost of the test kit caught their attention. Some said it attracted their attention because it did not seem that expensive (as noted above), while others said it attracted their attention because it introduced a marketing element to the whole enterprise that made them a bit skeptical.
- *Every time we go to the supermarket we're using educated guesses about what we should eat and what we shouldn't eat*: Some participants were struck by this quotation because it coincided with their own experience when shopping for food.
- *Sciona Inc*.: The name of the company or one of the companies providing such testing caught the attention of some participants because it provided a concrete referential point.

Finally, a few participants in most groups said their attention was drawn to the fact that a registered dietician did not know that she had a specific vitamin deficiency. This struck them as odd because they assumed that a dietician would know this. It also spoke to the utility of the nutrigenomic tests since if there is information that a dietician can learn from the tests, there must be real, meaningful learning available to the rest of us.

Article Clarifies Role of Genes for Most

While the article did not significantly alter participants' thinking regarding the role genes play in their health and making them who they are, most said that it did provide perspective, clarify things, or give them more to think about. As reported earlier, most participants felt that genetics can have a significant impact and the article tended to confirm the importance of genes. However, it also clarified the extent to which diet can

influence their impact. As noted, the idea that the impact of genes can be modified by what we eat was new to many, and this appeared to be one of the main contributions of the article to participants' thinking regarding the role genes play in their health. For some, however, the idea that diet can influence the impact of genes confirmed their impression about the influence of lifestyle factors on one's health.

Participants Readily Identify Potential Benefits & Harms of Nutrigenomic Testing

Although the topic of nutrigenomics was new to participants and the media article they read was their first exposure or introduction to the topic, they had no difficulty identifying what they perceived to be potential benefits and risks associated with nutrigenomic testing like that described in the article. Moreover, participants in each group tended to identify the same benefits and drawbacks, and most identified both perceived benefits and perceived risks or drawbacks. Indeed, very few participants felt that there were only benefits or drawbacks to nutrigenomic testing.

Tailored, Focused Approach to Health – Main Perceived Benefit of Nutrigenomics

All of the perceived benefits associated with nutrigenomics testing had to do with the possibility of improving one's health, and in this sense they were all related to each other. Leading the way among perceived benefits was the possibility of a tailored approach to health care that would be adapted to the specific needs or unique make-up of individuals. Related to this was the idea of eliminating or reducing guesswork when it comes to prescribing a diet for individuals.

Other perceived benefits routinely identified included the following:

- *Early diagnosis/detection*: The ability to detect or diagnose a potential condition before it develops into an actual one, especially in children, was identified as a benefit of nutrigenomics. Related to this, some added that this could benefit other family members, especially children, who might be prone to the same condition. In other words, if someone learns something through nutrigenomics testing, they could inform the members of their biological family.
- *Preventative treatment*: Participants routinely identified preventative treatment as a benefit of nutrigenomics (i.e. acting proactively instead of retroactively to reduce the likelihood of a condition developing to which one is genetically prone).
- *Understanding one's genetic make-u*p: Simply knowing about or understanding the link between one's genes and one's health was considered a benefit of nutrigenomics. In other words, 'knowledge is power' and knowing is always better than not knowing.
- *Improved diet*: Changing one's diet in order to improve one's health was identified by many as a benefit associated with nutrigenomics. Even if test results did nothing more than lead people to improve their diet, this would be beneficial.
- *Increased concern with health*: Many also felt that nutrigenomics might encourage people to be more interested in their health in general or take it more seriously.

Benefits mentioned less often but still identified in many groups included the possibility of reducing health care costs (for society as a whole) and the possibility for adopted children who do not know their natural parents to learn if they have genetic or hereditary conditions that could potentially affect them in the future.

Possible Misdiagnosis –Main Perceived Risk or Harm of Nutrigenomics

The potential risk or harm associated with nutrigenomics identified most often was the possibility of a misdiagnosis or a mix-up of test results leading to a faulty or mistaken prescription that could adversely affect someone.

A number of other perceived risks or drawbacks were regularly identified, including:

- *Seeing nutrigenomics as a magic bullet*: It was suggested that people could become over-reliant or overly optimistic about nutrigenomics, regarding it as a cure-all or the answer to all their health problems. A related drawback identified by some was the potential for ignoring more traditional approaches to health care, including regular check-ups, on the assumption that nutrigenomics is the solution to their health problems.
- *Over-compensation*: Many felt that people might become rigidly fixated on a program or diet prescribed through nutrigenomics and based on test results showing that they are deficient in certain vitamins or nutrients. The concern was that they might overcompensate for this deficiency in their diet, the result being deficiencies in other nutrients that they also need.
- *Fraud*: The possibility that companies might be providing phony test results, not even carrying out tests, or prescribing supplements that are not needed were concerns voiced by many participants. They did note, however, that this was a possibility and not something they considered likely.
- *Privacy of information*: Many participants expressed concerns related to privacy of information, specifically what might or could be done with the results and who might have access to them. In particular, some wondered whether insurance companies might be able to gain access to this information and deny coverage to someone based on their test results.
- *Inconclusive results*: It was suggested that results of testing might not be clear or conclusive and that this ambiguity might foster unnecessary worry or concern among individuals.
- *Possible waste of time and money*: Since they only test for 19 genes and most of the research targets heart disease and cancer, it seems possible that one might have a condition that testing will not discover.
- *Worries/preoccupations*: More generally, many participants felt that nutrigenomics testing could raise anxiety levels and cause worries among people getting tested and that this could even have a negative impact on their health. In addition to inconclusive results, such anxiety could be caused by delays in getting results, over-interpretation of results (e.g. interpreting a detected predisposition towards a certain condition as actually having that condition), or the identification of conditions that one can do nothing about and that might cause future harm (e.g.

people might learn about bad things that could happen in future, but about which they can do nothing, thus increasing stress levels).

Perceived Benefits of Testing Outweigh Risks, Many Uncertain About Both

Overall, based on the information participants found in the article they read, most felt that the potential benefits of nutrigenomics testing outweigh the possible risks or drawbacks. That said, many were uncertain or said they did not know, and some felt that the risks outweighed the benefits because the science is still in its infancy and there seems to be much that is still not known.

Article Motivates Participants to Want More Information About Nutrigenomics

Nearly all participants said that reading the article encourages or motivates them to look for more information about nutrigenomics. Curiosity, interest, and unanswered or remaining questions (see below) were routinely offered as reasons to explain why. Relatively few participants said they were not motivated to want more information. Most of these said they were not interested in the topic but a few said that the topic seems too complicated or difficult to understand.

Internet & Health Care Professionals – Main Sources of Information

When asked where they would go for more information about nutrigenomics, participants tended to identify the same sources they identified when asked where they would go for information about how their genetic make-up affects their personal nutrition and health. The Internet and health care professionals were the two most-frequently-identified sources. Health Canada, public health authorities, government in general, universities, libraries, and medical journals were also regularly identified.

Many also said they would consult companies offering these services, such as Sciona, for more information. Moreover, some specified that this would be their first (though not their only) source of information. While some did not regard the companies themselves as the best sources for reliable information about genetics and nutrition, since it was assumed they have a vested interest in selling their products and services, others explained that it was only natural to seek information about nutrigenomics from those offering the services.

Many Outstanding Questions About Nutrigenomics Remain

As noted, remaining or unanswered questions was one of the reasons motivating participants to want more information about nutrigenomics. When asked explicitly if they had any questions about nutrigenomics after reading the article or if there was anything else they would you like to know about it, nearly everyone answered in the affirmative. Moreover, participants collectively identified a range of questions they had, most of which came up repeatedly (i.e. in every/most groups). These questions included the following:

- Is there proof/evidence about the claims made by nutrigenomics (e.g. success rates, statistics)?
- Are the tests certified in any way?
- How accurate are the results since only 19 genes are tested?

- What/how many conditions can they actually test for?
- How reliable are the home tests that form the basis for the evaluation?
- Who actually does the testing/where is it done (e.g. laboratories)?
- Is there or is there going to be any public oversight/regulation of nutrigenomics?
- How is confidentiality/privacy of information maintained or assured?
- What are the costs of testing and will these be covered under public health care?
- What is done with the samples that are sent once testing is complete (e.g. are they thrown out/disposed of?)
- Are there any age limits/restrictions to testing?
- Is nutrigenomics testing taking place in Canada?
- How long does it take to get test results?
- Is retesting at a later date necessary? If not, how does one know if a prescribed treatment is effective?
- Is there any way of verifying that tests are actually conducted?
- How common is testing (i.e. how many people have taken such tests)?

Most Not Ready to Take Test Based on Article, But Many Would Consider it

While nearly all participants said that reading the article encourages or motivates them to look for more information about nutrigenomics, most are not yet ready to consider getting a genetic test done for themselves or someone else in their family. The most frequently-given explanation was the desire for more information, with some re-iterating the questions they would like answered. Related to this, some said that this is a new field, still in development, and they would feel a little like guinea pigs if they were tested at this point in time. Other reasons included lack of interest and/or a desire to rely on more traditional/ established methods to improve health, such as exercise and food guides, and apprehension about what a nutrigenomics test might reveal.

That said, some participants said they were ready to consider a test. Most of these explained that there is nothing to lose from simply being tested (except for the expense) and that they would be curious about the results. Some that they would like to know if they are predisposed to any illnesses or conditions in order to be able take preventative measures, while others said they would like to know if they have any vitamin deficiencies, and if so, how to improve their diet to address this.

<u>Website</u>

In order to give participants an idea of the types of nutrigenomics products and services available online, they were shown a mock-up of a website modelled on those of firms that offer nutrigenomic services. A projector was used to give them an overview of the site and to draw their attention to certain features. Following this, they were given handouts of the same pages they viewed on screen so that they could read and review them on their own.

Reaction to Website Usually Critical Due Mainly to Perceived Marketing Dimension

Once participants had reviewed the web pages on screen and in hard copy format, they were asked for their initial reaction to the website information. Most participants became more critical or sceptical of nutrigenomics after reviewing the web pages. Indeed, this tendency manifested itself in all groups. While some participants' opinion of nutrigenomics remained relatively positive after reviewing the web pages, no one's impression *improved* as a result of reviewing them.

Critical reaction to the website was based primarily on what was described as its marketing or commercial aspect. There was a widespread sense that companies selling nutrigenomics products and services might be more interested in a money-making venture than in promoting health, or that the latter could be used as a vehicle to achieve the former. Many focused specifically on the marketing of nutritional supplements. Some expressed surprise about this, saying they would have expected the focus to be on diet modification as opposed to recommending supplements. Others saw this as a clear conflict of interest, suggesting that the company carrying out the genetic tests should not also be involved in marketing supplements.

In addition to the marketing or commercial aspect, a number of participants reacted negatively to the Internet-based dimension of nutrigenomics. However, since participants were asked about this specifically, it will be dealt with below.

Some Not Disturbed by Commercial/Marketing Dimension of Website

As noted above, some participants' views of nutrigenomics remained positive as a result of reviewing the web pages. These participants expressed interest in the products and services offered and were not disturbed by the commercial aspect of the website. In response to criticism of the website, some of these participants acknowledged the commercial aspect but added that there is nothing surprising or particularly disturbing about this. They suggested that while such companies are clearly interested in making money, this is not incompatible with the provision of quality products and services.

Marketing of Supplements – Main New Information Provided by Website

The fact that nutrigenomics companies offer a range of nutritional supplements and that this seems to be an important part of their activities was most often identified as new information learned through the website. Some re-iterated that they would have expected more of a focus on dietary changes. The Internet-based nature of nutrigenomics (i.e. the fact that interaction between clients and company takes place over the Internet) was also identified by many as new information. Other information identified as new by some participants included the variety of nutrigenomics tests to choose from and the counseling services.

Most Express Concern About Purchase of Tests Over Internet

As noted above, a number of participants reacted negatively to the Internet-based dimension of nutrigenomics testing. Asked specifically what they think about consumers buying tests like these over the Internet, most expressed concern or said they did not like it.

Many volunteered that they would prefer to be tested in an actual physical establishment like a clinic or a laboratory, and some said they took it for granted that this would be the case. Some also volunteered that they would not take a nutrigenomics test unless it was done in a clinic or laboratory or unless their physician was involved in some way.

Underlying critical reaction to buying tests like these over the Internet, as well as mailing-in one's sample, was a widespread impression that this is too important an issue to be handled in this way. Most participants made it clear that when it comes to health-related issues like this one, they want more dimensions or factors in place to frame and circumscribe the process. Specifically, participants drew attention to the following:

- *Personal dimension*: Many said they do not like the impersonal aspect of buying these services over the Internet. It was suggested that the process involves too much anonymity, and that even the one-on-one counseling probably takes place over the phone or by email instead of in-person. There was a widespread desire to deal with people in person, especially the people carrying out the testing, which implies the ability to be tested in an establishment like a clinic or laboratory.
- *Regulation/oversight*: Many participants said that there seems to be an absence of oversight in a process that takes place entirely over the Internet. These participants want the involvement of intermediaries or third parties to ensure some form of regulation so that the process is not exclusively between them and the company. Examples of possible intermediaries included Health Canada and the Canadian Medical Association (CMA).
- *Involvement of family physician*: Many also said that they would like their family physician to have some direct involvement in the process. However, they suggested that if the process takes place over the Internet and by mailing in one's sample, their physician is excluded entirely from the process.
- *Follow-up/recourse*: Some participants said that they would want to be tested in a physical location because this makes it easier for them should they need to follow-up with someone or ask questions. It was suggested that the Internet is not the best medium for this and a few added that the lack of an actual physical location makes them nervous. Other perceived benefits of having nutrigenomics testing done in a local building/facility is the credibility that comes with a physical presence (compared to a virtual presence, such as through online), convenience of access, greater confidence that the tests would actually be performed and that the results would not be mixed up with others, perceived greater likelihood that the process would be regulated, having the ability to see the lab where the tests would be performed and related quality control measures, and having a place to go to complain if one was not satisfied with the results.

Critics of Website Able to Dissociate Nutrigenomics From Commercial Aspect

Despite criticism of the commercial aspect of the website and the Internet-based nature of the activities, critics were able to dissociate the value of nutrigenomic testing from the marketing dimensions or aspects they did not like. In other words, their criticism did not lead them to call into question the value of nutrigenomics per se or its possible contribution to personalized health care.

Expectation That Test Results Would be Intelligible & Prescriptive

Generally speaking, participants expect that these types of tests would be useful to them and that the results would be conveyed in an intelligible and prescriptive manner. By 'intelligible', participants made it clear that they would expect results to be provided in layperson's terms. It was suggested that while there might be scientific terms included, the results would not include too much technical jargon and would be designed to convey meaning to laypeople. Related to this, a few said they would expect a glossary of terms to accompany their results and which they could consult if they did not understand the meaning a certain term or expression. By 'prescriptive', participants meant that the results would include clear advice or recommendations on what they need to do in terms of diet based on test results.

More specifically, participants routinely identified both of the following as what they would expect in terms of results:

- A description of deficiencies and/or predispositions based on test results (e.g. 'test results reveal that you have/are predisposed to…').
- Clear dietary advice/instructions on how to address deficiencies/predispositions, including types of foods to eat and in what amounts (e.g. 'In order to address this you should…').

Expectations identified less often but by a few participants in many groups included:

- An explanation of the possible reason for a deficiency.
- Information on how long it might take to redress a deficiency by following the prescribed course of action.
- Possible side-effects of addressing a deficiency and how to deal with them.
- Information on where to find types of foods recommended should these not be commonly available (i.e. types of stores).
- An emphasis on dietary advice as opposed to recommendations to use/purchase supplements.

Nearly All Desire More Information Before Considering Test

Based on everything they had learned about nutrigenomics up until this point, participants were asked how interested they would be in considering nutrigenomic testing for them or their family by placing themselves in one of the following groups:

- Ready to consider getting a nutrigenomic test
- Need to know more before they considering test
- Would avoid getting nutrigenomic test regardless

In response, most participants, a majority in all groups, indicated that they would need to know more before they considered testing. Moreover, some of those who had indicated earlier that they would be ready to consider a test changed their mind after reviewing the

web pages. They explained that based on their review of the website, they would want certain questions answered first (see below).

Most of those remaining said they would be ready to consider getting a nutrigenomic test (only a few said they would avoid getting a nutrigenomic test regardless). Reasons given for considering getting a test or not were the same ones given when participants were asked this question after reading the media article.

Review of Website Generates Additional Questions

In addition to the outstanding questions participants had about nutrigenomics as a result of reading the media article, the following additional ones were generated as a result of reviewing the web pages. Not surprisingly, most are questions about the companies themselves and their products and services. Many said they would like more information in general about these companies and the products they offer.

More specific questions included the following:

- How do people decide which test kit to order/which one is best for them?
- What do the test result reports look like (e.g. what do they include, how detailed are they)?
- What are the qualifications of their nutritional and genetic scientists?
- What are the standards used to certify nutrigenomics tests?
- Who are the companies' investors?
- Where do the testimonials come from?
- Are the nutritional supplements provided natural or not?

Based on their review of the web pages, many also wanted to know what the Government of Canada and/or Health Canada have to say about nutrigenomics. Many also re-iterated the following question they asked after reading the media article: Is there or is there going to be any public oversight/regulation of nutrigenomics?

Increased Likelihood of Changing Diet as Result of Nutrigenomics Testing

Nearly all participants thought they would be more likely to change their dietary behaviour if they had nutrigenomic testing than if they were given dietary advice without any genetic information. Moreover, they all gave the same reason to explain why: the impression that recommendations would be scientifically-based and personalized as opposed to a general or 'one size fits all' approach. Many added, however, that while they would be more likely to change their dietary behaviour if they had nutrigenomic testing, they are not sure how long they would stick to the diet.

Most Assume Results Would be Relatively Easy to Interpret, But Still Uncertainty

Most participants assume that if they had genetic testing done by buying the service from a company over the Internet, it would be relatively easy to interpret the results. In explaining why, many said that it is simply in the company's best interest to do this, otherwise it would lose business or spend resources helping people understand the results. Many added, however, that this is just an assumption on their part and they have no real basis for

assuming this. Many others said they hoped this would be the case, but said they did not know. Finally, some thought the results might be hard to understand if they included technical jargon and scientific terms.

Most Would Consult Health Care Professionals for Help Interpreting Test Results

If they needed help understanding the results of their test, most said they would consult health care professionals, though many began by saying that they would go to the firm who did the testing for help first. Among the health care professionals identified, the ones identified most often included geneticists, pharmacists, dieticians, and nutritionists. While many said they would consult their family physicians, there was a sense that they might not be familiar enough with nutrigenomics to be helpful, and would not have the time to spend with them to go over the results in any detail.

REVIEW OF INFORMATION DOCUMENT ON NUTRIGENOMICS

This section presents participant reaction to a short information document on nutrigenomics prepared specifically for these focus groups. Participants were asked to read the document and circle anything that was unclear to them. They were also asked to put a 'plus sign' beside anything they reacted positively to, and a 'negative sign' besides anything they reacted negatively to, for whatever reason.

Overall Positive Reaction to Information Piece on Nutrigenomics

Overall reaction to the information document was positive and in some cases very positive. To the extent that there was criticism, it focused on specific details as opposed to the document in general.

Participants routinely pointed to the following aspects of the document to explain their positive impressions:

- *Good overview*: There was a virtual consensus among participants that the document provides a good overview of the topic and helps clarify the issues. Many said they felt more informed in general on the basis of this document.
- *Clarity*: There was widespread agreement that the document was clear and easy to understand. This was corroborated by the fact that virtually no words were circled by participants to indicate a lack of clarity. Terms that were circled were technical or scientific terms, including homocysteine and folic acid.
- *Balanced approach*: There was also widespread agreement that the document is fair and balanced because it includes different perspectives, describing both the 'pros and cons' of nutrigenomics based on what is known to date.
- *Identifies concerns raised by participants*: Many also liked the fact that the document raises or addresses issues or points they themselves raised, including the possibility that test results may not be black and white and that companies may market costly but unnecessary supplements.
- *Emphasis on new/developing character of nutrigenomics*: Many said they liked the fact that the document emphasizes that nutrigenomics is still in its infancy.

Positive Reaction Most Likely to be Elicited by Pros & Cons of Nutrigenomics

What was most likely to stand out and catch participants' attention in a positive sense was the section titled 'Nutrigenomics: Some Issues' which provides an overview of the pros and cons of nutrigenomics. Other aspects to which participants routinely reacted positively included the reference to nutrigenomics still being in its infancy, the future hope around nutrigenomics, and the examples of how food intake can affect health. Some reacted positively to the definition of nutrigenomics in the first paragraph and the identification of the three key questions asked by nutrigenomic researchers.

Negative Reaction Most Likely to be Elicited by Marketing Aspects

The content of the document elicited relatively little in terms of negative or critical reaction from participants, with the exception of the information related to possible marketing tactics. This included the possibility that some companies might overstate the benefits of test result, the possibility that Internet marketing of these tests could make predictions that are not accurate or unproven, and the marketing of costly but potentially unnecessary supplements. Some participants also reacted critically to the fact that test kits have not yet been tested or reviewed by government regulators.

Document Clarifies Nutrigenomics Without Really Changing Understanding

While the reading of this document did not change most participants' understanding of nutrigenomics that developed earlier in the group, it definitely clarified things and gave them additional information to ponder. In explaining why or how their understanding was clarified, participants tended to re-iterate the points they made when describing their overall positive reaction to the document. Some said that learning that results are rarely black and white helped clarify things for them, while some others said that the document helped them understand the link between genetic make-up and group identity. Until then, they explained that they tended to link genetic make-up primarily to the individual.

A few said that reading the document changed their understanding in that it made them either more positive or more critical of nutrigenomics. Reasons for being more positive or receptive included recognition that the science is still in its early stages, recognition that it could make a major contribution to health care, and a belief that public authorities will ultimately get involved to provide oversight and regulation. Reasons for being more critical focused on the potential for marketing unnecessary dietary supplements, as well as the fact that tests are not currently regulated by government.

Remaining/Outstanding Questions About Nutrigenomics

While the document helped clarify the topic of nutrigenomics, participants tended to have the same questions they had since the beginning of the discussion or similar ones. The key questions, however, after everything they looked at and read, included the following:

- Where/what is the proof that nutrigenomics works/is effective?
- Will the government get involved in regulating/overseeing nutrigenomics?
- Where does Health Canada stand on nutrigenomics?
- Will the medical community get involved in some way in nutrigenomics and/or will nutrigenomics become part of the health care system?

Perceived Benefits & Risks Tend to Remain Constant Over Course of Discussion

Like their questions, participants' perceptions of the benefits and risks of nutrigenomics over the course of the group discussion remained relatively constant. This was especially the case regarding perceived benefits, which remained virtually unchanged from start to finish. In the case of perceived drawbacks, the only significant change was elicited by

review of the web pages. This had the effect of generating a certain number of perceived risks associated with the firms marketing these products.

Healthy Scepticism But Willingness to Believe – Summary Verdict on Nutrigenomics

The overall result of participants' exposure to information about nutrigenomics was to foster a healthy scepticism that did not result in cynicism. When all is said and done, participants regard nutrigenomics as a serious undertaking with the potential to make a major contribution in the field of health. As noted earlier, they were able to dissociate their criticism of the marketing and commercial aspects they find distasteful from their assessment of the science itself. They understand that it is still in its early stages and are willing to reserve judgement on it. At the same time, they expect it to prove itself in time by providing credible evidence in support of its claims.

Sense Among Many That Value of Nutrigenomics is Matter of 'When', Not 'If'

Many participants were more positive and definite in their overall assessment. They see significant potential for nutrigenomics in the future and the main issue for them is not *if* nutrigenomics will enter the mainstream of the health sciences but rather *when*. According to them, nutrigenomics represents a new, significant frontier in terms of advances in medicine and health care.

Most Not Interested in Nutrigenomics Testing Without Further Information

While most remain uninterested in taking a test without first getting further information, some participants said they are prepared to take such a test. In addition, some participants who are not interested in taking a test without first getting further information did identify circumstances that would increase their likelihood of considering such tests. This included the following circumstances:

- If they had exhausted all forms of treatment for a condition.
- If they had a problem which no one could diagnose.
- If there was public regulation/oversight.
- If their doctor recommended it.
- If testing were free.
- If a family member died suddenly of a specific disease.
- If they knew someone who had taken the test and recommended it.

RELATED COMMUNICATIONS ISSUES

This section reports on related communications issues surrounding nutrigenomics. This includes participant perceptions of the type of information that is important for Canadians to know, the best way to inform Canadians about nutrigenomics, and the most trustworthy sources for up-to-date and accurate information on nutrigenomic testing.

Pros & Cons of Nutrigenomics – Key Information for Public to Know

Participants identified various types of information that they felt were important for Canadians to know so that they can make an informed decision about nutrigenomics and whether it is something for them or their family. Leading the way was information about what was routinely described as the 'pros and cons' of nutrigenomics. There was a virtual consensus that this was important information, and most participants pointed to the section titled 'Nutrigenomics: Some Issues' in the information document they reviewed as an example what they meant by this. Essentially, participants felt it was important for Canadians to have access to information about the positives and negatives, strengths and weaknesses, benefits and drawbacks of nutrigenomics because only on this basis could they make an informed decision regarding it (i.e. whether or not they want to consider such tests for themselves and/or their families).

Specific information routinely identified as important underscores the general desire for a balanced view of nutrigenomics. This included the following types of information, many of which had been identified earlier by participants as outstanding information they wanted about nutrigenomics:

- Is there any proof/hard evidence about the success of nutrigenomics? This can include things like cases studies and peer reviews of testing.
- Who, if anyone endorses, nutrigenomics? What do organizations like the Canadian Medical Association, Health Canada, and the Food and Drug Administration in the U.S. have to say about it?
- How reliable are the home tests that form the basis for the evaluation?
- Who actually does the testing/where is it done (e.g. laboratories)?
- What/how many conditions can they actually test for?
- Is there any or is there going to be any public oversight/regulation of nutrigenomics?
- How is confidentiality/privacy of information going to be maintained or assured?
- What are the costs of testing and will they be covered under public health care?

Information characterized as important but identified less often or by small numbers of participants included:

- Information about the companies providing these services (e.g. investors, reputation).
- Does a lack of something (e.g. folate) necessarily signal a deficiency?
- Testimonials from satisfied clients/customers.
- Can there be any side-effects from taking recommended supplements?

Pamphlets in Health Care Facilities Recommended as Best Way to Inform People

Participants identified a variety of ways to inform Canadians about this type of information, and most were routinely identified in most or all groups. The most frequently-suggested means was to place pamphlets or brochures in doctors' offices/clinics and health care facilities. Many also suggested placing such pamphlets in pharmacies.

Infomercials and Public Service Announcements were also frequently identified as a means of informing people about this, and many added that these announcements should provide sources for additional information (e.g. a website). Placing information on the Internet in general or specific websites was also identified by participants in all/most groups as a way to inform Canadians. Specific sites identified included that of Health Canada, the CMA, the FDA, and associations of dieticians and nutritionists.

Ways identified less often but still relatively frequently included health conferences or fairs, documentaries, and news stories/investigative reports. Some also suggested making such information available in schools. Some participants suggested contacting the companies in question or visiting their websites, at least as a first step in informing Canadians about this type of information.

Health Canada, Scientific Experts – Most Credible Sources on Nutrigenomic Testing

When asked who they would trust to give them up-to-date, accurate information on nutrigenomic testing, many participants suggested in a general way that key elements in this regard would be expertise, lack of vested interest (i.e. no conflict of interest), and a mandate/responsibility for oversight of the well-being of the public.

The types of organizations and individuals regularly identified as credible or trustworthy sources of information seem to embody one or more of these criteria:

- Health Canada
- Public Health Agencies in general
- Food and Drug Administration
- Government in general
- Organizations representing health care professionals (e.g. CMA, College of Physicians and Surgeons)
- Universities/academic institutions
- Scientific/medical journals
- Geneticists
- Heart and Stroke Foundation.

Health care professionals in general were also regularly identified as credible, but geneticists in particular were singled out. While many identified family physicians, dieticians, and nutritionists as credible and trustworthy, some felt that these health care professionals might not yet be up-to-speed on nutrigenomics (especially family physicians) because of the relative newness of the field. Finally, some said they would look for information from the companies providing such services, at least as a first step in trying to learn about nutrigenomics.

HEALTH CARE PROFESSIONALS

CONTEXTUAL ISSUES

This section provides contextual information on the perceptions and behaviour of health care professionals regarding personal health and nutrition. This includes feedback provided during the focus group discussion, as well as feedback provided through the questionnaire they were asked to complete prior to the group discussion.

Variety of Factors Considered Important in Relation to Personal Health

Not surprisingly, health care professionals had no difficulty identifying what they consider to be the most important factors related to personal health, with most factors identified or acknowledged as important by most or all participants. In other words, there was a virtual consensus among health care professionals about the most important factors contributing to personal health. This cluster of routinely-identified factors included the following:

- Nutrition/diet
- Exercise
- Stress
- Lifestyle
- Sleep
- Attitude/mental health
- Environment
- Genes/genetics/heredity factors.

As was the case with members of the general public, genetics was not usually among the first factors identified, but it was acknowledged as important when it was identified by participants. Many specified that a balanced lifestyle, including a broad view of what constitutes health, is important, although dieticians/nutritionists/naturopaths were the most likely to say this. Factors identified less often included socio-economic situation and access to basic services (e.g. shelter), proper hygiene, social network (family and friends), and regular medical check-ups.

Consensus That Diet Has Significant Impact on Health

There was a consensus that diet has a significant impact on a person's health. As was the case with members of the general public, this link was taken for granted as self-evident and health care professionals also typically referred to the old adage "You are what you eat" to explain why. More specifically, there was a consensus that a proper diet can help decrease the risk of certain diseases or conditions, while a poor diet can increase the risk. Examples included heart disease and stroke, diabetes, osteoporosis, and obesity.

Leaving aside specific conditions, a proper diet (e.g. eating healthy foods) was seen as contributing to health in more a general way by making one stronger and more resistant. Some dieticians, nutritionists, and naturopaths added that diet affects mood in a direct way.

Most Consider Themselves Knowledgeable About Link Between Nutrition & Health

Most health care professionals think they are at least moderately knowledgeable about the link between nutrition and health as it relates to their patients/clients. In the questionnaire they were asked to complete prior to the group discussion, they were asked to use a 5-point scale (1 = not knowledgeable at all; 5 = very knowledgeable) to indicate how well informed they think they are about this. In response, most provided scores of 4 or 5. Among the rest, all but one situated themselves at the mid-point on the scale (i.e. 3).

Perhaps not surprisingly, dieticians, nutritionists, and naturopaths were much more likely than physicians and pharmacists to consider themselves knowledgeable in this area, with most rating themselves as *very* knowledgeable. By contrast, none of the physicians and pharmacists considered themselves as *very* knowledgeable. Instead, they all situated themselves at the mid-point of the scale or just above it.

Clients of Dieticians/Nutritionists/Naturopaths More Concerned About Nutrition & Health

Dieticians, nutritionists, and naturopaths were also much more likely to say that their patients/clients are concerned about the link between personal nutrition and health. Once again, this may not be surprising since consulting such professionals suggests an interest not to say a concern about this. Using a similar 5-point scale (1 = not concerned at all; 5 = very concerned), all but one of the dieticians, nutritionists, and naturopaths indicated that their patients are at least somewhat concerned about this, with almost equal numbers providing scores of 4 or 5. By contrast, physicians and pharmacists were more likely to provide scores clustered around the mid-point of the scale, suggesting more limited concern. This was confirmed in the focus group discussion.

Personal Behaviour in Relation to Health Products

The questionnaire also asked health care professionals about their own personal behaviour when it comes to heath. Dieticians, nutritionists, and naturopaths were more likely than physicians and pharmacists to say they regularly use natural health products. All but two of them said they do this on a regular basis and most said they do so daily. By comparison, only half the physicians and pharmacists said they do this on a daily basis, with the rest doing so occasionally or rarely.

While health professionals, regardless of profession, were almost equally likely to say they buy foods with specific properties because they are supposed to be beneficial to health, dieticians, nutritionists, and naturopaths were more likely to say they buy health supplements, and much more likely to say they use complimentary and alternative medicine.

Consensus That Genetics Affects Health

There was also a consensus that a person's genetic make-up has or can have a significant impact on their health. While it was recognized that the extent of this impact can vary, there was agreement that genetic make-up is the biological basis or foundation of our being

and that we are 'programmed' in a certain way, which includes being predisposed to certain conditions. While these predispositions can be triggered or activated as well as controlled or altered by factors, such as environment and diet, there was general recognition that genetic make-up is a kind of 'default programming' that determines or prescribes to a certain extent how we will develop. Examples given included predispositions towards obesity, heart conditions, cancer, and diabetes.

In discussing or describing the impact of genetic make-up, health care professionals were much more likely than members of the general public to use biological or biology-based terms and referents (e.g. weak genes, defective genes, metabolic rates) and to link genetic make-up to group factors, such as race and gender. While they did refer to family history and heredity, as well as to idiosyncratic aspects of genetic make-up (i.e. differences between individuals), they were much less likely to focus on these than members of the general public.

Consensus That Both Nature & Nurture Affect Health

As noted above, health care professionals acknowledged that predispositions can be triggered as well as controlled or altered by environment factors. In this sense there was agreement that both nature and nurture affect a person's health. Differences emerged when participants were asked about the extent to which genes play a role versus other factors in making a person who they are, including their health.

Generally speaking, physicians and pharmacists accorded more importance to genes than dieticians, nutritionists, and naturopaths, though everyone considered genes important. Most health care professionals were reluctant to use percentages to indicate the extent to which genes play a role vs. other factors, and many prefaced their answer by saying that they were speaking generally or making educated guesses. That said, most physicians and pharmacists thought that genes were responsible for between 50-70% of a person's health. For their part, dieticians, nutritionists, and naturopaths tended to suggest that genes account for between 30-50% of a person's health, though one felt that it could be as low as 5-10%. Dieticians, nutritionists, and naturopaths generally accorded more importance to environmental factors like diet and supplements, though physicians and pharmacists also considered diet to be very important.

General Sense That Much Still to be Learned About How Genes Affects Health

All participants felt that they themselves, as well as the scientific and medical community of which they are part, do not yet have a very good understanding of how someone's genetic make-up affects their health. There was a consensus that there are still many mysteries or 'black holes' and that much remains to be learned. It was observed as well that this is a complicated field because of the number of factors involved (e.g. diet, lifestyle, environment), the difficulty testing/screening and isolating certain factors, and the inability/difficulty to make definite causal links. A few added that there will probably never be a consensus in the scientific community about this.

The types of things that participants themselves said they know about included testing for genetic markers (i.e. detectable traits), profiles to assess the risk of certain diseases, the

treatment of deficiencies in nutrients, and the inability to absorb or intolerance to certain nutrients (e.g. iron).

Consensus That Genetics Influences How Body Responds to Food

All health care professionals were of the opinion that a person's genetic make-up influences how their body responds to food, and they were readily able to provide examples. The examples given typically included weight gain/obesity, lactose intolerance, allergies, cholesterol levels, inability to absorb or tolerate certain nutrients, and underproduction or overproduction of certain enzymes.

All Interested in Knowing More About How Body Responds to Food

Health care professionals were also unanimous about wanting to know more about how someone's body responds to food. Some added that they are seeing more and more patients who have problems related to food, including allergies, digestion problems, and celiac disease. A few said that while patients/clients may not necessarily have food-related problems, many are coming with questions about diet/nutrition, including questions about specific diets or the latest 'nutrition fad' they have heard about.

Dietary Advice Based Mostly on Family History & Specific Conditions

Most health care professionals say they have given advice to patients/clients related to the link between their genetic makeup and their diet. This was based primarily on the patient's/ client's family history (e.g. heart disease, cancer) or actual conditions requiring treatment. The latter included levels of good vs. bad cholesterol, calcium deficiencies, inability to tolerate certain natural nutrients and the need to address this through synthetic supplements, allergies, and low levels of folic acid or B-12. A few said they provided advice based on test results. These included gene tests to detect genetic markers and a lipid profile to assess the risk of heart disease. Dieticians, nutritionists, and naturopaths were more likely to say they have done this than physicians and pharmacists.

A few physicians said that while they have not given advice themselves, they have recommended to patients that they consult dieticians or nutritionists. However, they specified that they recommended to patients that they consult a dietician or nutritionist about diet, not about the link between their genetic makeup and their diet.

AWARENESS AND PERCEPTIONS OF NUTRIGENOMICS

This section reports on health care professionals' awareness and understanding of nutrigenomics.

Awareness of Nutrigenomics is Limited, Higher Among Nutritionists/Dieticians/ Naturopaths

Prior to their participation in the study, most health care professionals said they had never heard the term 'nutrigenomics'. However, there was a clear difference in awareness between the two groups of professionals. Approximately half the dieticians, nutritionists, and naturopaths said they had previously heard the term, while none of the physicians and pharmacists had heard of it.

Those familiar with the term had learned of it in different ways. A few recalled hearing about it at a seminar or conference, a few came across references to it on the Internet, including on a dietician's website, and a few said they know enterprises that apparently describe what they do as nutrigenomics. One of these is a laboratory that does amino acid testing and develops an amino acid profile supplement adapted to a particular patient. Another identified a company that claims to optimize individual health through nutrition based on a person's genetics. A third is a different company. A couple of participants said they could not recall where they heard the expression.

General Impression That Nutrigenomics Explores Link Between Diet & Genes

Despite their relatively limited familiarity with the expression, most health care professionals intuited that it refers to a link between diet or nutrition and genetics. This was especially the case among dieticians, nutritionists, and naturopaths. Among those who did not capture its correct or proper meaning on the advance questionnaire, some described it as having to do with the link between health and nutrition or nutrition in general, and a few associated it with genetically modified foods. Among the few who wrote nothing or said they were unfamiliar with the expression, all but one were physicians or pharmacists.

Presented below are the descriptions or definitions of nutrigenomics provided by participants in the questionnaire they were asked to complete prior to the group discussion. The definitions provided by dieticians, nutritionists, and naturopaths are provided first, followed by those provided by physicians and pharmacists. The purpose of this division is to facilitate comparison of the descriptions or definitions provided by each group of professionals since, as indicated above, dieticians, nutritionists, and naturopaths were more likely to identify elements of nutrigenomics.

<u>Definitions of nutrigenomics provided by dieticians, nutritionists, and naturopaths</u>:

- *Nutrients that modify or regulate gene expression.*
- *The study/application of how nutrition affects genetic expression.*
- *Nutrition based on genetics; affecting gene expression via genetics.*

- *An individual's genes make one predisposed to a condition, but clinical nutrition can prevent this condition.*
- *The study of how nutrition/specific nutrients can have an impact on individuals because of their unique genetic make-up.*
- *Relation of nutrition to genomics; how nutrition can affect your genes.*
- *Nutritional approach with genetic implications.*
- *The interplay between nutrition and gene expression.*
- *Nutritional considerations with respect to specific genetic profiles.*
- *Nutrition related to genetics/genes. Using food and nutrient intake specific to one's genetics.*
- *Nutritional perspective that takes into account individuality.*
- *Creation of custom foods not naturally found in nature.*
- *Genetically modified to alter nutritional content.*

Definitions of nutrigenomics provided by physicians and pharmacists:

- *The study of the link between nutrition and genetics.*
- *Using genetics to improve nutrition or using nutrition to improve one's genetics.*
- *Choosing foods specific to one's genetic make-up.*
- *Nutritional and dietary advice based on genetic make-up.*
- *Targeted nutritional therapy based on genetics.*
- *The study of nutrition in humans.*
- *Something to do with nutrition-health balance.*
- *A branch of science focusing mainly on nutrition and how it affects everyone's health.*
- *Genetic changes in nutrients.*

Focus of 'Personal Nutrition' on Personalized Plan

Health care professionals were also asked to write one or two sentences to explain what the term 'personalized nutrition' means to them. All of them were able to provide an interpretation of this term and the core element of nearly all interpretations was some kind of nutritional plan or regime adapted to or designed for an individual based on their needs, goals, or preferences (but primarily their needs).

Listed below are the descriptions or definitions of personalized nutrition provided by health care professionals. Because definitions tended to be similar, regardless of profession, they have been grouped together.

- *Nutritional program geared towards an individual's needs (e.g. pregnant mother, infant, elderly person, athlete).*
- *Nutrition specific to your body's needs.*
- *A nutrition program designed for a person's specific needs.*
- *Nutritional program designed to meet individual needs.*
- *Individualized nutrition based on personal needs.*
- *Nutrition that is geared towards each individual's specific needs.*
- *Assessing one's unique nutritional needs for optimal functioning.*
- *A diet composed of specific nutrients to cater to individual needs.*
- *Someone's specific dietary needs in relation to allergies and health.*
- *Food intake plan tailored to an individual and their specific needs.*
- *Nutrition geared to each individual's health.*
- *Eating properly from the five food groups with the help of a nutritionist or medical professional.*
- *An individualized approach to designing the most appropriate eating plan for a person.*
- *Individualized nutrition plan.*
- *Making a nutrition plan that is specific to a particular person (i.e. a person's genetics).*
- *Nutritional and dietary advice based on a personalized plan.*
- *Nutrition that caters to a person's lifestyle, genetics, religion, individual preferences, etc.*
- *Establishing a nutritional protocol that meets the health goals of the individual.*
- *Taking into consideration an individual's unique make-up and circumstances, genetic as well as environmental and social, and designing nutrition plans for that person.*
- *Getting external expertise to become more familiar with food intake which will promote your health and help facilitate your wellness goals.*
- *Nutrition as it relates to the individual and their own personal history.*
- *Individualized diet and supplement regime.*
- *Custom nutrition care plans based on the goals and lifestyle of the client.*
- *Individualized diet/nutrition modification.*

Definition of Nutrigenomics Tends to Coincide With Professionals' Understanding or Assumptions

Health care professionals were given the following definition of nutrigenomics and asked to what extent it is consistent with their own understanding of the term:

> Genes and their biological environments interact. Different environments can cause the same gene to behave differently. Equally, the environment can cause different outcomes for individuals with different genes. Nutrients are environmental factors that can affect the expression and regulation of genes, and variations in genes can alter how nutrients are metabolised. Nutritional genomics can be broadly understood to involve the study of how nutrients in food interact with our genes at the molecular and cellular levels, and the impacts these reactions have on our health. The goal is to promote human health through optimal nutrition, taking into account genetic variation between people. One application of nutrigenomics is personalized nutrition, in which a person's knowledge about their genetics is used in everyday decisions about nutrition. People can learn about their genetics by means of genetic testing, or based on family history or personal experience.

Most participants, but especially dieticians, nutritionists, and naturopaths, felt that that this definition is more detailed than, but not in contradiction with, their understanding of nutrigenomics. In other words, it tended to coincide with their understanding of the term. Some added that nutrigenomics is more of a 'two-way street' than they thought, referring to the idea of interaction between genes and nutrients and how they can mutually have an impact on one another. A few others said that nutrigenomics probes more deeply than they thought, referring to the idea of studying how nutrients interact with genes at the molecular and cellular levels.

Health care professionals who indicated that this definition of nutrigenomics did not coincide with their understanding of it were those who had linked nutrigenomics to nutrition in general, associated it with genetically modified foods, or wrote nothing or said they were unfamiliar with the expression.

Some Consider Claims of Nutrigenomics Far-Fetched or Futuristic

Some health care professionals reacted to the definition of nutrigenomics with a certain amount of scepticism, considering the claims to be slightly far-fetched. Specifically, they reacted to the statement that "Nutritional genomics can be broadly understood to involve the study of how nutrients in food interact with our genes at the molecular and cellular levels, and the impacts these reactions have on our health". It was suggested there are too many factors and variables at play at the molecular and cellular levels to be able to develop a definite picture of how this affects our health.

One physician thought that nutrigenomics, as defined, would not have a widespread practical application. More specifically, this participant felt that such testing might be warranted or applicable in special cases, such as athletes who are looking for ways to enhance their performance and people who have weak or defective genes and suffer from conditions such as celiac disease.

Limited Awareness of Companies Offering Nutrigenomics Services

While there was widespread awareness of genetic testing in general, especially through blood tests, only a few health care professionals claimed to be aware of nutrigenomics testing specifically. In fact, only five participants claimed to be aware of nutrigenomic services and they were all dieticians, nutritionists, and naturopaths. The services they were aware of had been identified earlier when participants were asked if they were familiar with the term nutrigenomics. All three firms identified were described as places that do genetic tests based on blood samples. These include allergy testing, enzyme testing, amino acid testing, and folic acid testing.

Few Have Clients/Patients Who Have Asked About Genetic Testing

Only a few health care professionals indicated that they have had patients ask about genetic tests (not about nutrigenomics specifically or by name). Moreover, this has happened rarely. These patients asked about the possibility (and cost) of getting tests to see if they were predisposed to certain diseases, including cancer and heart disease. Two of the health care professionals helped these patients get the tests they asked about, and one helped interpret the results by contacting the company in question that carried out the test. One health care professional advised the patient in question to put off testing for the moment as it did not seem warranted and the cost was prohibitive.

Internet, Colleagues, Literature – Likely Sources for Information on Nutrigenomics

Health care professionals identified various sources they would turn to for information about nutrigenomics and the benefits and risks or harms that this might pose to their patients/clients. The most frequently-identified source, and often the first one mentioned, was the Internet. As a first step, many said they would use a general search engine like Google, but pay close attention to the 'hits' this gave in order to focus on reputable or recognized sources of information. Many said they would go to special sites. These included Medline, Pub Med, Pharmacy Links, and the International Journal of Pharmaceutical Compounding.

In addition to the Internet, participants routinely identified colleagues and professional literature as sources they would consult. Many added that they would contact the companies offering these services as well. Sources identified less often but by at least a couple of participants in each group included Health Canada, the Canadian Medical Association, and medical schools. A few also identified the Mayo clinic as a possible source of information.

Company Claims & Nature of Tests – Key Information to Counsel Patients/Clients

Information related to the claims made by companies offering nutrigenomics services and the nature of the tests they undertake were most often identified as the most important types of information in order to counsel patients properly. Specifically, this included information about the following:

- What the companies test for (i.e. which conditions)
- The range of tests available
- Clinical practice guidelines
- The degree of reliability of tests and how they establish correlations
- Case-study-based evidence of success and success rates
- The nature of prescriptive treatments
- Do the companies help clients interpret results?

Other key information included the cost of tests, privacy/confidentiality guidelines, and the extensiveness of testing (e.g. how common is this, how many people have taken such tests).

Geneticists, Nutritionists, Dieticians – Where They'd Refer Patients for Further Info

Geneticists, nutritionists, and dieticians were the most frequently-identified health care professionals to whom participants would refer a patient or client for further information about nutrigenomics. Some said they would refer their patients to researchers or professors at universities or medical schools, and a few said they might recommend a naturopath. A few physicians said they were unsure to whom they would refer patients.

EXPOSURE TO WEBSITE

In order to provide health care professionals with a sense of the types of nutrigenomics products and services available online, they were shown the same mock-up of a website offering nutrigenomic services that was shown to members of the general public.

Widespread Scepticism, But Desire to Know More – Main Reaction to Website

Most health care professionals, regardless of their profession, reacted to the website with a certain amount of scepticism. To the extent that there was any difference in reaction, it related to the *degree* of scepticism, with physicians and pharmacists more likely to express strong scepticism. Typical reactions or questions that underlay this scepticism included the following:

- Where is the proof/evidence for the effectiveness of these services?
- Testing 19 genes for five possible conditions seems limited.
- Where is the regulation/oversight of this type of service?
- It is impersonal and devalues/diminishes interaction with health care professionals.
- It seems like a ploy to market nutritional supplements.
- There seems to be a conflict of interest (i.e. carrying out tests and selling supplements).
- If this is effective, why have they as health professionals not heard of this before?

Despite the widespread scepticism, all health care professionals expressed interest in this information, and many described this as important for them to know about as health care professionals. Some asked specifically how long such companies have been in existence and how extensive are the services (i.e. how many such companies exist).

While most reacted with scepticism, some reacted more positively, describing the information as intriguing and suggesting that such services could potentially be very beneficial.

Consensus That Process Should be Mediated, Regulated

All the health care professionals were of the opinion that these services need to be mediated by qualified health care professionals or, at the very least, that there needs to be some kind of oversight or regulation on the part of Health Canada or government. A few specified that these services do not have to be mediated by a health care professional as long as there is some kind of public oversight or regulation. Some added that when they first read the definition of nutrigenomics, they simply assumed that this type of service would be clinically-based (i.e. in a physical location) and mediated in some way by health care professionals. It was also observed that there is no way to stop this kind of activity over the Internet, but that it needs to be regulated precisely because the nature of this type of online interaction is one that excludes health care professionals.

Health care professionals were also readily able to explain why they thought the process should be mediated or regulated. The following reasons were identified in each of the groups conducted with health care professionals:

- Patients are going to be visiting their health care providers with questions about such tests and therefore the latter should be involved in the process in some way.
- Health care providers may have to deal with negative fall-out or consequences resulting from these tests and should not only be brought in at the end of the process.
- Health care professionals are in a position to ask pertinent questions about these services that their patients may not think of asking.
- There should be some way to guarantee the legitimacy of these tests and the claims being made about nutrigenomics.

Information Could be Useful Regarding Predispositions, Interpretation is Key

No one was prepared to discount nutrigenomic testing as useless or irrelevant to their patients or clients. To the contrary, there was a sense that this could be useful and relevant, but health care professionals were reluctant to endorse it in a general and unqualified way. It was noted, for example, that nutrigenomics could be useful in the following ways:

- In detecting predispositions to certain conditions and treating them in a preventative manner, such as the five conditions that are tested for.
- As a wake-up call to certain patients who are reluctant to acknowledge certain health problems or deal with them.
- By fostering more interest in a healthy diet in general.
- As a fail-safe or final measure, when other treatments yield no results.

Many also specified that the usefulness and relevance of nutrigenomics would depend on the accuracy of the results and the way in which test results are interpreted, including whether a prescribed treatment is actually warranted by the results.

Widespread Interest in Nutrigenomics Mainly Because it Exists as Option

As noted, all health care professionals expressed interest in this information and many described it as important for them to know about as health care professionals. When asked why they were interested, they usually explained that, as health care professionals, they need to keep abreast of developments in health care. Many also re-iterated that whether they want to or not, they will inevitably have to be involved in this because their patients will be coming to them with questions about it or to ask their advice about it.

Proactivity, Greater Interest in Nutrition – Main Perceived Benefits of Testing

Despite their concerns or reservations, all health care professionals were able to identify perceived benefits associated with nutrigenomic testing. The benefits identified most often were a proactive approach to health care through preventative measures, and greater

interest in healthy eating in general. Many also suggested that nutrigenomics could potentially be very useful in targeted treatment of specific conditions or predispositions to them. Other benefits that were identified include lower health care costs (a spin-off of more preventative care), fostering health-related lifestyle changes, and stimulating research in the link between genetics and diet/nutrition

Validity of Results & Possible Consequences – Main Concerns About Testing

When it came to perceived risks or potential harms, health care professionals were most likely to raise concerns about the accuracy or validity of results, with some raising the issue of how to verify that tests are actually conducted. Related to the issue of validity of results were the possible health-related consequences of a misdiagnosis or inaccurate results.

Other perceived risks routinely identified included the following:

- Self-treatment resulting from excluding health care professionals from the process.
- The possibility that people will regard nutrigenomics as a magic bullet/cure-all.
- Possible side-effects resulting from medication being taken at the same time as prescribed treatment.
- The possibility that patients will focus too much on the test results and ignore other health problems.
- Overcompensating for deficiencies through the use of supplements.
- Psychological risks arising from negative or inconclusive tests results (e.g. depression, anxiety).
- Psychological risks arising from positive tests results (i.e. euphoria resulting from someone's belief that they are healthy when they may have a condition that is not detected through testing).
- Privacy-related concerns, including whether employers and insurance companies will have access to this information.

Existence of Nutrigenomics Websites Motivates Professionals to Want to Know More

The existence of websites of companies offering nutrigenomics services, and the fact that their patients/clients have access to them, motivates all health care professionals to want to know more about nutrigenomic testing. Information considered important included the following:

- Proof/evidence/case studies for the effectiveness of these services.
- Will there be regulation/oversight of this type of service?
- What are the costs of nutrigenomics tests?
- What is the nature of the home test?

- What do the test result reports look like (e.g. what do they include, how detailed are they)?
- What is the nature of the supplements being marketed?
- How many such companies currently exist?
- What, if anything, do health care professional associations have to say about nutrigenomics?

Most Would Recommend Qualified Professional to Patients Seeking Dietary Advice

Asked how they would respond if a patient/client came to them with test results and wanted advice about understanding them and modifying his/her diet or taking supplements, most said they would recommend qualified professionals like nutritionists and dieticians. Most physicians and pharmacists added that they would disqualify themselves, and some said they would caution patients about nutrigenomics test results. One said that depending on the prescribed course of action she might recommend that her patient put the results aside.

Health care professionals also routinely said that they would search for information in peer-reviewed journals or on websites of professional associations. Some said that, depending on the results, they would contact the company itself to discuss the results or get clarification. Some nutritionists, dieticians and naturopaths said they would recommend to their clients that they look at lifestyle issues first, before relying on test results.

Only one participant indicated that a patient/client has ever come with test results to get advice about understanding the results. This did not include seeking advice on diet modification or taking supplements.

Sense That Results Would Motivate Behaviour Change, But Mainly Over Short Term

While there was a consensus that personalized information like this would motivate behaviour change because it is based on customized, genetically-based results, there was also widespread agreement that the behaviour change would be over the short-term. Many health care professionals added that they often prescribe certain changes in behaviour to their clients that the latter either ignore or abandon after a short period of time.

Genetic Testing Most Likely to be Recommended Based on Family History

None of the health care professionals said they would recommend a genetic test to someone, or suggest that a genetic test be done specifically in order to optimize their diet based on that test, as a first measure or a first step. Moreover, all the physicians and pharmacists indicated that they would not feel qualified to recommend a genetic test done specifically in order to optimize a diet based on that test. One qualified this by saying that she might only do this in a case of obesity.

The most frequently identified situation under which such tests might be recommended was where someone's family history pointed to a clear predisposition to a certain

condition. Many said they would only recommend this as a last resort – i.e. if nothing else yielded results in treating a condition. Other situations included ones where there was documented evidence or case studies substantiating the effectiveness of such tests.

REVIEW OF INFORMATION DOCUMENT ON NUTRIGENOMICS

This section reports on health care professionals' reaction to the short information document on nutrigenomics prepared specifically for these focus groups.

Widespread Perception That Information Piece Provides Balance, Perspective

The reaction of health care professionals to this document was very similar to that of members of the general public. There was widespread agreement that it provides a good overview of the topic and helps clarify the issues involved by providing balanced coverage of the 'pros and cons' of nutrigenomics. Some added, however, that based on the information in this document, the negatives of nutrigenomics currently outweigh the positives.

Generally speaking, dieticians, nutritionists, and naturopaths felt a sense of familiarity with the information presented in the document. Some explained that it dealt with issues they already knew about and, while they reacted positively to it, there was little if any new learning for them. In addition, some dieticians, nutritionists, and naturopaths said the document reinforced their belief that one must take a holistic approach to health issue. The naturopaths in particular emphasized the need to get the 'big picture' when it comes to health and not be reductionist in one's perspective.

Positive Reaction Most Likely to be Elicited by Pros & Cons of Nutrigenomics

Like members of the general public, health care professionals were most likely to react positively to information in the section titled 'Nutrigenomics: Some Issues'. Many said that this section made them think (or reinforced their belief) that there is much left to learn regarding the link between nutrition and genetics in particular, or genes and environmental factors in general. Some said that this section made them think that one must be vigilant but open-minded about nutrigenomics.

Other aspects to which health care professionals reacted positively included the reference to nutrigenomics still being a new and developing science, the hope around nutrigenomics, and the examples of how food intake can affect health. That said, some reacted negatively to these examples, as will be seen below.

Negative Reaction Elicited by Variety of Things, None of Which Dominates

The document elicited relatively little in terms of negative or critical reaction from health care professionals. Small numbers reacted critically to each of the following:

- The lack of certainty regarding the possible benefits of nutrigenomics, including the use of the word 'could' to describe the benefits of nutrigenomics.
- The specific example of lactose intolerance. It was suggested that there is no need for a gene test to diagnose lactose intolerance.
- The definition of nutrigenomics because it suggests a reductionist view of what affects health. Specifically, the definition focuses on how nutrients and genes

interact when, in fact, there are other factors that affect both health and how nutrients and genes interact.

- The examples of how food intake can affect health. These were described as providing nothing new in terms of information.

Document Clarifies Nutrigenomics & Increases Receptivity for Some

The document did not change any of the health care professionals' understanding of nutrigenomics, nor did it alter their understanding of the role genes play in making someone who they are, including their health. That said, most acknowledged that it clarified the issues for them. Physicians and pharmacists were more likely to say this than dieticians, nutritionists, and naturopaths, and a few physicians added that by clarifying the issues, the document made them more receptive to nutrigenomics.

Remaining Questions About Nutrigenomics Focus on Regulation/Oversight

The most frequently-identified outstanding question about nutrigenomics considered important by health care professionals involved its potential regulation and/or oversight. This included the following aspects of this issue:

- The claims nutrigenomics firms can make about their products and services.
- The types of supplements they can provide or market.
- Standards governing testing and safety.
- Regulation of home test kits.
- Standards governing the interpretation of results.
- Standards governing confidentiality and privacy of information

Many also re-iterated that they would like to see proof or evidence of the effectiveness of these services. Finally, some wanted to know what, if anything, is being done to advise or inform health care professionals about the existence of nutrigenomics.

RELATED COMMUNICATIONS ISSUES

This section explores communications issues related to nutrigenomics. This includes participant perceptions of who should provide information to help in answering patients' questions about nutrigenomic testing, the type of information it is important for Canadians to know, the best way to inform Canadians about nutrigenomics, and the kind of measures that should be put in place to regulate or oversee nutrigenomics testing.

Professionals, Associations, Health Canada – Many Key to Information Provision

Health care professionals believe that numerous actors have a supporting role to play in helping them provide information to help answer patients' questions about nutrigenomic testing. These include Health Canada, the community of professionals involved in providing health care, associations representing health care professionals, university researchers and medical schools, and regulatory bodies responsible for creating guidelines governing health-related practices.

Consensus That Nutrigenomics Testing Should Not be Left to Marketplace

Not surprisingly in light of the importance participants attributed to regulating or overseeing the field of nutrigenomics, there was unanimity that nutrigenomics testing should not be left exclusively to the marketplace. Asked specifically what the Public Health Agency of Canada (PHAC) could do to support them in dealing with their patients' regarding nutrigenomic testing or in helping serve patients in general, the following suggestions were made:

- Provide information to health care professionals and professional associations on what Health Canada and PHAC think of nutrigenomics, including information on what they know about nutrigenomics companies. This could include creating a website identifying all such companies, including any involved in fraudulent practices or in trouble with the law.
- Create pamphlets/brochures on nutrigenomics for members of the general public that provide basic information about it and advise them to involve their health care provider in any decisions about getting a test.
- Sponsor/fund research into the area of nutrigenomics through universities or research institutions with no vested interests.
- Fund public laboratories to carry out nutrigenomics testing.
- Provide support to naturopaths and alternative health care providers who are already out there in the field of health care. This could include hiring some naturopaths to include their voice in any decisions taken by PHAC.
- Create an overseeing body (e.g. a college of nutrigenomists) to ensure professional credentials of practitioners in the field.

It was suggested that Health Canada put together a team that includes representatives from various fields (i.e. physicians, pharmacists, dieticians, nutritionists, and naturopaths) to look into nutrigenomics and make recommendations regarding its regulation.

Pros & Cons of Nutrigenomics – Key Information for Public to Know

Health care professionals identified various types of information which they felt were important for Canadians to know so that they can make an informed decision about nutrigenomics and whether it is something for them or their family. Leading the way, as was the case with members of the general public, was information about what the 'pros and cons' of nutrigenomics based on what is currently known.

Other information considered to be important, much of which is the same as that seen to be important by the general public, included:

- Reputable sources of information about nutrigenomics in general.
- Things to consider or do before deciding on whether or not to take a test (e.g. consult health care providers).
- A list of nutrigenomics companies with contact information.
- Health Canada's position regarding nutrigenomics (e.g. do they endorse it and why/why not)?
- Whether or not there is or is going to be public oversight/regulation of nutrigenomics.
- Confidentiality/privacy of information issues.
- Will costs of testing be covered under public health care?

Health Care Professionals, Pamphlets in Facilities – Best Ways to Inform

Health care professionals identified a variety of ways to inform Canadians about nutrigenomics. The most frequently-suggested means was through health care professionals (i.e. family physicians, dieticians, nutritionists, naturopaths, pharmacists), as well as pamphlets, brochures, and posters in their facilities/offices. Placing information on specific websites was also routinely identified. These included YouTube, Health Canada, and sites of associations of health care professionals. Infomercials and television ads were also identified. A few identified documentaries as a means of informing people about this as well.

Summary Measures Regarding Oversight of Nutrigenomics

As a final indication of their views regarding oversight or regulation of nutrigenomics, participants were asked for their views on the following:

- Should Health Canada be in the business of informing consumers – i.e. explaining the benefits and harms of this kind of testing?
- Should there be any regulations affecting what companies can claim about the testing products they are promoting?
- Should health professional associations (licensing bodies, etc.) be creating guidelines for the appropriate counselling of patients on nutrigenomic issues?

In response, there was widespread support for all three of these measures. Support was highest for Health Canada informing consumers of this kind of testing, followed by support for regulations affecting what companies can claim about the testing products they are promoting. Regarding the latter, a few suggested that regulations should forbid the same company from carrying out the tests and selling supplements. There was slightly less support for health professional associations creating guidelines for the appropriate counselling of patients on nutrigenomic issues. While most supported this measure, some felt that it was not appropriate because it implied a certain amount of paternalism (i.e. it implied that certain professionals in the field of health care are qualified to comment on another field). Moreover, it was also suggested that professional associations would probably be reluctant to do this, especially if nutrigenomics began to prove its worth based on scientific evidence.

APPENDIX

RECRUITMENT SCREENERS

Recruitment Screener: General Public

PROFILE CHARACTERISTICS

— 12 focus groups in five locations: Toronto [2], Montreal [4], Halifax [2], Vancouver [2], and Edmonton [2].

— Groups to be recruited according to participants' levels of education as follows:

1. Participants with high school education or less.
2. Participants with at least some post-secondary education. This will include a mix of participants with some college or university education, college/ university graduates, and those who have post-graduate/professional degrees.

— Approximately half of the participants (or more) in each group will:

- have kids in the home,
- be consumers of natural health products, and
- have used the Internet to look for health-related information.

— All groups will include a mix of participants by gender, age, income, marital status, and ethnicity.

— All participants to be 18 years of age and older.

— 12 participants to be recruited for 7-8 to show per group.

— Participants to be paid $60 to participate.

— At least half to have <u>never</u> participated in a focus group/paid interview.

— Sponsorship of the study to be revealed (i.e. PHAC/Government of Canada). Disclosure will also identify university researchers.

— The following table presents the proposed distribution and timing of the groups:

	Toronto	**Halifax**	**Montreal**	**Montreal**	**Vancouver**	**Edmonton**
	English	**English**	**French**	**French**	**English**	**English**
Date	**Nov. 22**	**Nov. 26**	**Nov. 28**	**Nov. 29**	**Nov. 27**	**Nov. 28**
6:00 pm	High school or less	Post-secondary	High school or less	Post-secondary	Post-secondary	High school or less
8:00 pm	Post-secondary	High school or less	Post-secondary	High school or less	High school or less	Post-secondary

SCREENER

Hello, my name is _____. I'm calling on behalf of Phoenix, a public opinion research firm. We've been commissioned by the Public Health Agency of Canada, part of the Government of Canada, to conduct a series of discussion groups to explore health-related issues with Canadians.

Each discussion group will last up to two hours. People who take part will be paid a cash honorarium to thank them for their time, and light refreshments will be served. Participation in the research is completely voluntary and your decision on whether or not to participate will not affect any dealings you may have with the Government of Canada. Your answers will be kept confidential and will be used for research purposes only in accordance with laws designed to protect your privacy.

May I ask you a few questions to see whether you qualify for the research?

Yes	1	
No	2	THANK/DISCONTINUE

IF RESPONDENT QUESTIONS VALIDITY OF THE RESEARCH, INVITE HIM/HER TO CALL ROSS DUNCAN OF THE GOVERNMENT OF CANADA OR HAVE ROSS CALL THE RESPONDENT. ROSS CAN BE REACHED AT (613) 952-5121.

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1. Do you, or does any member of your household or immediate family, work in any of the following fields? (READ LIST)

   Marketing research, public relations firm, or advertising agency
   The media (radio, television, newspapers, magazines, etc.)
   Federal, provincial or municipal government health department/agency
   Healthcare sector (e.g. hospitals, clinics, nurses, doctors, radiologists, etc.)
   Pharmaceutical or drug companies
   Natural health products*

Yes	1	THANK/DISCONTINUE
No	2	CONTINUE

*IF ASKED, SAY: "This includes employment in any area related to things like dietary supplements, such as vitamins, minerals, herbs or specialty supplements, natural and organic foods, personal care or household products, and functional foods."

2. What is the highest level of education you have completed? (READ LIST IF NECESSARY; ENSURE GOOD MIX FOR EACH GROUP)

Less than high school	1	HS OR LESS
High school	2	HS OR LESS
Some college/technical school/CEGEP	3	POST-SEC

Graduated college/technical school/CEGEP	4	POST-SEC
Some university	5	POST-SEC
Graduated university	6	POST-SEC

3. Could you please tell me which of the following age groups you fall into…? (READ LIST; GET GOOD MIX)

Under 18	1	THANK/DISCONTINUE
18-24	2	
25-34	3	
35-44	4	
45-54	5	
55-64	6	
65-70	7	
Over 70	8	THANK/DISCONTINUE

4. During the past year or so, have you personally looked for health-related information on the Internet? This includes information on things like health and wellness, diseases and conditions, or drugs and vitamins. (ENSURE AT LEAST HALF HAVE DONE THIS. NO UPPER LIMIT – I.E. ALL COULD HAVE DONE THIS)

Yes	1
No	2
Do not use the Internet	3

5. Do you regularly use over-the-counter natural health products? This includes things like vitamins and minerals, herbal products, homeopathic medicines, traditional medicines, and things of this nature. (ENSURE AT LEAST HALF HAVE DONE THIS. NO UPPER LIMIT – I.E. ALL COULD HAVE DONE THIS)

Yes	1
No	2

6. What is your marital status? (ENSURE GOOD MIX)

Married/common law	1
Single/divorced/widowed/separated	2

7. Do you have any children under 18 years of age living with you in your home? This includes children living with you full-time or part-time as part of a shared custody arrangement. (WATCH QUOTAS. ENSURE AT LEAST HALF HAVE CHILDREN IN HOME)

Yes	1
No	2

8. Of which ethnic or cultural group are you a member?* (ENSURE GOOD MIX)

Ethno-cultural group: _____

***NOTE**: IF INDIVIDUAL IS UNCLEAR ABOUT WHAT IS MEANT PROVIDE EXAMPLES (E.G. FRENCH CANADIAN, ENGLISH CANADIAN, ABORIGINAL CANADIAN, CHINESE, ETC.).

9. During the last 12 months, what was your total household income before taxes and deductions, from all sources? Was it…? (READ LIST; GET MIX.)

Less than $20,000	1
$20,001 to 40,000	2
$40,001 to $60,000	3
$60,001 to $80,000	4
$80,001 to $100,000	5
More than $100,000	6

10. Have you ever attended a discussion group or interview which was arranged in advance and for which you received a small sum of money?

Yes	1	
No	2	GO TO END SECTION

11. When did you last attend one of these discussion groups or interviews?

Less than 12 months ago	1	THANK/DISCONTINUE
Over 12 months ago	2	

12. Have you attended more than three discussion groups or paid interviews in your lifetime?

Yes	1	THANK/DISCONTINUE
No	2	

RECORD GENDER BY OBSERVATION (ENSURE APPROXIMATE SPLIT)

Female	1
Male	2

The group discussion will take place on (DAY OF WEEK), (MONTH/DATE), at (TIME). It will last approximately two hours. People who attend will receive $60 to thank them for their time, and light refreshments will be served. Would you be willing to attend?

Yes	1	
No	2	THANK/DISCONTINUE

Do you have a pen handy so that I can give you the address where the discussion group will be held? It will be held at _____. Please tell people you are there for a focus group. I would like to remind you that the group is at (TIME) on (DATE). Please come 20

minutes early because there will be a short questionnaire we would like you to fill out. If you use glasses to read, please remember to bring them with you.

The group will be video-taped for research purposes and members of the research team will be observing the discussion from an adjoining room. You will be asked to sign a waiver to acknowledge that you will be video-taped during the session. The video recordings will only be used for research purposes by: (1) employees of Phoenix Strategic Perspectives; (2) employees and contractors of the Public Health Agency of Canada and Health Canada; and (3) a research team based at the University of Ottawa and University of Alberta that is working on issues related to this research. All information collected will be used for research purposes only and administered in accordance with laws designed to protect your privacy.

As we are only inviting a small number of people to attend, your participation is very important to us. If for some reason you are unable to attend, please call so that we can get someone to replace you. You can reach us at ____ at our office. Please ask for ____. Someone will call you the day before to remind you about the discussion group.
Could I please confirm your name and phone number?

RESPONDENT'S NAME: _____
HOME PHONE #: _____
INTERVIEW TIME/LOCATION: _____

Thank you.

Entrevue de sélection : grand public

CARACTÉRISTIQUES DU PROFIL

— 12 groupes réunis à cinq endroits : Toronto [2], Montréal [4], Halifax [2], Vancouver [2] et Edmonton [2].

— Les membres des groupes seront recrutés en fonction de leur niveau de scolarité :

3. Des participants du niveau de l'école secondaire ou moins.
4. Des participants ayant fait au moins un peu d'études postsecondaires. On aura ainsi un mélange de participants ayant fait un peu d'études collégiales ou universitaires, des diplômés de collège/d'université et des personnes ayant un diplôme professionnel/d'études supérieures.

— À peu près la moitié (ou plus) des participants de chaque groupe :

- auront des enfants qui vivent à la maison,
- seront des consommateurs de produits de santé naturels, et
- auront cherché dans Internet des renseignements sur la santé.

— Les participants de tous les groupes présenteront une bonne répartition selon le sexe, l'âge, le revenu, l'état civil et l'origine ethnique.

— Tous les participants seront âgés de 18 ans et plus.

— Il faut recruter 12 participants pour que 7 ou 8 se présentent dans chaque groupe.

— Les participants recevront 60 $ en guise de remerciement.

— La moitié au moins doivent n'avoir <u>jamais</u> participé à une discussion de groupe/entrevue rémunérée.

— Le commanditaire de l'étude sera révélé (i.e. ASPC/gouvernement du Canada). On mentionnera aussi des chercheurs universitaires.

— Le tableau ci-dessous présente la composition des groupes et le moment de la discussion, tels qu'envisagés :

	Toronto	**Halifax**	**Montréal**	**Montréal**	**Vancouver**	**Edmonton**
	Anglais	**Anglais**	**Français**	**Français**	**Anglais**	**Anglais**
Date	**22 nov.**	**26 nov.**	**28 nov.**	**29 nov.**	**27 nov.**	**28 nov.**
18 h	Secondaire ou moins	Post-secondaire	Secondaire ou moins	Post-secondaire	Post-secondaire	Secondaire ou moins
20 h	Post-secondaire	Secondaire ou moins	Post-secondaire	Secondaire ou moins	Secondaire ou moins	Post-secondaire

ENTREVUE DE SÉLECTION

Bonjour Madame/Monsieur. Je m'appelle _____ et je vous téléphone de la part de Phoenix, une maison de recherche sur l'opinion publique. L'Agence de santé publique du Canada, qui fait partie du gouvernement du Canada, nous a chargés de mener une série de discussions de groupe afin d'étudier avec des Canadiens diverses questions de santé.

Chaque discussion de groupe va durer deux heures tout au plus. Les personnes qui y prendront part toucheront une certaine somme en guise de remerciement et il y aura une collation de servie. Vous êtes tout à fait libre de participer à cette recherche et votre décision de le faire ou non n'aura aucun effet sur les relations que vous avez ou pourriez avoir avec le gouvernement du Canada. Vos réponses seront traitées de façon confidentielle et ne serviront qu'aux fins de la recherche et en conformité avec les lois destinées à protéger les renseignements personnels vous concernant.

Puis-je vous poser quelques questions pour savoir si vous êtes admissible?

Oui	1	
Non	2	REMERCIER/TERMINER L'ENTREVUE

SI LE RÉPONDANT MET EN DOUTE LA VALIDITÉ DE LA RECHERCHE, L'INVITER À TÉLÉPHONER À ROSS DUNCAN DU GOUVERNEMENT CANADIEN OU DEMANDER À ROSS D'APPELER LE RÉPONDANT. ROSS PEUT ÊTRE REJOINT AU (613) 952-5121.

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1. Travaillez-vous ou un membre de votre ménage ou de votre famille immédiate travaille-t-il dans l'un ou l'autre des domaines suivants? (LIRE LA LISTE)

   Recherche en marketing, société de relations publiques ou agence de publicité
   Médias (radio, télévision, journaux, magazines, etc.)
   Ministère ou organisme fédéral, provincial ou municipal de la santé
   Secteur des soins de santé (p. ex., hôpital, clinique, infirmière, médecin, radiologiste, etc.)
   Compagnie de médicaments ou de produits pharmaceutiques
   Produits de santé naturels*

Oui	1	REMERCIER/TERMINER L'ENTREVUE
Non	2	CONTINUER

*SI ON LE DEMANDE, DIRE : « Cela comprend un emploi dans tout domaine relié, par exemple, à des suppléments alimentaires comme les vitamines, les minéraux, les produits d'herboristerie, les aliments naturels et biologiques, les produits d'hygiène ou de ménage et les aliments fonctionnels (nutriceutiques). »

2. Quel est le plus haut niveau de scolarité que vous avez atteint? (LIRE LA LISTE, AU BESOIN; OBTENIR UNE BONNE RÉPARTITION DANS CHAQUE GROUPE)

Moins que l'école secondaire	1	ÉS OU MOINS
École secondaire	2	ÉS OU MOINS
Un peu de collège/école technique/CEGEP	3	POSTSEC
Diplômé de collège/école technique/CEGEP	4	POSTSEC
Un peu d'université	5	POSTSEC
Diplômé d'université	6	POSTSEC

3. Me diriez-vous, s'il vous plaît, dans quel groupe d'âges vous vous situez parmi les suivants…? (LIRE LA LISTE; RECHERCHER LA DIVERSITÉ)

Moins de 18	1	REMERCIER/TERMINER L'ENTREVUE
18-24	2	
25-34	3	
35-44	4	
45-54	5	
55-64	6	
65-70	7	
Plus de 70	8	REMERCIER/TERMINER L'ENTREVUE

4. Depuis environ un an, avez-vous cherché vous-même dans Internet des renseignements en matière de santé? Cela comprend des renseignements touchant, par exemple, la santé et le mieux-être, des maladies ou affections, des médicaments ou vitamines. (VOUS ASSURER QU'AU MOINS LA MOITIÉ L'ONT FAIT. PAS DE MAXIMUM – I.E. TOUS POURRAIENT L'AVOIR FAIT)

Oui	1
Non	2
Je n'utilise pas Internet	3

5. Consommez-vous régulièrement des produits de santé naturels en vente libre? Cela comprend, par exemple, les vitamines et minéraux, les produits d'herboristerie, homéopathiques, de médicine traditionnelle et ainsi de suite. (VOUS ASSURER QU'AU MOINS LA MOITIÉ LE FONT. PAS DE MAXIMUM – I.E. TOUS POURRAIENT LE FAIRE)

Oui	1
Non	2

6. Quelle est votre situation de famille? (ASSURER UNE BONNE DIVERSITÉ)

Marié/conjoint de fait	1
Célibataire/divorcé/veuf/séparé	2

7. Avez-vous des enfants de moins de 18 ans qui vivent avec vous à votre domicile? Il peut s'agir d'enfants qui vivent avec vous à temps plein ou à temps partiel dans le cadre d'une garde partagée. (SURVEILLER LES QUOTAS. VOIR À CE QU'AU MOINS LA MOITIÉ AIENT DES ENFANTS À LA MAISON)

Oui	1

Non 2

8. De quel groupe ethnique ou culturel faites-vous partie?* (ASSURER UNE BONNE DIVERSITÉ)

   Groupe ethnoculturel : _____

   ***NOTE** : SI LE RÉPONDANT NE COMPREND PAS BIEN LE SENS DE LA QUESTION, LUI DONNER DES EXEMPLES (P. EX., CANADIEN FRANÇAIS, CANADIEN ANGLAIS, CANADIEN AUTOCHTONE, CHINOIS, ETC.).

9. Au cours des 12 derniers mois, quel a été le revenu global de votre ménage, de toutes sources, avant impôts et déductions? Était-ce…? (LIRE LA LISTE; OBTENIR UNE DIVERSITÉ.)

Moins de 20 000 $	1
20 001 $ à 40 000 $	2
40 001 $ à 60 000 $	3
60 001 $ à 80 000 $	4
80 001 $ à 100 000 $	5
Plus de 100 000 $	6

10. Avez-vous déjà pris part à une discussion de groupe ou à une entrevue organisée à l'avance et pour laquelle vous avez reçu une petite somme d'argent?

Oui	1	
Non	2	ALLER À LA FIN DE LA SECTION

11. Quand avez-vous pris part la dernière fois à l'une de ces discussions ou entrevues?

Il y a moins de 12 mois	1	REMERCIER/TERMINER L'ENTREVUE
Il y a plus de 12 mois	2	

12. Avez-vous pris part à plus de trois discussions de groupe ou entrevues rémunérées au cours de votre vie?

Oui	1	REMERCIER/TERMINER L'ENTREVUE
Non	2	

INSCRIRE LE SEXE D'APRÈS VOTRE OBSERVATION (ASSURER UNE ASSEZ BONNE DIVERSITÉ)

Femme	1
Homme	2

La discussion de groupe aura lieu le (JOUR DE LA SEMAINE), (DATE/MOIS), à (HEURE). Elle devrait durer environ deux heures. Comme je l'ai mentionné, les participants vont recevoir

60 $ pour les remercier de nous avoir accordé de leur temps, et il y aura une collation de servie. Seriez-vous d'accord pour y participer?

Oui	1	
Non	2	REMERCIER/TERMINER L'ENTREVUE

Avez-vous un crayon sous la main pour prendre note de l'adresse où aura lieu la discussion de groupe? Ce sera à _____. Dites aux préposés que vous venez pour une discussion de groupe. Je vous rappelle que la séance sera à (HEURE) le (DATE). Veuillez vous présenter 20 minutes à l'avance pour pouvoir remplir un bref questionnaire. Si vous avez besoin de lunettes pour lire, n'oubliez pas de les apporter.

La discussion sera enregistrée sur bande vidéo aux fins de la recherche et des membres de l'équipe de recherche en observeront le déroulement dans une pièce adjacente. On va vous demander votre consentement écrit à l'enregistrement sur bande vidéo au cours de la séance. Cet enregistrement ne servira qu'aux travaux de recherche réalisés par : 1) les employés de Phoenix Strategic Perspectives; 2) les employés et entrepreneurs de l'Agence de santé publique du Canada et de Santé Canada; 3) une équipe de chercheurs de l'Université d'Ottawa et de l'Université de l'Alberta qui travaillent dans ce domaine. Tous les renseignements recueillis serviront uniquement à des fins de recherche et seront traités conformément aux dispositions des lois visant à protéger les renseignements personnels.

Puisque nous n'invitons qu'un petit nombre de personnes, votre participation nous est très importante. Si pour une raison quelconque il vous est impossible de vous présenter, veuillez nous en avertir afin que nous puissions vous trouver un remplaçant. Vous pourrez téléphoner à notre bureau, au ____. Demandez à parler à ____. Quelqu'un va vous appeler la veille de la discussion de groupe pour vous rappeler sa tenue.

Pouvez-vous me confirmer votre nom et votre numéro de téléphone?

NOM DU RÉPONDANT :
NUMÉRO DE TÉLÉPHONE À LA MAISON :
MOMENT/LIEU DE L'ENTREVUE :

Merci beaucoup.

Recruitment Screener: Health Care Providers

PROFILE CHARACTERISTICS

- Four focus groups in two locations: Toronto [2] and Vancouver [2].
- One group in each city to be conducted with doctors and pharmacists, and the other with naturopaths, dietitians and nutritionists.
- The groups with doctors and pharmacists to include a mix of doctors by type of practice (e.g. family doctors, private clinics, community/public health, acute vs. long-term care), and pharmacists by practice setting.
- The groups with naturopaths, dietitians and nutritionists to include a mix by type of practitioner and type of practice (includes sports nutritionists).
- All groups to include a mix by age, with an approximate gender split.
- Doctors and pharmacists to be paid $200 to participate, and naturopaths, dietitians and nutritionists to receive $100.
- 8 participants to be recruited for 5-6 to show per group.
- At least half to have never participated in a focus group/paid interview.
- Sponsorship of the study to be revealed (i.e. PHAC/Government of Canada). Disclosure will also identify university researchers.
- The following table presents the proposed distribution and timing of the groups:

	Vancouver	**Toronto**
	English	**English**
Date	**Nov. 26**	**Nov. 27**
6:00 pm	Naturopaths Dietitians/Nutritionists	Doctors/Pharmacists
8:00 pm	Doctors/Pharmacists	Naturopaths Dietitians/Nutritionists

SCREENER

Hello, my name is _____. I'm calling on behalf of Phoenix, a public opinion research firm. We've been commissioned by the Public Health Agency of Canada, part of the Government of Canada, to conduct a series of discussion groups to explore health-related issues with practitioners.

Each discussion group will last up to two hours. People who take part will be paid a cash honorarium to thank them for their time, and light refreshments will be served. Participation in the research is completely voluntary and your decision on whether or not to participate will not affect any dealings you may have with the Government of Canada. Your answers will be kept confidential and will be used for research purposes only in accordance with laws designed to protect your privacy. Participation in this research is limited to one discussion group only (i.e. no ongoing commitment involving multiple sessions).

May I ask you a few questions to see whether you qualify for the research?

Yes	1	
No	2	THANK/DISCONTINUE

IF RESPONDENT QUESTIONS VALIDITY OF THE RESEARCH, INVITE HIM/HER TO CALL ROSS DUNCAN OF THE GOVERNMENT OF CANADA OR HAVE ROSS CALL THE RESPONDENT. ROSS CAN BE REACHED AT (613) 952-5121.

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1. Do you, or does any member of your household or immediate family, work in any of the following fields? (READ LIST)

   Marketing research, public relations firm, or advertising agency
   The media (radio, television, newspapers, magazines, etc.)
   Federal, provincial or municipal government health department/agency

Yes	1	THANK/DISCONTINUE
No	2	CONTINUE

ASK DOCTORS:

2. What is your specialty? (READ LIST, GET MIX)

Family practice	1
Internal medicine or related sub-specialty	2
Surgical specialty	3
Psychiatry	4
Other. Please specify: _____	

3. What is your work setting? (READ LIST, GET MIX)

Private office or clinic	1
Community clinic	2
Academic health centre	3
Community hospital	4
Nursing home	5
Other. Please specify: _____	

4. Do you offer nutrition counselling?

Yes	1
No	2

GO TO Q11

ASK PHARMACISTS:

5. Do you work in a…? (READ LIST, GET MIX)

Hospital	1
Long-term care institution	2
Community setting	3
Other. Please specify: _____	

GO TO Q11

ASK NATUROPATHS:

6. What is your work setting? (READ LIST, GET MIX)

Solo practice	1
Hospital	2
Multi-disciplinary clinic	3
Specialized health centre	4
Other. Please specify: _____	

7. Do you serve special populations or offer specialized services (e.g. nutritional advice for athletes, genetic-based nutrition)? If so, what type of specialized population or services? (GET MIX)

No	1
Yes,	
Sports medicine	2
Genetics	3
Other. Please specify: _____	

8. Do you offer nutrition counselling?

Yes	1
No	2

GO TO Q11

ASK DIETITIANS/NUTRITIONISTS:

9. What is your work setting? (READ LIST, GET MIX)

Hospital or other clinical setting	1
Other institution (e.g. school, nursing home)	2
Private practice or consulting	3
Food industry	4
Other. Please specify: _____	

10. Which of the following titles best describes your position? (READ LIST; GET MIX)

Dietitian	1
Registered dietitian	2
Diet technician	3
Nutritionist	4

ASK EVERYONE:

11. Could you please tell me which of the following age groups you fall into…? (READ LIST; GET MIX)

18-24	1
25-34	2
35-44	3
45-54	4
55-64	5
65-70	6
Over 70	7

12. Have you ever attended a discussion group or interview which was arranged in advance and for which you received a small sum of money?

Yes	1	
No	2	GO TO END SECTION

13. When did you last attend one of these discussion groups or interviews?

Less than 12 months ago	1	THANK/DISCONTINUE
Over 12 months ago	2	

14. Have you attended more than three discussion groups or paid interviews in your lifetime?

Yes	1	THANK/DISCONTINUE
No	2	

RECORD GENDER BY OBSERVATION (GET MIX)

Female	1
Male	2

The group discussion will take place on (DAY OF WEEK), (MONTH/DATE), at (TIME). It will last approximately two hours. As mentioned, people who attend will receive ($200 for Doctors/Pharmacists; $100 for Naturopaths/Dietitians/Nutritionists) to thank them for their time, and light refreshments will be served. Would you be willing to attend?

Yes	1	
No	2	THANK/DISCONTINUE

Do you have a pen handy so that I can give you the address where the discussion group will be held? It will be held at _____. Please tell people you are there for a focus group. I would like to remind you that the group is at (TIME) on (DATE). Please come 20 minutes early because there will be a short questionnaire we would like you to fill out. If you use glasses to read, please remember to bring them with you.

The group will be video-taped for research purposes and members of the research team will be observing the discussion from an adjoining room. You will be asked to sign a waiver to acknowledge that you will be video-taped during the session. The video recordings will only be used for research purposes by: (1) employees of Phoenix Strategic Perspectives; (2) employees and contractors of the Public Health Agency of Canada and Health Canada; and (3) a research team based at the University of Ottawa and University of Alberta that is working on issues related to this research. All information collected will be used for research purposes only and administered in accordance with laws designed to protect your privacy.

As we are only inviting a small number of people to attend, your participation is very important to us. If for some reason you are unable to attend, please call so that we can get someone to replace you. You can reach us at ____ at our office. Please ask for ____. Someone will call you the day before to remind you about the discussion group.

Could I please confirm your name and phone number?

RESPONDENT'S NAME: _____
BUSINESS PHONE #: _____
INTERVIEW TIME/LOCATION: _____

Entrevue de sélection : fournisseurs de soins de santé

CARACTÉRISTIQUES DU PROFIL

- Quatre discussions de groupe à deux endroits : Toronto [2] et Vancouver [2].
- Dans chaque ville, un groupe formé de médecins et de pharmaciens, l'autre de naturopathes, de diététistes et de nutritionnistes.
- Les groupes de médecins et de pharmaciens doivent comprendre des médecins de pratiques variées (p. ex., médecins de famille, qui exercent en clinique privée, qui font de la santé publique/communautaire, qui procurent des soins aigus ou de longue durée) et des pharmaciens qui travaillent dans divers établissements.
- Les groupes de naturopathes, de diététistes et de nutritionnistes doivent présenter une diversité de praticiens et de genres de discipline (et comprendre des nutritionnistes des sports).
- Tous les groupes doivent comprendre des personnes d'âges divers et une bonne répartition d'hommes et de femmes.
- Les médecins et pharmaciens recevront 200 $ en guise de remerciement et les naturopathes, diététistes et nutritionnistes recevront 100 $.
- Il faut recruter 8 participants pour que 5 ou 6 se présentent dans chaque groupe.
- La moitié au moins doivent n'avoir <u>jamais</u> participé à une discussion de groupe/entrevue rémunérée.
- Le commanditaire de l'étude sera révélé (i.e. ASPC/gouvernement du Canada). On mentionnera aussi des chercheurs universitaires.
- Le tableau ci-dessous présente la composition des groupes et le moment de la discussion, tels qu'envisagés :

	Vancouver	**Toronto**
	Anglais	**Anglais**
Date	**26 nov.**	**27 nov.**
18 h	Naturopathes/ diététistes/nutritionnistes	Médecins/pharmaciens
20 h	Médecins/pharmaciens	Naturopathes/ diététistes/nutritionnistes

ENTREVUE DE SÉLECTION

Bonjour Madame/Monsieur. Je m'appelle _____ et je vous téléphone de la part de Phoenix, une maison de recherche sur l'opinion publique. L'Agence de santé publique du Canada, qui fait partie du gouvernement du Canada, nous a chargés de mener une série de discussions de groupe afin d'étudier diverses questions avec des professionnels de la santé.

Chaque discussion de groupe va durer deux heures tout au plus. Les personnes qui y prendront part toucheront une certaine somme en guise de remerciement et il y aura une collation de servie. Vous êtes tout à fait libre de participer à cette recherche et votre décision de le faire ou non n'aura aucun effet sur les relations que vous avez ou pourriez avoir avec le gouvernement du Canada. Vos réponses seront traitées de façon confidentielle et ne serviront qu'aux fins de la recherche, en conformité avec les lois destinées à protéger les renseignements personnels vous concernant. La participation à la présente recherche se limite à une seule discussion de groupe (i. e. il n'y aura pas d'engagement de votre part à participer à plusieurs séances).

Puis-je vous poser quelques questions pour savoir si vous êtes admissible?

Oui	1	
Non	2	REMERCIER/TERMINER L'ENTREVUE

SI LE RÉPONDANT MET EN DOUTE LA VALIDITÉ DE LA RECHERCHE, L'INVITER À TÉLÉPHONER À ROSS DUNCAN DU GOUVERNEMENT CANADIEN OU DEMANDER À ROSS D'APPELER LE RÉPONDANT. ROSS PEUT ÊTRE REJOINT AU (613) 952-5121.

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1. Travaillez-vous ou un membre de votre ménage ou de votre famille immédiate travaille-t-il dans l'un ou l'autre des domaines suivants? (LIRE LA LISTE)

   Recherche en marketing, société de relations publiques ou agence de publicité
   Médias (radio, télévision, journaux, magazines, etc.)
   Ministère ou organisme fédéral, provincial ou municipal de la santé

Oui	1	REMERCIER/TERMINER L'ENTREVUE
Non	2	CONTINUER

DEMANDER AUX MÉDECINS :

2. Quelle est votre spécialité? (LIRE LA LISTE, ASSURER UNE DIVERSITÉ)

Pratique familiale	1
Médecine interne ou sous-spécialité connexe	2
Spécialité chirurgicale	3
Psychiatrie	4
Autre. Veuillez préciser : _____	

3. Dans quel établissement travaillez-vous? (LIRE LA LISTE, ASSURER UNE DIVERSITÉ)

Cabinet privé ou clinique privée	1
Clinique communautaire	2
Centre de santé universitaire	3
Hôpital communautaire	4
Établissement de soins infirmiers	5
Autre. Veuillez préciser : _____	

4. Offrez-vous des conseils nutritionnels?

Oui	1
Non	2

PASSER À Q11

DEMANDER AUX PHARMACIENS :

5. Travaillez-vous dans…? (LIRE LA LISTE, ASSURER UNE DIVERSITÉ)

Un hôpital	1
Un établissement de soins de longue durée	2
Un établissement communautaire	3
Autre. Veuillez préciser : _____	

PASSER À Q11

DEMANDER AUX NATUROPATHES :

6. Dans quel établissement travaillez-vous? (LIRE LA LISTE, ASSURER UNE DIVERSITÉ)

Bureau indépendant	1
Hôpital	2
Clinique multidisciplinaire	3
Centre de santé spécialisé	4
Autre. Veuillez préciser : _____	

7. Servez-vous des populations particulières ou offrez-vous des services spécialisés (p. ex., conseils nutritionnels à des athlètes, nutrition fondée sur la génétique)? En l'occurrence, quels genres de population particulière ou de services spécialisés? (ASSURER UNE DIVERSITÉ)

Non	1
Oui,	
Médecine sportive	2
Génétique	3
Autre. Veuillez préciser : _____	

8. Offrez-vous des conseils nutritionnels?

Oui	1
Non	2

PASSER À Q11

DEMANDER AUX DIÉTÉTISTES/NUTRITIONNISTES :

9. Dans quel établissement travaillez-vous? (LIRE LA LISTE, ASSURER UNE DIVERSITÉ)

Hôpital ou clinique	1
Autre établissement (p. ex., école, centre de soins infirmiers)	2
Pratique privée ou consultation	3
Industrie alimentaire	4
Autre. Veuillez préciser : _____	

10. Lequel des titres suivants décrit le mieux votre position? (LIRE LA LISTE; ASSURER UNE DIVERSITÉ)

Diététiste	1
Diététiste professionnel	2
Technicien en diététique	3
Nutritionniste	4

DEMANDER À TOUS :

11. Me diriez-vous, s'il vous plaît, dans quel groupe d'âges vous vous situez parmi les suivants…? (LIRE LA LISTE; ASSURER UNE DIVERSITÉ)

18-24	1
25-34	2
35-44	3
45-54	4
55-64	5
65-70	6
Plus de 70	7

12. Avez-vous déjà pris part à une discussion de groupe ou à une entrevue organisée à l'avance et pour laquelle vous avez reçu une petite somme d'argent? .

Oui	1	
Non	2	ALLER À LA FIN DE LA SECTION

13. Quand avez-vous pris part la dernière fois à l'une de ces discussions ou entrevues?

Il y a moins de 12 mois	1	REMERCIER/TERMINER L'ENTREVUE
Il y a plus de 12 mois	2	

14. Avez-vous pris part à plus de trois discussions de groupe ou entrevues rémunérées au cours de votre vie?

Oui	1	REMERCIER/TERMINER L'ENTREVUE
Non	2	

INSCRIRE LE SEXE D'APRÈS VOTRE OBSERVATION (ASSURER UNE DIVERSITÉ)

Femme	1
Homme	2

La discussion de groupe aura lieu le (JOUR DE LA SEMAINE), (DATE/MOIS), à (HEURE). Elle devrait durer environ deux heures. Comme je l'ai mentionné, les participants vont recevoir (200 $, médecins/pharmaciens; 100 $, naturopathes/diététistes/nutritionnistes) pour les remercier de nous avoir accordé de leur temps, et il y aura une collation de servie. Seriez-vous d'accord pour y participer?

Oui	1	
Non	2	REMERCIER/TERMINER L'ENTREVUE

Avez-vous un crayon sous la main pour prendre note de l'adresse où aura lieu la discussion de groupe? Ce sera à _____. Dites aux préposés que vous venez pour une discussion de groupe. Je vous rappelle que la séance sera à (HEURE) le (DATE). Veuillez vous présenter 20 minutes à l'avance pour pouvoir remplir un bref questionnaire. Si vous avez besoin de lunettes pour lire, n'oubliez pas de les apporter.

La discussion sera enregistrée sur bande vidéo aux fins de la recherche et des membres de l'équipe de recherche en observeront le déroulement dans une pièce adjacente. On va vous demander votre consentement écrit à l'enregistrement sur bande vidéo au cours de la séance. Cet enregistrement ne servira qu'aux travaux de recherche réalisés par : 1) les employés de Phoenix Strategic Perspectives; 2) les employés et entrepreneurs de l'Agence de santé publique du Canada et de Santé Canada; 3) une équipe de chercheurs de l'Université d'Ottawa et de l'Université de l'Alberta qui travaillent dans ce domaine. Tous les renseignements recueillis serviront uniquement à des fins de recherche et seront traités conformément aux dispositions des lois visant à protéger les renseignements personnels.

Puisque nous n'invitons qu'un petit nombre de personnes, votre participation nous est très importante. Si pour une raison quelconque il vous est impossible de vous présenter, veuillez nous en avertir afin que nous puissions vous trouver un remplaçant. Vous pourrez téléphoner à notre bureau, au ____. Demandez à parler à ____. Quelqu'un va vous appeler la veille de la discussion de groupe pour vous rappeler sa tenue.

Pouvez-vous me confirmer votre nom et votre numéro de téléphone?

NOM DU RÉPONDANT : _____
NUMÉRO DE TÉLÉPHONE AU TRAVAIL : _____
MOMENT/LIEU DE L'ENTREVUE : _____

MODERATOR'S GUIDES

General Public

Introduction (5 minutes)

- Introduce moderator/Phoenix
- Thanks for attending/value your being here
- Explain general purpose of focus group discussions:

  - Gauge *opinions* about issues/ideas/products

  - Not a knowledge test; no right or wrong answers (interested in opinions)

  - Okay to disagree; want people to speak up if hold different view
- Tonight, we're conducting research on behalf of Health Canada to explore issues related to personal nutrition and health.
- Looking for candour and honesty; comments treated in confidence; reporting in aggregate form only; observers behind one-way mirror; taping for note-taking purposes only.
- The video recordings and your completed questionnaires will only be used by Phoenix researchers and University of Ottawa researchers, who are working with Health Canada on this project.
- Duration: 2 hours
- Please turn off cell phones, pagers, etc.
- Any questions? ACCEPT BRIEF QUESTIONS BUT DO NOT LINGER.
- Lot to cover tonight, so will move on quickly at times.
- Roundtable introduction: please tell us your first name and one of your favourite interests or hobbies.

Contextual Issues (20 minutes)

I'd like to start with a few questions about factors related to personal health.

1. What would you say are the most important factors related to personal health?

   Probe: - food and nutrition, exercise, family history, drugs, vitamins, supplements, herbs etc.

2. To what extent do you think a person's diet – what they eat – affects their health? Why do you say that? In what ways does diet affect health?

   Probe: - effects other than weight gain

3. How interested would you say you are in the link between personal nutrition and the health of you/your family? What types of things interest you in this area? And what types of things do not interest you?

4. Have you ever looked for information related to personal nutrition and health, either for yourself or other family members? If so, what type of information did you look for? Where did you go for this type of information? Were you able to obtain what you wanted? If not, why not? If so, was it useful?

   Probe: - types of information
   - information sources
   - most trustworthy sources of information
   - value/usefulness of information (and why)

5. Have you taken any (other) action to improve the health of you/your family through personal nutrition or diet, including things like taking vitamins and supplements? [HAND COUNT] If so, what type of actions or activities have you undertaken? Any others?

6. To what extent do you think a person's genetic make-up affects their health? By genetic make-up, I mean the genes that you were born with, handed down to you from your biological parents. In what ways does someone's genetic make-up affect their health?

   Probe: - nature of link between genetics and health
   - family history seen to equate to genetic make-up?

7. How good an understanding do you think you have about how genetics affects your health or the health of family members? Do you have examples of how your genetic make-up, or the genetic make-up of family members, affects your/their health?

8. Do you think your genetic make-up, or the genetic make-up of family members, influences how your/their body responds to food? If so, in what ways? Do you have any examples of this? Is this something you would like to know more about? Why/why not? Is there anything specific you would want to know?

Awareness & Initial Perceptions of Nutrigenomics (15 minutes)

9. Before tonight, who had previously heard the term 'nutrigenomics'? Just so you know, I had never heard of it before I became involved in this project. So, who had heard of this term before? [HAND COUNT]

10. What comes to mind when you hear the term 'nutrigenomics'? What did people write down on the short questionnaire we asked you to complete before the focus group began? Anything else? [ROUNDTABLE REVIEW OF WHAT PEOPLE WROTE]

11. And what did people write down for 'personalized nutrition' on the questionnaire we asked you to complete? Anything else?

I'd now like to give you a definition of 'nutrigenomics'.

Nutrigenomics is about how our genetic makeup affects how we respond to what we eat and drink, and how we can change our diet to help promote health and reduce our genetic risks of disease. For instance, because of differences in their genetic makeup, some people respond differently to caffeine. Recent clinical research has identified a range of health effects associated with the consumption of caffeine. For example, three people that drink two cups of coffee every day can experience three distinct health effects because of their genetic make-up:

- One person may not be affected at all
- Another person may be at greater risk for heart disease, and
- The third person may reduce their risk of heart disease.

12. After hearing this definition or description of 'nutrigenomics', what does it make you think of? That is, please tell me in your own words what you think nutrigenomics is, and what it is not.

    Probe: - understanding of nutrigenomics based on definition
    - avoid trying to answer questions, just note questions

13. If you wanted to know more about how your unique genetic make-up affects your personal nutrition and health, where would you go for this type of information? Why? Would you go to a health care professional? If yes, what type of health care professional?

    Probe: - preferred sources of information (e.g. websites, magazines)
    - go-to health professional

14. Have you seen or heard about any nutrigenomic services available to Canadians that explore the link between someone's genetic make-up, their nutrition and their health? That is, are you aware of any companies currently offering services in this area? Have you heard of any tests being marketed on radio, TV or in print trying to get people to have their personal genetic make-up mapped out?

IF YES, ASK:

15. What do you know about this? How did you hear about it?

    Probe: - type of service provider and service(s) (e.g. nutrigenomic testing)

Exposure to Article & Website(s) (40 mins)

I'm now going to hand out an article that appeared in the media about nutrigenomics. I'd like you to read the article, on your own in silence, and then we'll talk about it when everyone is finished. Please circle anything that is unclear to you.

HAND OUT COPIES OF ARTICLE. ONCE PEOPLE HAVE READ IT, CONTINUE.

16. What's your initial reaction to the article? What did it make you think about? Anything else?

17. When reading the article, what stood out? That is, what caught your attention? Why? Anything else?

18. What does the article say to you about the role genes play in your health and making you who you are, including your health? Have you changed your thinking on the role of genes? If so, how?

19. How much do you trust the content of the article? Why do you say that?

ROTATE NEXT TWO QUESTIONS:

20. In your opinion, are there risks or potential harm associated with nutrigenomic testing like that described in the article? If yes, what are they? Any others? How likely do you think it is that this would actually occur?

21. In your opinion, are there benefits associated with nutrigenomic testing like that described in the article? If yes, what are the benefits? Any others? How likely do you think it is that this would actually occur?

22. Overall, do you think the benefits exceed the potential harms in nutrigenomic testing?

23. Does reading the article encourage or motivate you to look for more information about nutrigenomics? Why/why not? If yes, where would you go for this information? Who would you trust to provide you with reliable information about genetics and nutrition?

24. What questions do you have about nutrigenomics after reading the article? That is, what else would you like to know? Anything else?

25. Does reading the article encourage or motivate you get a genetic test done for you or someone else in your family? Why/why not? Is there anything else you would want to know before you went and had a nutrigenomic test?

I'd now like to review some pages that were pulled from websites of firms that offer nutrigenomic services. I'm going to walk you through a few pages, and then we'll talk about them when I'm finished.

MODERATOR SHOWS WEB PAGES USING PROJECTOR/SCREEN, AND DRAWS ATTENTION TO VARIOUS FEATURES/ELEMENTS. ONCE FINISHED, CONTINUE.

26. What's your initial reaction to the website information? Why do you say that?

27. Did you learn anything new? If so, what more did you learn about nutrigenomics? Was this important or useful information? Do you trust this information?

28. What do you think about consumers buying tests like these over the Internet?

29. Do you think information from these types of tests would be useful, either for you or others? Why/why not? What would you expect to receive from the firm in terms of results?

    Probe: - what expect to do next with the information
    - expect it to give them specific instructions
    - excepted acuracy of results

30. How interested would you say you are in considering nutrigenomic testing for you or your family? Why do you say that?

    Probe: - which group are people in?
    1) ready to consider getting a nutrigenomic test
    2) need to know more before they considering test
    3) would avoid getting nutrigenomic test regardless

31. Is there something else you would want to know before deciding whether or not to pursue nutrigenomic testing for you/your family? If so, what? Where would you go for this information?

32. Do you think you would be more likely to change your dietary behaviour if you had nutrigenomic testing than if you were simply given dietary advice (for example, from the Canadian Food Guide) without any genetic information? If so, why?

33. What do you think would be the main benefits or advantages of such tests? And what do you think would be the main drawbacks or disadvantages of such tests?

34. If you had genetic testing done by buying the service from a company over the Internet, do you think it would be easy to interpret the results? Why/why not? If you needed help understanding the results, where would you go for that help?

Review of Information Document on Nutrigenomics (35 minutes)

I'd now like you to read a short document about nutrigenomics prepared for use with these focus groups. I'll give you about 7-8 minutes to read this. Please read it on your own, in silence, and we'll talk about it as a group when everyone is finished. When you are reading the document, please circle anything that is unclear to you, and put a 'plus sign' beside anything you reacted positively to, and a 'negative sign' besides anything you reacted

negatively to, for whatever reason, or potentially caused concern. Is this clear? CLARIFY AS NEEDED.

HAND OUT DOCUMENT, ALLOW RESPONDENTS 7-8 MINUTES TO READ IT. CONTINUE.

35. First, what's your initial reaction to what you just read? Why? Anything else?

36. What did this information make you think about? What stood out and caught your attention? What did you react positively to and put 'plus signs' beside? And what did you react negatively to or caused concern (put 'negative signs beside)?

    Probe: - information with plus signs and negative signs

37. Did reading this information change your understanding of nutrigenomics in any way? If so, in what way(s)? Does it add clarity or not?

38. Are there things about nutrigenomics that are still not clear to you? If so, what? After everything you've looked at tonight, do you have any questions that have not been answered? That is, anything else you'd like to know? If so, what? Who would you want to get that information from?

ROTATE NEXT TWO QUESTIONS:

So, based on what you have read and heard tonight,

39. Are there risks or potential harm associated with using nutrigenomic testing? If yes, what are they? How likely do you think this would actually occur? What could be done to prevent or reduce the potential harm?

40. Are there benefits associated with using nutrigenomic testing? If yes, what are the benefits? How likely do you think it is that this would actually occur?

41. All things considered, how interested are you in considering nutrigenomic testing for you or your family? Why? Are there any circumstances that would increase the likelihood of you being more interested in considering such tests?

    Probe: - specific illness in the family

Related Issues (5 minutes)

42. What type of information is it important for Canadians to know so that they can make an informed decision about nutrigenomics, and whether it is something for them or their family? Anything else?

    Probe: - information types: non-commercial, government/health agency, nutritional supplement manufacturer, doctor's visit

43. And what do you think is the best way to inform Canadians about this type of information?

44. Who do you trust to give you up-to-date and accurate information on this kind of testing?

Conclusion

45. Do you have any final comments or suggestions about anything we've talked about tonight before we conclude the discussion?

THANK PARTICIPANTS AND COLLECT MATERIALS.

Grand public

Introduction (5 minutes)

- Présenter l'animateur et Phœnix.
- Remercier les participants de leur présence et souligner l'importance de celle-ci.
- Expliquer le but de ce genre de rencontre :

  - recueillir vos *opinions* sur les questions, les idées ou les produits présentés;

  - il ne s'agit pas d'évaluer vos connaissances; il n'y a pas de bonnes ou de mauvaises réponses (nous voulons connaître votre opinion);

  - vous avez le droit de ne pas être d'accord; n'hésitez pas à exprimer un point de vue différent.
- Ce soir, nous réalisons une étude pour Santé Canada au sujet de la nutrition et de la santé.
- Nous vous demandons d'être francs et honnêtes. Les commentaires seront traités de manière confidentielle. Nous ne rapporterons que l'ensemble des commentaires. Il y a des observateurs derrière le miroir sans tain. L'enregistrement servira uniquement à la préparation du rapport.
- L'enregistrement vidéo et les questionnaires que vous avez remplis seront utilisés uniquement par les chercheurs de Phœnix et de l'Université d'Ottawa qui travaillent avec Santé Canada sur ce projet.
- Durée : 2 heures
- Veuillez désactiver la sonnerie de votre téléphone cellulaire, de votre téléavertisseur, etc.
- Avez-vous des questions ? RÉPONDRE BRIÈVEMENT. NE PAS S'ATTARDER SUR CES QUESTIONS.
- Nous avons beaucoup de pain sur la planche ce soir, donc nous devrons accélérer les choses par moments.
- Présentations par tour de table : Veuillez vous présenter par votre prénom et nous parler d'un de vos principaux intérêts ou d'un de vos passe-temps préférés.

Questions contextuelles (20 minutes)

Commençons par quelques questions au sujet des facteurs qui influencent la santé.

1. Selon vous, quels sont les plus importants facteurs qui influencent la santé ?

   Sonder : - aliments et nutrition, exercice, antécédents familiaux, médicaments, vitamines, suppléments, plantes, etc.

2. Dans quelle mesure le régime alimentaire d'une personne – ce qu'elle mange – affecte-t-il sa santé ? Pourquoi dites-vous cela ? Comment le régime alimentaire affecte-t-il la santé ?

   Sonder : - effets autres que la prise de poids

3. Dans quelle mesure vous intéressez-vous au lien entre l'alimentation et votre santé ou celle de votre famille ? Qu'est-ce qui vous intéresse à ce chapitre ? Et qu'est-ce qui ne vous intéresse pas ?

4. Avez-vous déjà cherché des renseignements sur l'alimentation et la santé, pour vous-mêmes ou pour un membre de votre famille ? Si oui, quels genres de renseignements avez-vous cherchés ? Où avez-vous cherché ces renseignements ? Avez-vous obtenu les renseignements que vous cherchiez ? Si non, pourquoi ? Si oui, les renseignements vous ont-ils été utiles ?

   Sonder : - genres de renseignements
   - sources de renseignements
   - sources les plus dignes de confiance
   - utilité des renseignements (et pourquoi)

5. Avez-vous fait quelque chose (ou autre chose) pour améliorer votre santé ou celle de votre famille au moyen de l'alimentation ou par la prise de vitamines et de suppléments ? [DEMANDER AUX PARTICIPANTS DE LEVER LA MAIN; COMPTER] Si oui, qu'avez-vous fait ? Autre chose ?

6. Selon vous, dans quelle mesure le patrimoine génétique d'une personne influence-t-il sa santé ? Par « patrimoine génétique » j'entends les gènes hérités à la naissance de vos parents biologiques. Comment le patrimoine génétique d'une personne influence-t-il sa santé ?

   Sonder : - nature du lien entre la génétique et la santé
   - associe-t-on les antécédents familiaux au patrimoine génétique ?

7. Jusqu'à quel point comprenez-vous bien la façon dont la génétique influence votre santé ou celle de votre famille ? Pouvez-vous nous donner un exemple de la façon dont votre patrimoine génétique influence votre santé ou la façon dont le patrimoine génétique des membres de votre famille influence leur santé ?

8. Croyez-vous que votre patrimoine génétique influence la façon dont votre corps réagit aux aliments ou que le patrimoine génétique des membres de votre famille influence la façon dont leur corps réagit aux aliments qu'ils consomment ? Si oui, comment ? Pouvez-vous nous donner un exemple ? Aimeriez-vous en savoir davantage à ce sujet ? Pourquoi / pourquoi pas ? Aimeriez-vous savoir quelque chose en particulier ?

Connaissance de la nutrigénomique et opinions initiales sur le sujet (15 minutes)

9. Avant ce soir, qui avait déjà entendu le terme « nutrigénomique » ? Je vous avoue que je n'avais jamais encore entendu ce terme avant de participer à ce projet. Donc, qui avait déjà entendu ce terme ? [DEMANDER AUX PARTICIPANTS DE LEVER LA MAIN; COMPTER]

10. Qu'est-ce qui vous vient à l'esprit quand vous entendez le terme « nutrigénomique » ? Qu'avez-vous écrit dans le petit questionnaire que nous vous avons demandé de remplir avant la rencontre ? Autre chose ? [TOUR DE TABLE POUR SAVOIR CE QUE LES PARTICIPANTS AVAIENT ÉCRIT]

11. Et qu'avez-vous écrit sur la signification de « nutrition individualisée », dans le questionnaire que nous vous avons demandé de remplir ? Autre chose ?

J'aimerais maintenant vous donner une définition de « nutrigénomique ».

La **nutrigénomique** s'intéresse à l'influence de notre patrimoine génétique sur la façon dont notre corps réagit à ce que nous consommons et aux changements que nous pouvons apporter à notre alimentation pour améliorer notre santé et réduire le risque de maladie héréditaire. Par exemple, en raison d'un patrimoine génétique différent, certaines personnes réagissent différemment à la caféine. Des recherches cliniques récentes ont identifié une gamme d'effets sur la santé associés avec la consomption de caféine. Par exemple, trois personnes qui consomment deux tasses de café par jour peuvent faire l'expérience de trois effets distincts sur la santé à cause de leur patrimoine génétique :

- Une personne pourrait ne pas être affectée du tout
- Une autre personne pourrait accroitre son risque de maladie du cœur, et
- La troisième personne pourrait réduire son risque de maladie du cœur.

12. Après avoir entendu cette définition ou description de la nutrigénomique, qu'est-ce qui vous vient à l'esprit ? Dites-moi ce qu'est la nutrigénomique, en vos propres mots, et ce qu'elle n'est pas.

    Sonder : - compréhension de la nutrigénomique à partir de la définition
    - noter les questions sans essayer d'y répondre

13. Si vous vouliez savoir comment votre propre patrimoine génétique influence votre nutrition ou votre santé, où vous adresseriez-vous pour obtenir ces renseignements ? Pourquoi ? Consulteriez-vous un professionnel de la santé ? Si oui, quel genre de professionnel de la santé ?

    Sonder : - sources de renseignements privilégiées (sites Web, revues, etc.)
    - consultation d'un professionnel de la santé

14. Êtes-vous au courant ou avez-vous entendu parler de services d'analyse nutrigénomique, offerts aux Canadiens, dans le cadre desquels on étudie le lien entre le patrimoine génétique d'une personne, son alimentation et sa santé ? Autrement dit,

connaissez-vous des entreprises offrant ce genre de services actuellement ? Avez-vous entendu parler de publicités à la radio, à la télévision, dans les journaux ou les revues faisant la promotion de tels tests et invitant la population à demander une analyse de leur patrimoine génétique ?

SI OUI, POSER LA QUESTION SUIVANTE :

15. Que savez-vous à ce sujet ? Comment en avez-vous entendu parler ?

    Sonder : - type de fournisseur de services / services offerts (p. ex., analyses nutrigénomiques)

Opinions sur l'article et le(s) site(s) Web (40 minutes)

Je vais maintenant distribuer un article paru dans les journaux au sujet de la nutrigénomique. Veuillez lire cet article seul et en silence; nous en discuterons une fois que tous et toutes l'auront lu. Encerclez les passages que vous comprenez moins bien.

DISTRIBUER L'ARTICLE. UNE FOIS QUE LES PARTICIPANTS L'AURONT LU, CONTINUER.

16. Quelle a été votre première réaction à cet article ? Qu'est-ce qui vous est venu à l'esprit en le lisant ? Autre chose ?

17. Qu'est-ce qui ressort de cet article ? Autrement dit, qu'est-ce qui a retenu votre attention dans cet article ? Pourquoi ? Autre chose ?

18. Qu'avez-vous appris, à la lecture de cet article, sur la façon dont vos gènes influencent votre santé et qui vous êtes ? Voyez-vous différemment maintenant le rôle que jouent vos gènes ? Si oui, veuillez expliquer.

19. Dans quelle mesure peut-on se fier au contenu de cet article ? Pourquoi dites-vous cela ?

ALTERNER LES DEUX PROCHAINES QUESTIONS :

20. Selon vous, les analyses nutrigénomiques, telles que celles décrites dans cet article, comportent-elles des risques ? Si oui, lesquels ? Autre chose ? Quelle est la probabilité que cela se produise ?

21. Selon vous, les analyses nutrigénomiques, telles que celles décrites dans cet article, présentent-elles des avantages ? Si oui, lesquels ? Autre chose ? Quelle est la probabilité que cela se produise ?

22. Dans l'ensemble, croyez-vous que les analyses nutrigénomiques présentent plus d'avantages que de risques ?

23. Cet article vous encourage-t-il ou vous motive-t-il à vous renseigner davantage sur la nutrigénomique ? Pourquoi / pourquoi pas ? Si oui, où vous adresseriez-vous pour

obtenir plus de renseignements ? Selon vous, qui pourrait vous offrir des renseignements fiables sur la génétique et la nutrition ?

24. Après avoir lu cet article, quelles questions vous posez-vous ? Autrement dit, qu'aimeriez-vous savoir ? Autre chose ?

25. Cet article vous encourage-t-il ou vous motive-t-il à demander une analyse génétique pour vous-même ou un membre de votre famille ? Pourquoi / pourquoi pas ? Qu'aimeriez-vous savoir avant de demander une analyse nutrigénomique ?

J'aimerais maintenant discuter de certaines pages tirées du site Web de quelques entreprises qui offrent des services en matière de nutrigénomique. Je vais vous présenter ces pages et nous en discuterons une fois que nous les aurons toutes étudiées.

UTILISER LE PROJECTEUR POUR ATTIRER L'ATTENTION SUR CERTAINS ÉLÉMENTS DES PAGES WEB. UNE FOIS TERMINÉ, REPRENDRE LA DISCUSSION.

26. Quelle a été votre première réaction au contenu de ces pages Web ? Pourquoi dites-vous cela ?

27. Avez-vous appris quelque chose ? Si oui, qu'avez-vous appris au sujet de la nutrigénomique ? Ces renseignements étaient-ils importants ou utiles ? Peut-on se fier à ces renseignements ?

28. Que pensez-vous de la possibilité de commander de telles trousses d'analyse sur Internet ?

29. Les renseignements découlant de ce genre d'analyse vous seraient-ils utiles ou le seraient-ils pour d'autres ? Pourquoi / pourquoi pas ? Quelles seraient vos attentes à l'égard de l'entreprise en ce qui concerne les résultats ?

    Sonder : - que faire de ces renseignements ?
    - s'attend-on à ce qu'on leur donne des directives particulières ?
    - attentes par rapport à la justesse des résultats

30. Dans quelle mesure seriez-vous intéressés à demander une analyse nutrigénomique pour vous-mêmes ou un membre de votre famille ? Pourquoi dites-vous cela ?

    Sonder : - À quelle catégorie appartient-on ?
    1) Intéressés à demander une analyse nutrigénomique
    2) Souhaitent obtenir davantage de renseignements avant d'aller plus loin
    3) Ne seraient pas intéressés à obtenir une telle analyse, quoi qu'il en soit

31. Aimeriez-vous obtenir d'autres renseignements avant de décider de demander ou non une analyse nutrigénomique pour vous-mêmes ou un membre de votre famille ? Si oui,

quels renseignements aimeriez-vous obtenir ? Où vous adresseriez-vous pour obtenir ces renseignements ?

32. Seriez-vous plus susceptibles de modifier vos habitudes alimentaires à la suite d'une analyse nutrigénomique qu'après avoir reçu des conseils alimentaires (à partir du *Guide alimentaire canadien*, par exemple) non fondés sur une telle analyse ? Si oui, pourquoi ?

33. Selon vous, quels seraient les principaux avantages d'une telle analyse ? Et quels seraient les principaux inconvénients d'une telle analyse ?

34. Supposons que vous commandiez une analyse nutrigénomique d'une entreprise offrant ce service sur Internet. Croyez-vous qu'il vous serait facile d'interpréter les résultats ? Pourquoi / pourquoi pas ? Si vous aviez besoin d'aide pour interpréter les résultats, que feriez-vous pour obtenir cette aide ?

Réactions au document explicatif sur la nutrigénomique (35 minutes)

Je vais maintenant vous demander de lire un court document sur la nutrigénomique préparé pour les rencontres de discussion organisées dans le cadre de cette étude. Vous aurez 7 ou 8 minutes pour le lire. Veuillez lire ce document seul et en silence; nous en discuterons une fois que tous et toutes l'auront lu. Pendant votre lecture, encerclez les passages que vous comprenez moins bien, placez un plus (+) à côté des passages auxquels vous avez bien réagi et placez un moins (-) à côté de ceux auxquels vous avez mal réagi, pour une raison ou pour une autre, ou ceux qui ont suscité des préoccupations. Avez-vous bien compris ? CLARIFIER LES CHOSES AU BESOIN.

DISTRIBUER LE DOCUMENT. ACCORDER 7 OU 8 MINUTES AUX PARTICIPANTS POUR LE LIRE. CONTINUER.

35. Quelle a été votre première réaction au contenu de ce document ? Pourquoi ? Autre chose ?

36. Qu'est-ce qui vous est venu à l'esprit en lisant ce document ? Qu'est-ce qui ressort de ce document ou qu'est-ce qui a retenu votre attention ? À quels passages avez-vous bien réagi, ou quels passages ont récolté des plus ? Et à quels passages avez-vous mal réagi, ou quels passages ont suscité chez vous des préoccupations (ceux qui ont récolté des moins) ?

    Sonder : - passages qui ont récolté des plus et des moins

37. Ce document a-t-il changé l'idée que vous vous faisiez de la nutrigénomique ? Si oui, comment ? A-t-il clarifié des choses ?

38. Est-ce que certains aspects de la nutrigénomique vous échappent encore ? Si oui, lesquels ? Après tout ce que vous avez lu ce soir, vous posez-vous encore des questions ? Qu'aimeriez-vous savoir ? De qui aimeriez-vous obtenir ces renseignements ?

ALTERNER LES DEUX PROCHAINES QUESTIONS :

Compte tenu de ce que vous avez lu et entendu ce soir…

39. …les analyses nutrigénomiques comportent-elles des risques ? Si oui, lesquels ? Quelle est la probabilité que cela se produise ? Comment pourrait-on éviter ou réduire les risques ?

40. …les analyses nutrigénomiques présentent-elles des avantages ? Si oui, lesquels ? Quelle est la probabilité que cela se produise ?

41. Tout bien considéré, dans quelle mesure seriez-vous intéressés à demander une analyse nutrigénomique pour vous-mêmes ou un membre de votre famille ? Pourquoi ? Dans quelles circonstances, s'il y a lieu, seriez-vous davantage intéressés à demander une telle analyse ?

    Sonder : - maladie dans la famille

Questions connexes (5 minutes)

42. Quels renseignements devrait-on communiquer aux Canadiens et Canadiennes pour leur permettre de prendre une décision éclairée en matière de nutrigénomique et de déterminer si une telle analyse leur conviendrait ? Autre chose ?

    Sonder : - genre de renseignements : non commerciaux, gouvernement / organisme de santé, fabricant de suppléments alimentaires, visite médicale

43. Et quelle serait la meilleure façon de communiquer ces renseignements aux Canadiens et Canadiennes ?

44. À qui peut-on se fier pour obtenir des renseignements à jour et exacts sur ce genre d'analyse ?

Conclusion

45. Avez-vous d'autres commentaires ou suggestions à formuler au sujet de ce dont nous avons parlé ce soir, avant de conclure la discussion ?

REMERCIER LES PARTICIPANTS ET REPRENDRE LE MATÉRIEL.

Moderator's Guide

Health Care Providers (ENGLISH ONLY)

Introduction (5 minutes)

- Introduce moderator/Phoenix
- Thanks for attending/value your being here
- Explain general purpose of focus group discussions:
  - Gauge *opinions* about issues/ideas/products
  - Not a knowledge test; no right or wrong answers (interested in opinions)
  - Okay to disagree; want people to speak up if hold different view
- Tonight, we're conducting research on behalf of Health Canada to explore issues related to personal nutrition and health.
- Looking for candour and honesty; comments treated in confidence; reporting in aggregate form only; observers behind one-way mirror; taping for note-taking purposes only.
- The video recordings and your completed questionnaires will only be used by Phoenix researchers and University of Ottawa researchers, who are working with Health Canada on this project.
- Duration: 2 hours
- Please turn off cell phones, pagers, etc.
- Any questions? ACCEPT BRIEF QUESTIONS BUT DO NOT LINGER.
- Lot to cover tonight, so will move on quickly at times.
- Roundtable introduction: please tell us your first name and very briefly describe what you do for a living (maximum of two sentences).

Contextual Issues (20 minutes)

I'd like to start with a few questions about factors related to personal health.

1. What would you say are the most important factors related to personal health?

   Probe: - food and nutrition, exercise, family history, etc.

2. To what extent do you think a person's diet – what they eat – affects their health? Why do you say that? In what ways does diet affect health? Any others?

3. To what extent do you think a person's genetic make-up affects their health? Why do you say that? In what ways does someone's genetic make-up affect their health? Any others?

   Probe: - nature of link between genetics and health
   - family history seen to equate to genetic make-up?

4. What role do you think genes play versus other factors in making a person who they are, including their health? For instance, do you think genes account for 10% of a person's health or 90%, or somewhere in between?

   Probe: - nature—nurture issue

5. How good an understanding do you think you have about how someone's genetic make-up affects their health? What are the types of things you know about? And what are the types of things you do not know about?

6. Do you think that someone's genetic make-up influences how their body responds to food? If so, in what way(s)? Is this something you would like to know more about?

7. Have you ever given any advice to patients/clients based on their genetic makeup and their diet?

8. What are the reasons behind your patient/client visits? Is it mainly for the treatment for symptoms/conditions, the prevention of disease, or more general improved health or performance?

Awareness & Perceptions of Nutrigenomics (30 minutes)

9. Before tonight, who had previously heard the term 'nutrigenomics'? [HAND COUNT]

10. What do you know about 'nutrigenomics'? What did people write down on the short questionnaire we asked you to complete before the focus group began? Anything else? [ROUNDTABLE REVIEW OF WHAT PEOPLE WROTE]

    Probe: - nature and depth of understanding

11. And what did people write down for 'personalized nutrition' on the questionnaire we asked you to complete? Anything else?

I'd now like to hand out a definition of nutrigenomics and have you read it. Once everyone is finished, we'll continue our discussion.

HAND OUT DEFINITION AND ALLOW TIME TO READ IT. ONCE FINISHED, CONTINUE.

12. Is this consistent with your own understanding of nutrigenomics? If not, how does it differ?

13. Have you seen or heard about any nutrigenomic services available to Canadians that explore the link between someone's genetic make-up, nutrition and health? That is, are you aware of any companies currently offering services in this area?

IF YES, ASK:

14. What do you know about this? How did you hear about it?

Probe: - type of service provider and service(s) (e.g. nutrigenomic testing)
- who was providing the service, what kind of outcomes promised?

15. Have any patients/clients asked you about nutrigenomics? If so, what did they ask about? Were you able to answer their questions? If yes, what did you tell them? If not, what did you do? Where did you go to seek further information? How often has this occurred?

16. If you wanted information about nutrigenomics, and the benefits and risks or harms that this might pose to your patients/clients, where would you go for this type of information? Why? Anywhere else?

17. What type of information would be most useful to you about nutrigenomics in order to counsel patients properly? That is, what is most important for you to know? Anything else?

18. If you were to refer a patient or client to another health care professional for further information about nutrigenomics, to what kind of health care professional would you refer them? Why?

Exposure to Website Information (25 mins)

I'd now like to review some pages that were pulled from websites of firms that offer nutrigenomic services. I'm going to walk you through a few pages, and then we'll talk about them when I'm finished.

MODERATOR SHOWS WEB PAGES USING PROJECTOR/SCREEN, AND DRAWS ATTENTION TO VARIOUS FEATURES/ELEMENTS. ONCE FINISHED, CONTINUE.

19. What's your overall impression of the website information? Why do you say that?

20. What do you think about consumers buying tests like these directly from private companies over the Internet? Do you think this information needs to be mediated by a health professional? Why/why not?

21. Do you think information from these types of tests would be useful for your patients/clients? Why/why not? How accurate do you think the results would be?

22. How relevant do you think this is for your patients/clients? Why do you say that?

23. Is this something that interests you? Why/why not?

ROTATE NEXT TWO QUESTIONS:

24. In your opinion, are there risks or potential associated with nutrigenomic testing like that described in the website information? If yes, what are they? Any others? How likely do you think it is that they would actually occur?

25. In your opinion, are there benefits associated with nutrigenomic testing? If yes, what are they? Any others? How likely do you think it is that they would actually occur?

26. Knowing that your patients/clients who use the Internet have access to websites like this, are you interested in obtaining more information about nutrigenomic testing? Does the very presence of these Internet sites stir you to want to know more? If so, what more would you want to know? Where would you go for this information?

27. Has a patient/client ever come to you with the test results and wanted advice about understanding the results and modifying his or her diet, or taking supplements? If yes, how did you respond?

28. If a patient/client did come to you with the test results and wanted advice about understanding the results and modifying his or her diet, or taking supplements, how would you respond?

29. Do you think personalized information like this would motivate behaviour change? If so, in what way(s)? How about…? [READ/ROTATE]:

    - where a patient has disease / elevated disease risk
    - for patient with no identified current risk
    - for a patient with a particular family history and is worried he/she might be at risk of a disease suffered by his/her ancestors.

30. Is there a difference between nutrigenomic counselling and nutritional counselling? Is there a difference in terms of the kind of advice given? Is there a difference in terms of the professional competency required to give one as opposed to the other kind of advice?

31. In your current practice, under what circumstances, if any, would you suggest to a patient/client that he/she have a genetic test done for them or someone else in their family?

    Probe: - finding out if people carry a gene for a disease and might pass it on to
    - testing for genetic diseases in adults before they cause symptoms
    - confirming a diagnosis in a person who has disease symptoms

32. Under what circumstances, if any, could you imagine yourself recommending to a patient/client that they get a genetic test done specifically in order to optimize their diet based on that test?

Review of Information Document on Nutrigenomics (25 minutes)

I'd now like you to read a short document about nutrigenomics prepared for use with these focus groups. I'll give you about 7-8 minutes to read this. Please read it on your own, in silence, and we'll talk about it as a group when everyone is finished. When you are reading the document, please circle anything that is unclear to you, and put a 'plus sign' beside anything you reacted positively to, and a 'negative sign' besides anything you reacted negatively to, for whatever reason, or potentially caused concern. Is this clear? CLARIFY AS NEEDED.

HAND OUT DOCUMENT, ALLOW RESPONDENTS 7-8 MINUTES TO READ IT. CONTINUE.

33. First, what's your initial reaction to what you just read? Why? Anything else?

34. Was anything unclear or potentially confusing? If so, what? Anything else?

35. What did this information make you think about? What stood out and caught your attention? What did you react positively to and put 'plus signs' beside? And what did you react negatively to or caused concern (put 'negative signs beside)?

    Probe: - information with plus signs and negative signs

36. Did reading this information change your understanding of nutrigenomics in any way? If so, in what way(s)? Did it change the way you 'feel' about nutrigenomic testing? If so, how?

37. What does this information make you think about the role genes play in making someone who they are, including their health? How well do you think you understand this?

38. Are there things about nutrigenomics that are not clear to you, but important to know? If so, what?

Related Issues (15 minutes)

39. Who should support you in providing information that would help in answering patients' questions about nutrigenomic testing?

    Probe: - medical colleges, dieticians, Health Canada/PHAC, industry associations

40. What can the Public Health Agency of Canada do to support you in answering your patients' questions about nutrigenomic testing? Should they do anything at all or leave

it to the marketplace? If they should act, in what way can they best help you serve your patients/clients?

41. What type of information is it important for Canadians to know so that they can make an informed decision about nutrigenomics, and whether it is something for them or their family? Anything else?

42. And what do you think is the best way to inform Canadians about this type of information?

43. In your view,

- Should Health Canada be in the business of informing consumers, i.e. explaining the benefits and harms of this kind of testing?
- Should there be any regulations affecting what companies can claim about the testing products they are promoting?
- Should health professional associations (licensing bodies, etc.) be creating guidelines for the appropriate counselling of patients on nutrigenomic issues?

Conclusion

44. Do you have any final comments or suggestions about anything we've talked about tonight before we conclude the discussion?

THANK PARTICIPANTS AND COLLECT MATERIALS.

MINI-QUESTIONNAIRES

General Public

Participant Instructions

Thank you for agreeing to participate in tonight's focus group. Please complete this short questionnaire before we begin the discussion. The questionnaire starts on the following page, and will be used to get a sense of your thoughts and opinions before the group discussion.

Please answer the questions to the best of your ability, but do this on your own. If you are unsure about something, just leave it blank.

When the focus group begins, please bring your questionnaire with you. The moderator might ask you to refer to it from time to time, and will collect it at the end of the group.

If you have any questions, please ask the host/hostess.

Thank you.

Questionnaire for Participants

Please answer the following questions.

1. What would it mean if you were told you were predisposed to getting a certain disease?

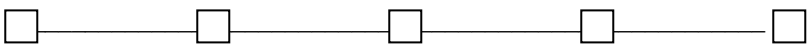
2. Please write one or two sentences on what the following words or phrases mean to you.

   a) Nutrigenomics

   b) Personalized nutrition

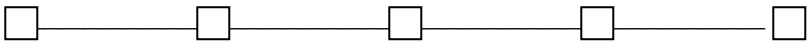
   c) A person's genetic make-up

3. How interested would you say you are in the link between nutrition and health as it relates to you/your family?



1	2	3	4	5
Not interested at all		Somewhat		Very interested

4. How <u>well informed</u> would you say you are about the link between nutrition and health as it relates to you/your family?



1	2	3	4	5
Not knowledgeable at all		Somewhat		Very knowledgeable

5. During the past two years or so, have you personally looked for health-related information, whether on the Internet or from other sources (e.g. library, doctor's office)? This includes information on things like health and wellness, diseases and conditions, or drugs and vitamins.

Yes	□
No	□

<u>IF YOU LOOKED FOR INFORMATION:</u>

6. Please provide examples of the type(s) of health information you were looking for.

_____

_____

_____

_____

7. How regularly do you use natural health products? This includes things like vitamins and minerals, herbal products, homeopathic medicines, traditional medicines, and things of this nature.

Daily	□
Very regularly (but not daily)	□
Occasionally	□
Rarely	□
Never	□

8. Which of the following do you regularly do? Please check all that apply.

□ Buy health supplements (e.g. vitamins, minerals)
□ Buy foods that have specific health properties that you eat because they are supposed to be beneficial to your health
□ Use complimentary and alternative medicine (e.g. acupuncture, homeopathy, herbal therapies, massage)

Directives à l'intention des participants et participantes

Nous vous remercions d'avoir accepté de participer à la discussion de ce soir. Veuillez remplir ce questionnaire avant la rencontre. Ce questionnaire, qui commence à la page suivante, servira à donner, à l'animateur, une idée de vos opinions avant le début de la rencontre.

Répondez de votre mieux aux questions et faites cet exercice seul(e). Si vous ne comprenez pas une question, n'y répondez pas.

Veuillez apporter le questionnaire rempli à la rencontre de discussion. L'animateur pourrait vous demander de vous y référer de temps à autre et vous demandera de le lui remettre à la fin de la rencontre.

Si vous avez des questions, veuillez vous adresser à l'hôte/hôtesse.

Merci.

Questionnaire à l'intention des participants et participantes

Veuillez répondre aux questions suivantes.

1. Si l'on vous disait que vous êtes prédisposé(e) à une certaine maladie, qu'est-ce que cela signifierait pour vous ?

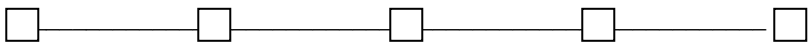
2. Expliquez, dans une phrase ou deux, ce que signifient les expressions suivantes, selon vous.

   a) La nutrigénomique

   b) La nutrition individualisée

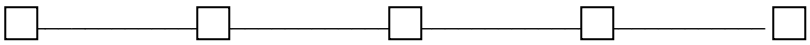
   c) Le patrimoine génétique d'une personne

3. À quel point le lien entre votre alimentation et votre santé, ou l'alimentation de votre famille et sa santé, vous intéresse-t-il ?



1	2	3	4	5
Ne m'intéresse pas du tout		M'intéresse		M'intéresse beaucoup

4. À quel point êtes-vous renseigné(e) sur le lien entre votre alimentation et votre santé, ou l'alimentation de votre famille et sa santé ?



1	2	3	4	5
Pas du tout renseigné(e)		Renseigné(e)		Très renseigné(e)

5. Au cours des deux dernières années environ, avez-vous cherché des renseignements sur la santé, dans Internet ou ailleurs (p. ex., à la bibliothèque, chez le médecin) ? Peut-être avez-vous cherché des renseignements sur la santé et le mieux-être, les maladies et les affections, les médicaments ou les vitamines ?

Oui □
Non □

SI VOUS AVEZ CHERCHÉ DES RENSEIGNEMENTS :

6. Veuillez donner quelques exemples des genres de renseignements que vous avez cherchés.

_____
_____
_____
_____

7. À quelle fréquence utilisez-vous des produits de santé naturels, comme des vitamines et des minéraux, des produits à base de plantes, des produits homéopathiques et des produits de médecines traditionnelles ?

Tous les jours □
Très souvent (mais pas tous les jours) □
À l'occasion □
Rarement □
Jamais □

8. Veuillez cocher toutes les activités ci-dessous que vous faites régulièrement.

□ J'achète des suppléments alimentaires (comme des vitamines et des minéraux).
□ J'achète des aliments qui ont des propriétés particulières et qui, semble-t-il, sont bons pour la santé.
□ J'ai recours aux médecines douces ou alternatives (comme l'acuponcture, l'homéopathie, la phytothérapie, les massages).

Health Care Providers (ENGLISH ONLY)

Participant Instructions

Thank you for agreeing to participate in tonight's focus group. Please complete this short questionnaire before we begin the discussion. The questionnaire starts on the following page, and will be used to get a sense of your thoughts and opinions before the group discussion.

Please answer the questions to the best of your ability, but do this on your own. If you are unsure about something, just leave it blank.

When the focus group begins, please bring your questionnaire with you. The moderator might ask you to refer to it from time to time, and will collect it at the end of the group.

If you have any questions, please ask the host/hostess.

Thank you.

Questionnaire for Participants

Please answer the following questions.

1. Please write one or two sentences on what the following words mean to you.

   a) Nutrigenomics _____

   _____

   _____

   _____

   _____

   b) Personalized nutrition _____

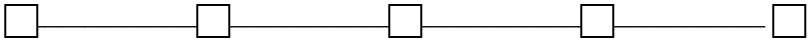
   _____

   _____

   _____

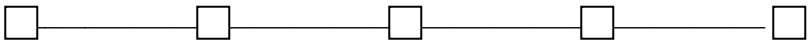
   _____

2. How <u>well informed</u> would you say you are about the link between nutrition and health as it relates to your patients/clients?



1	2	3	4	5
Not knowledgeable at all		Somewhat		Very knowledgeable

3. How <u>concerned</u> would you say your patients/clients are about the link between personal nutrition and their health?



1	2	3	4	5
Not concerned at all		Somewhat		Very concerned

Focusing on you personally,

4. How regularly do you use natural health products? This includes things like vitamins and minerals, herbal products, homeopathic medicines, traditional medicines, and things of this nature.

   Daily ☐
   Very regularly (but not daily) ☐
   Occasionally ☐

Rarely	☐
Never	☐

5. Which of the following do you regularly do? Please check all that apply.

   ☐ Buy health supplements (e.g. vitamins, minerals)
   ☐ Buy foods that have specific health properties that you eat because they are supposed to be beneficial to your health
   ☐ Use complimentary and alternative medicine (e.g. acupuncture, homeopathy, herbal therapies, massage)

6. What is your profession?

_____

_____

DEFINITION OF NUTRIGENOMICS

Nutrigenomics:

Genes and their biological environments interact. Different environments can cause the same gene to behave differently. Equally, the environment can cause different outcomes for individuals with different genes. Nutrients are environmental factors that can affect the expression and regulation of genes, and variations in genes can alter how nutrients are metabolised. Nutritional genomics can be broadly understood to involve the study of how nutrients in food interact with our genes at the molecular and cellular levels, and the impacts these reactions have on our health. The goal is to promote human health through optimal nutrition, taking into account genetic variation between people. One application of nutrigenomics is personalized nutrition, in which a person's knowledge about their genetics is used in everyday decisions about nutrition. People can learn about their genetics by means of genetic testing, or based on family history or personal experience.

MEDIA ARTICLE

Prince George Citizen. Prince George, B.C.

Credit: Associated Press

NEW YORK (AP) -- As a registered dietitian, Ruth DeBusk has eaten a healthy diet for a long time. As a geneticist, she wondered if she could do better.

So earlier this year, she had her DNA tested by a company that gives personalized nutrition advice based on genetics. The results indicated she needed more folate.

So DeBusk doubled her minimum amount of folate, a B vitamin found in leafy greens and citrus.

"I'm more diligent about being sure that I get it every day if possible, because it really matters," said DeBusk, who has a private practice in Tallahassee, Fla., and has written a book on nutrition and genetics.

"I'll actually make an effort to drink a glass of orange juice or eat an extra big salad in the evening, being aware it hasn't been one of my better folate days."

That's the way it's supposed to work in a field called nutritional genomics or nutrigenomics. The basic idea is this: There are genes that affect the risk of getting illnesses like heart disease, cancer, osteoporosis and diabetes, and the impact of those genes can be modified by what you eat. Everybody carries one version or another of each of those genes. So why not find out what gene versions you have and base dietary advice on that?

"Every time we go to the supermarket we're using educated guesses about what we should eat and what we shouldn't eat," says Raymond Rodriguez, director of the National Center of Excellence for Nutritional Genomics at the University of California, Davis.

In the future, more of that guesswork may be replaced with accurate, personal DNA-based dietary advice, which Rodriguez says is "rapidly emerging on the horizon."

But that time isn't here yet, most experts say. Nutrigenomics is still in its infancy, with plenty to be learned, and it's not yet clear what role it may play in standard medical practice.

Most of the research targets heart disease and cancer, and scientists may be ready to deliver personalized diet recommendations in those areas within five years, said Jose Ordovas, director of the nutrition and genomics laboratory at the U.S. Department of Agriculture Nutrition Research Center at Tufts University in Boston.

"We have scientific evidence that the concept is right, that we can provide something along those lines in the future," Ordovas said. "We are not there yet."

Right now people wanting an idea of what they should be eating can pay $99 US for a DNA test kit that will provide personalized diet advice for heart health, bone health, or any of three other areas.

It's from Sciona Inc., a small company based in Boulder, Colo., that started offering DNA-based diet advice in 2001. The tests are available by mail order and on the Internet.

Sciona customers collect their own DNA with a cheek swab, complete a diet and lifestyle questionnaire and send it all in for analysis. Sciona encourages customers to review its advice with a doctor.

The company acknowledges that some scientists say it's too soon to offer such a service, but says its testing is based on solid research. Current testing focuses on 19 genes and the company is studying others, said Rosalynn Gill-Garrison, chief scientific officer and a company founder.

Prince George Citizen. Prince George, Colombie-Britannique

Source : Associated Press

[TRADUCTION LIBRE]

NEW YORK (AP) — Ruth DeBusk, diététiste, s'alimentait bien depuis longtemps. En tant que généticienne, toutefois, elle s'est demandée si elle ne pouvait pas faire mieux encore.

Plus tôt cette année, elle a donc fait analyser son ADN par une entreprise offrant des conseils personnalisés en matière d'alimentation en fonction du patrimoine génétique d'un individu. Les résultats de l'analyse ont dévoilé chez elle une déficience en folate.

Ruth a alors doublé son apport minimal en folate, une vitamine du groupe B qu'on trouve dans les légumes-feuilles et les agrumes.

« Je fais davantage d'efforts pour l'inclure dans mon alimentation quotidienne; c'est important » indique Ruth, qui a un cabinet privé à Tallahassee, en Floride, et qui est l'auteure d'un manuel sur la nutrition et la génétique.

« Les jours où je n'ai pas consommé suffisamment de folate, je m'assure de boire un verre de jus d'orange ou de manger une grosse salade au souper. »

Voilà comment les choses devraient se passer dans ce domaine de la génomique nutritionnelle, aussi appelée « nutrigénomique ». Le principe de base est le suivant : certains gènes jouent un rôle dans l'apparition de certaines maladies comme les maladies du cœur, le cancer, l'ostéoporose et le diabète, et l'influence de ces gènes peut être modifiée par l'alimentation. Toute personne exprime une version ou une autre de chacun de ces gènes. Pourquoi ne pas déterminer laquelle de ces versions porte en lui un individu et lui offrir des conseils personnalisés en matière d'alimentation à la lumière de ces renseignements?

« Au moment de faire nos courses, nous avons une idée des aliments qui sont bons pour nous et de ceux qui ne le sont pas », explique Raymond Rodriguez, directeur du National Center of Excellence for Nutritional Genomics de l'Université de Californie (Davis).

À l'avenir, des renseignements nutritionnels précis, offerts à partir d'une analyse génétique, permettront de faire des choix alimentaires en meilleure connaissance de cause. Selon Raymond Rodriguez, un tel service « se profile à l'horizon ».

Mais nous n'en sommes pas encore là, selon la plupart des spécialistes. La nutrigénomique n'en est encore qu'à ses premiers balbutiements et nous avons encore beaucoup à apprendre en la matière. Aussi, nous ne savons pas encore quel rôle elle pourrait jouer dans la pratique courante de la médecine.

La plupart des études s'intéressent principalement aux maladies du cœur et au cancer et les scientifiques pourraient être en mesure d'offrir des recommandations nutritionnelles

relativement à ces maladies d'ici à cinq ans, selon Jose Ordovas, directeur du laboratoire de nutrition et de génomique du Nutrition Research Center de l'Université (Boston), centre financé par le ministère de l'Agriculture américain.

« Nous disposons de preuves scientifiques relatives à la validité de ce projet et à la possibilité d'offrir de tels renseignements à l'avenir, indique Jose Ordovas. Mais nous n'y sommes pas encore. »

Aujourd'hui, ceux qui désirent obtenir des conseils sur ce qu'ils devraient manger peuvent commander une trousse d'analyse de l'ADN pour la somme de 99 $ américains, et obtenir ainsi des conseils personnalisés en matière d'alimentation qui touchent cinq aspects de leur santé (cœur, os, etc.).

Cette trousse est distribuée par Sciona Inc., une petite entreprise de Boulder, au Colorado, qui a commencé à offrir, en 2001, des conseils personnalisés en matière d'alimentation en fonction de la génétique d'un individu. On peut commander cette trousse par la poste ou sur Internet.

Les clients de Sciona prélèvent eux-mêmes un échantillon de leur ADN, sur la face intérieure de la joue, remplissent un questionnaire au sujet de leur régime alimentaire et de leur mode de vie, et retournent le tout à l'entreprise à des fins d'analyse. Sciona encourage ses clients à discuter des conseils offerts par ses experts avec un médecin.

La direction de l'entreprise reconnaît que certains scientifiques jugent qu'il est trop tôt pour offrir un tel service, mais soutient que ses analyses sont fondées sur des études sérieuses. Les analyses offertes actuellement portent sur 19 gènes et l'entreprise envisage d'accroître ce nombre, indique Rosalynn Gill-Garrison, conseillère scientifique en chef et fondatrice de l'entreprise.

INFORMATION DOCUMENT

Introduction

Nutrigenomics is a new and developing science that studies the interaction between the nutrients in our food and the genes in our bodies. Nutrients in food, such as proteins and vitamins, provide our bodies with the energy we need to live.Genes are the basic biological materials that provide instructions to build and maintain our bodies. Nutrigenomics examines how nutrients and genes interact, where our genes affect how our bodies use nutrients and where nutrients influence how genes work

Studying nutrigenomics usually involves collecting a sample from a person (usually a cheek swab but in some cases through drawing blood), and looking at that individual's genetic make-up (this is a genetic test). Other personal information (such as gender, weight, age and other factors), plus an analysis of the nutrients normally consumed may also be examined. The hope around nutrigenomics is that it will provide individuals or groups of similar people with valuable information about how differences in their genes and diets can affect their health.

Nutrigenomics researchers ask three key questions:

1) What is the "normal" interaction between nutrients and genes?

2) How do differences in people's genetic make-up affect the way nutrients and genes interact?

3) Do interactions between nutrients and genes affect a person's health or lead to disease?

Examples of how food intake can affect health:

Examples of the interaction between nutrients in foods, personal genetic make-up, and health outcomes include:

1. ***Lactose Intolerance*** – Most people of non-European descent and some people of European descent experience an upset stomach when digesting milk and other dairy products. Two variations in those peoples' genetic make-up cause them to be less able to digest such foods, and those people may be advised to avoid dairy if they have symptoms of lactose intolerance.

2. ***Caffeine Metabolism*** –Not everyone can have coffee or tea late in the day and expect to have a good night's sleep because our bodies process caffeine differently. There may be a genetic reason why caffeine is processed more quickly by some people than others, and those who process caffeine more slowly may have a higher risk of heart disease, and thus might wish to limit their daily caffeine intake.

3. ***Folate Supplements*** – Homocysteine is a chemical in our blood that is associated with heart disease. Some people may have a high homocysteine level because of their personal genetics. They may have a gene that slows the speed at which an enzyme can clear homocysteine from their body, but by taking folate supplements (also known as folic acid), these people can lower their homocysteine, thus reducing their risk of heart disease.

4. ***Dietary Fat and Body Weight*** – Humans consume different kinds of fats and those who get a significant amount of their daily energy from eating fatty foods are more likely to be overweight. However, there are some people with a slightly different genetic make-up that allows them to consume high fat diets without gaining as much weight as expected. Since your genetic makeup can affect how your body processes certain types of fat, knowing those differences could help you steer clear of those kinds of fat and thus better manage your weight.

5. ***Diets and Populations*** – In parts of Arizona and Mexico there is a group of aboriginals called the Pima Indians. The Pima tend to stay closely-knit, especially in Arizona where they live on a reserve. Pima Indians who consume their traditional diet (high carbohydrate, low fat and low protein) tend to be slim, but those who consume a typical, modern diet are almost 20 times more likely to develop diabetes than the average American. This response to diet raises important questions about the difference in response to diet of people who share common ancestry.

Nutrigenomics: Some Issues

There is debate in the scientific community around the new and developing field of nutrigenomcis.

One perspective is that:

- knowing one's personal genetic make-up could be a foundation for personalized nutrition, and better health;
- tailoring one's diet to their specific genetic make-up could help prevent, reduce or delay the onset of certain diseases; and
- nutrigenomics could promote an increased understanding of how nutrition influences genes and the information could be used to prevent the development of disease (for example, chronic diet related diseases such as obesity and diabetes).

Another perspective is that:

- it may be too early to apply nutrigenomic science at this relatively early stage of its development;
- nutrigemonic (genetic) test results are rarely "black and white", in most cases, disease is caused by a variety of interactions between genes and many environmental factors;
- some companies marketing nutrigenomic tests may overstate the benefits of the test results/information they provide to customers;
- at home genetic tests have not yet been evaluated by government regulators; and
- internet marketing of these tests may be:
    - making predictions that are not yet accurate and/or medically proven; and
    - used as a means of marketing costly but possibly unnecessary "personalized" dietary supplements.

Introduction

La nutrigénomique est une science nouvelle et en plein développement qui s'intéresse à l'interaction entre les nutriments contenus dans nos aliments et les gènes de notre organisme. Les nutriments tels que les protéines et les vitamines donnent à notre organisme l'énergie dont il a besoin pour vivre. Les gènes, qui constituent la matière première biologique de notre organisme, fournissent les directives supervisant l'élaboration et le fonctionnement de ce dernier. La nutrigénomique étudie l'interaction entre les nutriments et les gènes : l'influence de nos gènes sur la façon dont notre organisme utilise les nutriments, et l'influence des nutriments sur le fonctionnement de nos gènes.

Une analyse nutrigénomique implique généralement le prélèvement d'un échantillon d'ADN (habituellement sur la face intérieure de la joue mais parfois, au moyen d'une prise de sang) et l'examen du patrimoine génétique de l'individu (analyse génétique). L'analyse peut aussi tenir compte d'autres facteurs, comme le sexe, le poids ou l'âge de la personne, et des aliments qu'elle consomme régulièrement. On espère que la nutrigénomique permettra d'offrir de précieux renseignements aux individus, ou à certains groupes d'individus aux caractéristiques semblables, sur l'influence qu'ont leurs gènes et leur alimentation sur leur santé.

Les chercheurs en nutrigénomique posent trois questions essentielles :

1) Qu'est-ce qu'une interaction « normale » entre les nutriments et les gènes?

2) Comment le patrimoine génétique de chacun influence-t-il l'interaction entre les nutriments et les gènes?

3) L'interaction entre les nutriments et les gènes influence-t-elle la santé d'un individu ou entraîne-t-elle la maladie?

Exemples de l'influence de certains aliments sur la santé :

Voici quelques exemples de l'interaction entre certains nutriments, le patrimoine génétique et la santé :

1. ***Intolérance au lactose*** – La plupart des personnes de descendance non européenne et certaines personnes de descendance européenne souffrent de troubles digestifs lorsqu'elles consomment du lait ou des produits laitiers. Deux variantes du patrimoine génétique de ces personnes les empêchent de bien digérer de tels aliments; on pourrait donc leur conseiller d'éviter les produits laitiers si elles ont des symptômes d'intolérance au lactose.

2. ***Métabolisme de la caféine*** – Certaines personnes sont sûres, si elles boivent un café ou un thé en fin de journée, de passer une bonne nuit parce que leur corps métabolise la caféine différemment. Il est possible que certaines personnes métabolisent la caféine plus rapidement que d'autres en raison de leur patrimoine génétique. Celles qui la métabolisent plus lentement présentent un risque plus élevé de maladie cardiaque et devraient, par conséquent, réduire leur consommation de caféine.

3. ***Suppléments de folate*** – L'homocystéine présente dans le sang est associée aux maladies cardiaques. Certaines personnes présentent un taux élevé d'homocystéine en raison de leur patrimoine génétique. Il est possible qu'un de leurs gènes soit responsable de

l'élimination lente de l'homocystéine; toutefois, la prise de suppléments de folate (acide folique) leur permet de réduire leur taux d'homocystéine et, par conséquent, leurs risques de maladie cardiaque.

4. ***Matières grasses et poids corporel*** – Nous consommons toutes sortes de matières grasses et ceux d'entre nous qui tirent une bonne partie de leur énergie des aliments riches en matières grasses sont plus susceptibles de faire de l'embonpoint. Par ailleurs, d'autres personnes, au patrimoine génétique légèrement différent, peuvent consommer une grande quantité de matières grasses sans prendre autant de poids. Puisque votre patrimoine génétique peut influencer la façon dont l'organisme métabolise certains types de matières grasses, il pourrait vous être utile de connaître les matières grasses en question afin de les éviter et d'ainsi mieux gérer votre poids.

5. ***Régimes alimentaires et populations*** – Les Pimas, des autochtones de l'Arizona et du Mexique, sont généralement intimement liés, surtout en Arizona où ils vivent dans une réserve. Les Pimas qui suivent le régime alimentaire traditionnel (riche en glucides, faible en gras et en protéines) sont généralement minces, mais ceux qui ont adopté le régime alimentaire moderne typique sont presque 20 fois plus susceptibles de présenter du diabète qu'un Américain moyen : voilà qui soulève d'importantes questions quant aux différences de réaction des personnes partageant la même origine ancestrale face aux aliments qu'elles consomment.

La nutrigénomique : quelques éléments à considérer

La nutrigénomique, domaine nouveau et en plein développement, fait l'objet d'un débat au sein de la communauté scientifique.

D'une part :

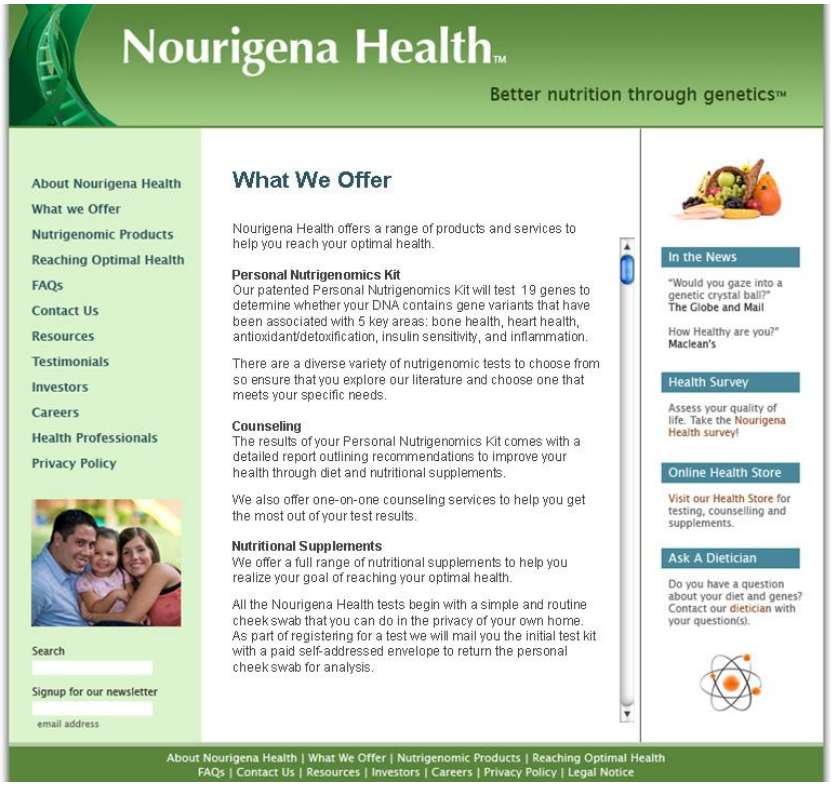
- la connaissance de son patrimoine génétique pourrait servir à personnaliser l'alimentation et à favoriser une meilleure santé;
- l'adaptation du régime alimentaire d'un individu à son patrimoine génétique pourrait contribuer à prévenir ou à retarder certaines maladies, voire à en réduire la gravité;
- la nutrigénomique permettrait de mieux comprendre comment l'alimentation influence les gènes, et cette connaissance pourrait servir à prévenir certaines maladies (par exemple, les maladies chroniques liées à l'alimentation telles que l'obésité ou le diabète).

D'autre part :

- la nutrigénomique est peut-être encore trop récente pour être appliquée dans la pratique;
- généralement, les résultats des analyses nutrigénomiques (génétiques) ne sont ni tout noirs ni tout blancs, les maladies étant généralement causées par des interactions entre les gènes et divers facteurs environnementaux;
- certaines entreprises faisant la promotion des analyses nutrigénomiques pourraient exagérer les avantages que l'on pourrait tirer des renseignements provenant de ces analyses;
- les trousses d'analyse à utiliser à la maison n'ont pas encore été évaluées par des organismes gouvernementaux de réglementation;
- il est possible que la publicité sur Internet concernant ce genre d'analyses :

- émette des conclusions inexactes ou qui n'ont pas encore été médicalement prouvées;
- serve à mousser les ventes de suppléments alimentaires « personnalisés » coûteux et probablement superflus.

WEBSITE MOCK-UP

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Nourigena Health's basic test program (NHTK Basic) consists of a full individualized genetic analysis based on a simple cheek swab, a full written report detailing personalized dietary and lifestyle recommendations prepared by our certified genetic counselors and a list of suggested supplements which conform to your individual genetic profile.
Nourigena Health's Test Kit Program (NHTK Premium Plus)
Nourigena Health's premier test product (NHTK Premium Plus) consists of the Basic program in addition to two individual telephone counseling sessions with one of our certified genetic counselors as well as a three-month supply of individualized supplements specially prepared which conform to your individual genetic profile.
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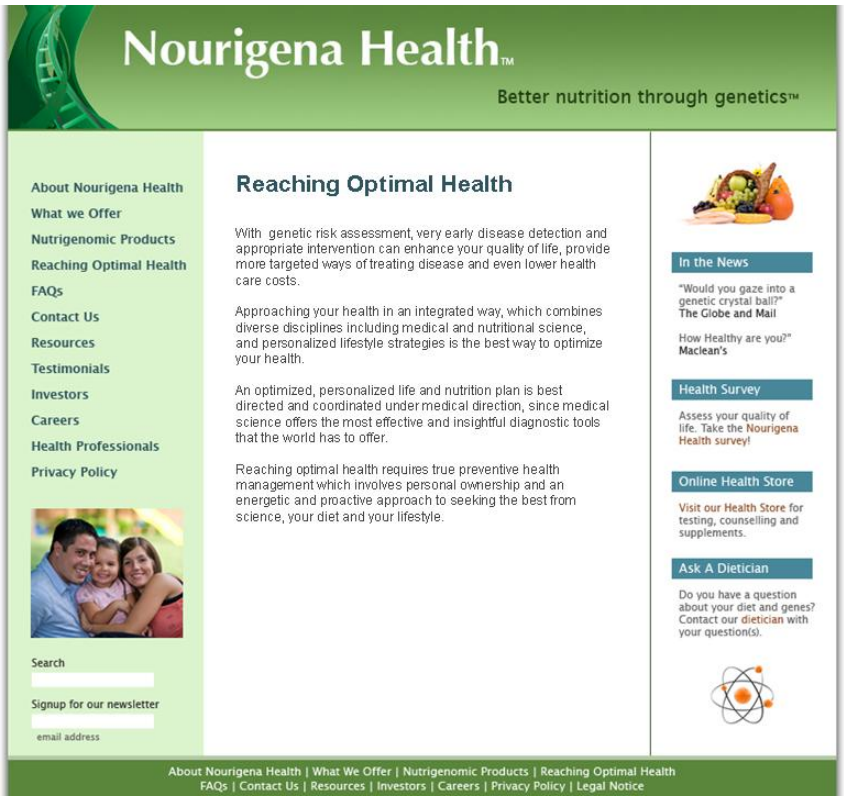
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With genetic risk assessment, very early disease detection and appropriate intervention can enhance your quality of life, provide more targeted ways of treating disease and even lower health care costs.
Approaching your health in an integrated way, which combines diverse disciplines including medical and nutritional science, and personalized lifestyle strategies is the best way to optimize your health.
An optimized, personalized life and nutrition plan is best directed and coordinated under medical direction, since medical science offers the most effective and insightful diagnostic tools that the world has to offer.
Reaching optimal health requires true preventive health management which involves personal ownership and an energetic and proactive approach to seeking the best from science, your diet and your lifestyle.
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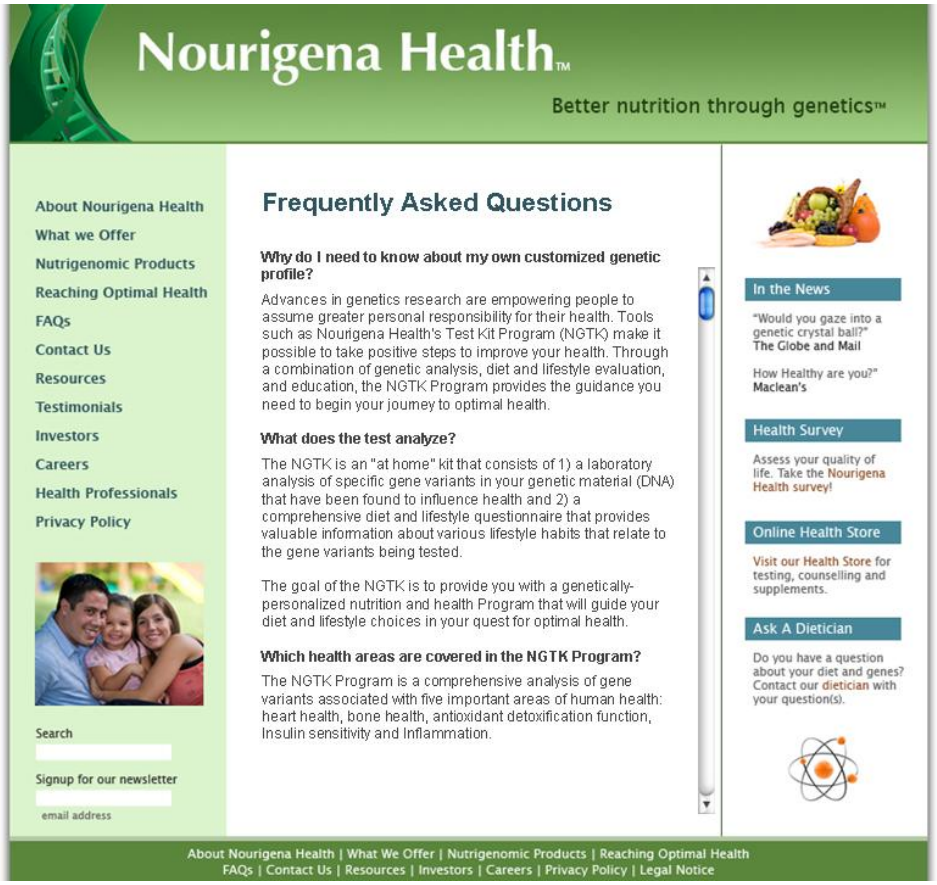
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Why do I need to know about my own customized genetic profile?
Advances in genetics research are empowering people to assume greater personal responsibility for their health. Tools such as Nourigena Health's Test Kit Program (NGTK) make it possible to take positive steps to improve your health. Through a combination of genetic analysis, diet and lifestyle evaluation, and education, the NGTK Program provides the guidance you need to begin your journey to optimal health.
What does the test analyze?
The NGTK is an "at home" kit that consists of 1) a laboratory analysis of specific gene variants in your genetic material (DNA) that have been found to influence health and 2) a comprehensive diet and lifestyle questionnaire that provides valuable information about various lifestyle habits that relate to the gene variants being tested.
The goal of the NGTK is to provide you with a genetically-personalized nutrition and health Program that will guide your diet and lifestyle choices in your quest for optimal health.
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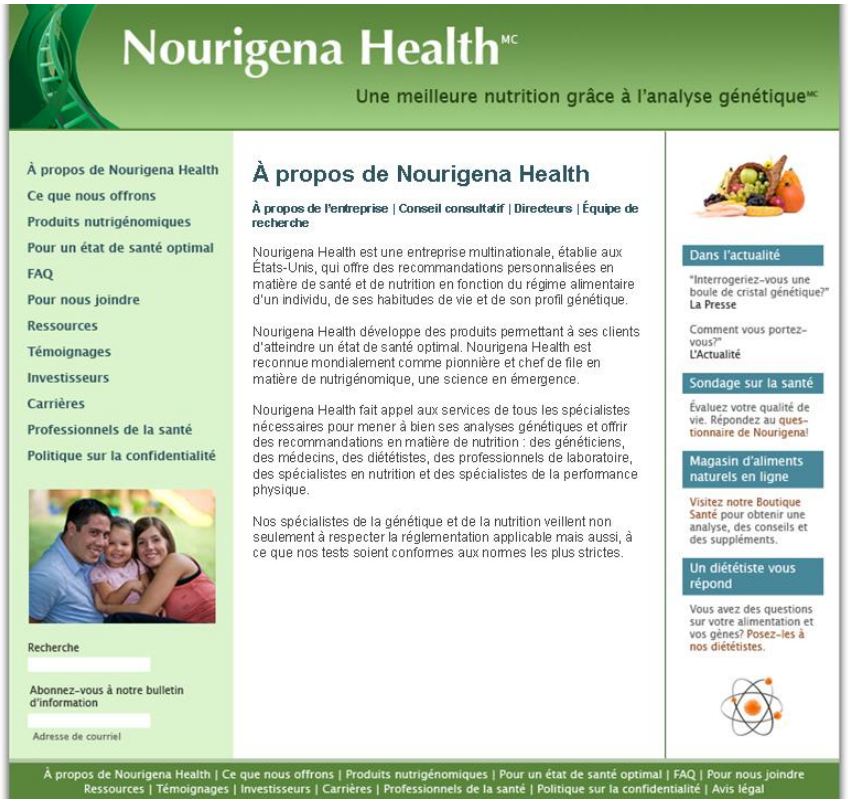
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Nourigena Health est une entreprise multinationale, établie aux États-Unis, qui offre des recommandations personnalisées en matière de santé et de nutrition en fonction du régime alimentaire d'un individu, de ses habitudes de vie et de son profil génétique.
Nourigena Health développe des produits permettant à ses clients d'atteindre un état de santé optimal. Nourigena Health est reconnue mondialement comme pionnière et chef de file en matière de nutrigénomique, une science en émergence.
Nourigena Health fait appel aux services de tous les spécialistes nécessaires pour mener à bien ses analyses génétiques et offrir des recommandations en matière de nutrition : des généticiens, des médecins, des diététistes, des professionnels de laboratoire, des spécialistes en nutrition et des spécialistes de la performance physique.
Nos spécialistes de la génétique et de la nutrition veillent non seulement à respecter la réglementation applicable mais aussi, à ce que nos tests soient conformes aux normes les plus strictes.
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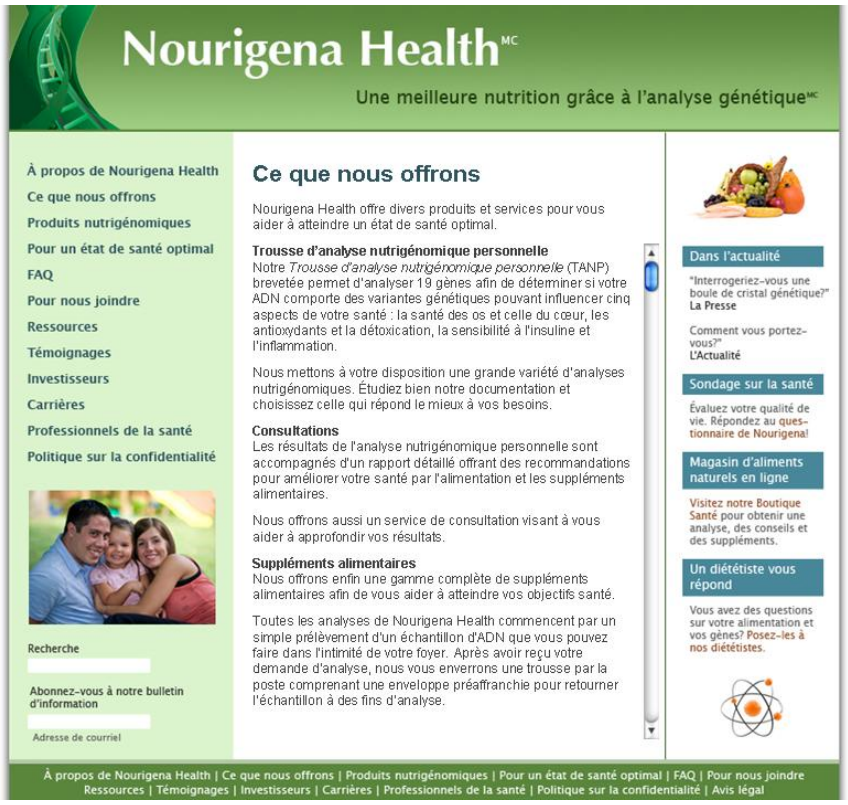
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Notre Trousse d'analyse nutrigénomique personnelle (TANP) brevetée permet d'analyser 19 gènes afin de déterminer si votre ADN comporte des variantes génétiques pouvant influencer cinq aspects de votre santé : la santé des os et celle du cœur, les antioxydants et la détoxication, la sensibilité à l'insuline et l'inflammation.
Nous mettons à votre disposition une grande variété d'analyses nutrigénomiques. Étudiez bien notre documentation et choisissez celle qui répond le mieux à vos besoins.
Consultations
Les résultats de l'analyse nutrigénomique personnelle sont accompagnés d'un rapport détaillé offrant des recommandations pour améliorer votre santé par l'alimentation et les suppléments alimentaires.
Nous offrons aussi un service de consultation visant à vous aider à approfondir vos résultats.
Suppléments alimentaires
Nous offrons enfin une gamme complète de suppléments alimentaires afin de vous aider à atteindre vos objectifs santé.
Toutes les analyses de Nourigena Health commencent par un simple prélèvement d'un échantillon d'ADN que vous pouvez faire dans l'intimité de votre foyer. Après avoir reçu votre demande d'analyse, nous vous enverrons une trousse par la poste comprenant une enveloppe préaffranchie pour retourner l'échantillon à des fins d'analyse.
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Produits nutrigénomiques
Trousse personnelle d'analyse nutrigénomique | Consultation | Suppléments
Trousse personnelle d'analyse nutrigénomique
Service d'analyse de Nourigena Health (SANH - de base)
Le service d'analyse de base de Nourigena Health (SANH - de base) consiste en une analyse génétique complète d'un échantillon recueilli sur la face intérieure de la joue. Celle-ci est accompagnée d'un rapport complet présentant des recommandations détaillées en matière d'alimentation et d'habitudes de vie, préparé par nos conseillers en génétique agréés, ainsi que d'une liste des suppléments suggérés tenant compte de votre profil génétique.
Service d'analyse de Nourigena Health (SANH - Valeur Plus)
Le service d'analyse « Valeur Plus » de Nourigena Health (SANH - Valeur Plus) comprend le service de base, deux consultations par téléphone avec un de nos conseillers en génétique ainsi qu'une provision de trois mois de suppléments, préparés spécialement en fonction de votre profil génétique.
Dans l'actualité
"Interrogeriez-vous une boule de cristal génétique?" La Presse
Comment vous portez-vous?" L'Actualité
Sondage sur la santé
Évaluez votre qualité de vie. Répondez au questionnaire de Nourigena!
Magasin d'aliments naturels en ligne
Visitez notre Boutique Santé pour obtenir une analyse, des conseils et des suppléments.
Un diététiste vous répond
Vous avez des questions sur votre alimentation et vos gènes? Posez-les à nos diététistes.
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Nourigena Health^MC
Une meilleure nutrition grâce à l'analyse génétique^MC
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Pour un état de santé optimal
L'évaluation des risques génétiques peut améliorer votre qualité de vie, permettre d'intervenir de manière plus ciblée et même, réduire les coûts liés aux soins de santé et ce, en permettant la détection précoce des maladies et l'application de mesures correctives appropriées .
Une approche intégrée réunissant d'une part diverses disciplines, comme les sciences médicales et nutritionnelles, et d'autre part, des stratégies visant à assainir vos habitudes de vie, constitue la meilleure façon d'optimiser votre santé.
Les professionnels du milieu médical sont les mieux placés pour encadrer et coordonner un plan de vie et de nutrition personnel, les sciences médicales offrant les outils de diagnostic les plus efficaces.
L'atteinte d'un état de santé optimal exige de gérer sa santé par une approche préventive qui, à son tour, nécessite un engagement personnel et une recherche énergique et proactive visant à améliorer sa santé grâce à la science, à un régime alimentaire adapté et des habitudes de vie plus saines.
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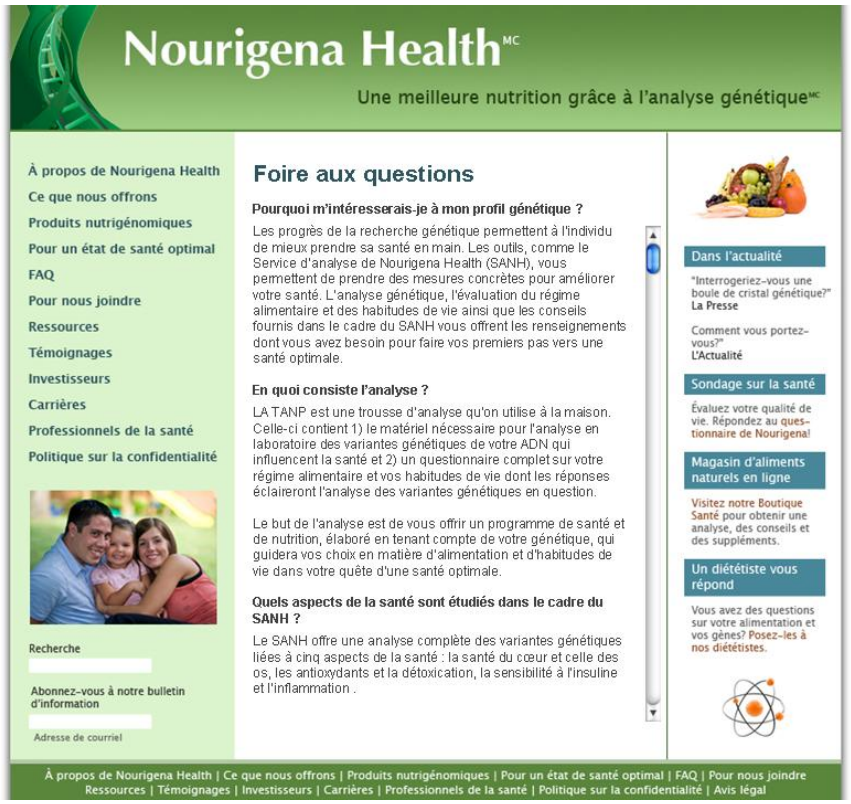
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Foire aux questions
Pourquoi m'intéresserais-je à mon profil génétique ?
Les progrès de la recherche génétique permettent à l'individu de mieux prendre sa santé en main. Les outils, comme le Service d'analyse de Nourigena Health (SANH), vous permettent de prendre des mesures concrètes pour améliorer votre santé. L'analyse génétique, l'évaluation du régime alimentaire et des habitudes de vie ainsi que les conseils fournis dans le cadre du SANH vous offrent les renseignements dont vous avez besoin pour faire vos premiers pas vers une santé optimale.
En quoi consiste l'analyse ?
LA TANP est une trousse d'analyse qu'on utilise à la maison. Celle-ci contient 1) le matériel nécessaire pour l'analyse en laboratoire des variantes génétiques de votre ADN qui influencent la santé et 2) un questionnaire complet sur votre régime alimentaire et vos habitudes de vie dont les réponses éclaireront l'analyse des variantes génétiques en question.
Le but de l'analyse est de vous offrir un programme de santé et de nutrition, élaboré en tenant compte de votre génétique, qui guidera vos choix en matière d'alimentation et d'habitudes de vie dans votre quête d'une santé optimale.
Quels aspects de la santé sont étudiés dans le cadre du SANH ?
Le SANH offre une analyse complète des variantes génétiques liées à cinq aspects de la santé : la santé du cœur et celle des os, les antioxydants et la détoxication, la sensibilité à l'insuline et l'inflammation .
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