Nutrition & Dietetics

# Personal genomic testing for nutrition and wellness in Australia: A content analysis of online information



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| Journal: | *Nutrition & Dietetics* |
| Manuscript ID | Draft |
| Manuscript Type: | Original Research |
| Keywords: | Workforce, Qualitative Research, Nutrigenomics/nutrigenetics, Marketing |
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## Introduction

Personal genomic testing for nutrition and wellness (PGT-NG) offers a novel way to tailor dietary advice to an individual. Informed by the evolving study of gene-nutrient interactions, broadly termed nutritional genomics,[1] PGT-NG claims to offer personalised dietary advice that will 'optimise' health.[2] While promising, in many instances the benefits of PGT-NG have yet to be proven.

Clinical validity refers to the reliability of a test to determine disease-risk based on a specific genetic variation, while clinical utility refers to its ability to inform healthcare decisions; both are key measures of the quality of a genetic test.[3] Australian guidelines recommend that healthcare providers should only offer PGT based on nutritional genomics if the test, and related dietary interventions, are sufficiently evidence-based.[4] To date however, many gene-nutrition relationships lack clinical validity.[5-7] Further, the evidence used to provide dietary recommendations often differs between PGT-NG companies, meaning consumers may receive different advice based on the test they take.[5, 8] Many PGT-NG also do not take into consideration the polygenic nature of many non-communicable diseases, nor non-genetic factors contributing to poor health.[9-11] Dietary advice is also rarely cross-culturally validated.[8, 12] As such, Grimaldi et al[6] recently published a set of guidelines for assessing the clinical validity of gene-nutrition interactions to help ensure only evidence-based information reaches the public. Of further concern, however, the genetic variants included in some PGT-NG also have associations with non-diet related conditions; for example, *APOE*-ε4 is related to Alzheimer risk as well as cholesterol regulation.[13, 14] The potential psychosocial implications of *APOE*-ε4 genotyping may not necessarily be communicated to consumers prior to having the test conducted, or during delivery of results.[13, 15]

The unregulated mass of online promotional content for PGT-NG only perpetuates public misunderstanding of the benefits, limitations and risks of PGT-NG.[6] Consequently, several key groups, including the Human Genetics Commission in the United Kingdom, have produced recommendations for transparent online advertising for health-related PGT.[16, 17] Nevertheless, content analyses of PGT websites internationally have revealed that these recommendations are frequently ignored.[18-20] Instead, website content is solely emotive, particularly appealing to the notion of consumer empowerment and health transformation.[21, 22] This starkly contrasts with evidence to suggest that even when given gene-based diets, consumers are unlikely to make lasting changes to their lifestyles as a result.[23, 24]

Ultimately, this presents an issue for informed content. The purpose of informed consent is two-fold: it protects an individual from harm, while also fostering autonomous choice.[13, 25] Internationally, health-related PGT are often sold online, direct-to-consumer, negating the need to involve a healthcare provider. This also eliminates the possibility for pre- and post-test counselling and, given that online information may be inadequate to ensure informed consent, consumers may be at risk of distress, false hope or 'buyer-regret'.[7, 13] In an attempt to minimise this risk, several PGT-NG companies have developed a direct-to-provider model,[26] whereby a healthcare provider is trained by the company to facilitate testing for their clients.

Nutritionists and dietitians have been identified as key HPs to offer nutritional genomic advice to clients,[27] however, it is unclear how many have incorporated PGT-NG into their practice to date. In Australia, dietitians are considered allied health professionals, and must acquire accreditation with the Dietitians Association of Australia.[28] Conversely, the term 'nutritionist', can refer to a variety of nutrition-related HP roles, including those in the field of complementary/alternative medicine (CAM).[28, 29] As such, PGT-NG may also be of interest to a vast array of HPs outside conventional dietetic practice, including naturopaths and homeopaths.

Thus, despites concerns, HPs are offering PGT-NG in Australian and are promoting their services online. In particular, the phrase 'genomic wellness' appears a popular way of advertising testing in Australia. Research into this promotional rhetoric is lacking however, and, internationally, a holistic analysis of the content, quality and marketing approaches of PGT-NG provider websites has yet to be conducted. The aim of this study was therefore to explore how PGT-NG is framed online to the Australian public.

## Method

A mixed-method content analysis was conducted using a framework built in REDCap (Research Electronic Data Capture) version 7.1.2.[30]

Website searches occurred between February and May 2017. To be eligible, websites needed to offer a PGT-NG service available to Australians, and provide a description of the service (e.g. websites that listed PGT-NG as a service but did not elaborate were excluded). The aim was to mimic the behavior of a potential consumer, and as such, the search terms and search strategy was designed with this in mind.[31] Popular testing companies were identified as result of the search strategy and subsequently included in the search terms. Thirteen simple terms (genomic wellness, personalised wellness test, MTHFR test, DNA wellness test, MTHFR wellness test, nutritional genomics testing, nutritional genomics Australia, nutrition and wellness test, personal genomic diet, personal genomics nutrition, [Company 1 name] practitioner, [Company 2 name] practitioner, [Company 3 name] practitioner) were entered into Google and Bing, two popular search engines. Internet users rarely look beyond the top 30 search links,[31] however, to ensure nothing was missed, unique links were collected from the first five pages of each search (ten links per page).

A novel framework was developed to meet the aims of the analysis (see Figure 1). The framework was informed by items proposed in published guidelines[4, 16, 17] and similar content analyses, [19, 20, 32]

which were modified for relevance to nutritional genomics. The Flesch Reading Ease [33] formula was used to aid an assessment of website understandability, whereby a 'lay-level' was considered a score between 60 and one hundred. This is freely available online scoring program in which the website text was copied into. The framework was piloted using international websites collected during website searching. This prompted minor changes to aid clarity and usability.

Websites were de-identified and assigned ID numbers. Microsoft Excel 2013 and REDCap were used to generate descriptive statistics, and NVivo 11 (QSR International) was used to collate website text. The text was analysed thematically, using a constant comparative approach.[34] Ten percent of the websites were co-analysed by one of the co-authors, with the percentage of inter-rater agreement calculated.



## Results

Thirty-nine websites were analysed; four PGT-NG testing company websites (three Australian-owned and one operating internationally) and 35 HP websites. All HP websites belonged to complementary/alternative medicine (CAM) practitioners (such as naturopaths) or clinics. Three naturopaths also referred to themselves as nutritionists, while two of the CAM clinic websites stated that a dietitian would facilitate testing. Only one HP website indicated that a genetic counsellor was available. Interrater agreement was 98%.

While website content varied (Table 1), most provided rationale for testing and a description of the service (e.g. 100% stated who would interpret results and 92% explained how returns would be returned). Only two studies cited specific evidence to support the rationale, and the technical and scientific aspects of PGT-NG were rarely touched upon (e.g. 20% explained the multifactorial nature of health).

Three of the PGT-NG websites of testing companies required a HP to facilitate testing and provided consumer-orientated sections and information for prospective HPs. Company 2 provided

a list of accredited HPs across Australia for the consumer to choose from, and while the majority came from the field of CAM, several HPs were medically trained (e.g. general practitioners). Company 4 offered testing direct-to-consumer and provided the least amount of information (4/17 framework items, 24%), meaning an assessment of quality could not be conducted. Company 1 provided the most detailed information, covering 65% of the framework items, however, the information was riddled with errors, particularly in the section aimed at practitioners. Company 1 was also the only website overall to explain how a genetic variant is considered clinically valid, however again, quality was poor (depth = *average*, accuracy = *somewhat*, exaggeration = *average*, understandability = *average*, credibility = *somewhat*).

Much of the information that appeared on HP websites appeared to have been copied directly from the testing company websites. When HPs attempted to provide information in their own words, quality varied (see Figure 2). In particular, credibility scores dropped due to poor grammar and typographical errors. Even for HP websites targeting consumers, language was not at a lay-level ($M$=46.27 for the Flesch Reading Ease Formula). Information was also highly skewed in favour of testing; all websites listed at least one benefit, while 2/39 described risk and 8/39 explained limitations.

Overall, the tone of the information was positive and motivational, with the most common emotional appeals being empowerment and transformation. HP22 wrote, *"Knowing your genetic blue-print can empower you to make the best lifestyle choices to optimise your genetic expression for optimal health."* Images were used to complement the textual material by 34 websites. For example, healthy, smiling individuals implied the benefits of testing.

The textual material was synthesised into major themes:

**PGT-NG is a superior tool for facilitating wellness:** Websites emphasised this by using the metaphor of PGT-NG being able to 'unlock' health information. HP1 stated, *"It is the closest thing you have to a crystal ball for your future health."*

**PGT-NG will reduce the guesswork around diet and lifestyle choices:** Websites promised that results would inform not only highly specific, but also easy to implement recommendations that would improve health. HP11 claimed, *"You will be provided with practical, easy to understand information on how you can modify your diet and lifestyle according to your individual genetic profile to optimize your health."*

**PGT-NG is relevant to healthy people:** Language such as 'maximise' health, and 'reach your full potential' implied that even though the consumer may think they are healthy, there is more that could be done to take health to the 'next level'. HP31 wrote, *"We specialise in Nutrigenomic DNA testing and can use the information to help structure a plan to help you reach your full health potential."*



## Discussion

Findings reveal that online PGT-NG information does not adequately communicate the complexities of nutritional genomics, including issues of clinical validity and utility. Websites emphasised genetic determination and the superiority of PGT-NG over other forms of dietary advice. Little attention was paid to the science of nutritional genomics and the current limitations of its application. This aligns with previous studies suggesting that transparency of health-related PGT websites is generally poor.[18, 19]

Despite three of the four PGT-NG testing companies targeting a range of HPs, this research has revealed that uptake of test facilitation is particularly prevalent in the CAM community in Australia. Most of these CAM providers relied on information taken directly from the PGT-NG company websites, decreasing understandability scores despite the lay target-audience. It is

clearly a challenge to communicate scientifically accurate information in the context of consumer-orientated advertising.[32] This reliance on PGT-NG testing company website information also brings into question the ability of these CAM providers to deliver adequate pre-test advice to consumers.

While test facilitation through a HP aims to minimise the risk that consumers may misinterpret their results, there remains concern that many providers may not be competent to interpret results.[35] Further, although guidelines published by Grimaldi et al[6] are a positive step towards ensuring PGT-NG is standardised and evidence-based, the authors argue that determining the clinical utility of associated dietary advice is the responsibility of the HP. Although it has been suggested that nutritionists and dietitians are well placed to deliver nutritional genomic advice to clients[27], this group has reported low knowledge and low confidence in Australia and internationally [36, 37]. In light of these findings,[36, 37] and the poor quality of the online information by CAM providers, the assumption made by Grimaldi et al[6] may not yet be entirely appropriate.

Clearly there is a need for greater training and educational support for HPs practising both conventional and complementary/alternative medicine who are interested in adopting PGT-NG into their practice.[38] Recognising this, Hurlimann et al[7] produced pre- and post-test counselling recommendations that should be addressed by HPs facilitating PGT-NG. The authors reinforce that pre- and post-test counselling, along with HP training, is essential to ensure consumers make informed choices to pursue PGT-NG.[7]

Currently in Australia, however, there is a distinct lack of independent bodies offering courses in nutritional genomics appropriate for HPs to upskill, as most require the completion of further tertiary studies.[38] Instead, HPs must acquire accreditation with certain PGT-NG testing companies before offering testing. Thus, many HPs have no choice but to rely on the testing companies for training and support. Already, interviews with North American HPs who facilitated health-related PGT with their patients revealed that most relied heavily upon testing company resources to

counsel their patients.[26] As with HPs using testing company information for their own websites, this reliance represents a conflict-of-interest, such that clients may receive biased or inadequate advice.

The PGT-NG testing company websites analysed in this study offered no information regarding what the in-house training involves and how competency is assessed. While the websites were professional in appearance, the poor ratings given to the PGT-NG testing company websites, which were then reflected in the information provided by the CAM providers, is a worrying indication of the quality of the training.

Given the potential that nutritional genomics offers the field of nutrition and dietetics, it is essential that the workforce is adequately supported to provide clients with high quality care and advice.[7, 36] One place to start is with the information available to consumers online. Thus, the findings from this study have revealed a need for greater nutritional genomics knowledge amongst HPs, and the importance of dissemination of accurate online information to the public.

Two websites had ceased advertising PGT-NG within the timeframe of the data collection and analysis. Thus, given how rapidly the area is changing, findings only represent a 'snapshot in time'. The study also only depicts the Australian landscape, however, given the growing popularity of nutritional genomics, findings can still inform a range of HPs, both nationally and internationally.

The authors propose a basic checklist of information that should be included on a website offering PGT-NG facilitation (see supplementary Table 1). Transparent information will help ensure both the public and HPs interested in PGT-NG are supported and informed.

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Figure 1 Novel framework for analysing online personal genomic testing for nutrition and wellness content

| Category | Description | Rating Metric |
|---|---|---|
| Content | 17 items relating to informational content (see Table 1) | Multiple choice-multiple answer, Yes/No |
| Service Information | Healthcare provider and consultation type (e.g. face-to-face) | Multiple choice-multiple answer |
| Credibility of the service | Credibility of the service provider (e.g. qualifications listed) | Yes/No |
| Currency | Date last updated easily viewable | Yes/No |
| Balanced nature of the information | Presence of at least one benefit, risk and/or limitation | Yes/No |
| Emotional appeals | Empowerment, entitlement, peace of mind, autonomy, fear, transformation, regret and excitement | Scale: 1 = *none*, 2 = *some*, 3 = *average,* 4 = *a lot,* 5 = *all* |
| Images | Scientific, people, emotions, food and nature | Yes/No |

**Quality**

Three content items were used to assess quality (see Table 1)

* Explanation of nutritional genomics
* Explanation of the genes analysed and their relevance to health
* Explanation of how the genetic variations are considered clinically valid

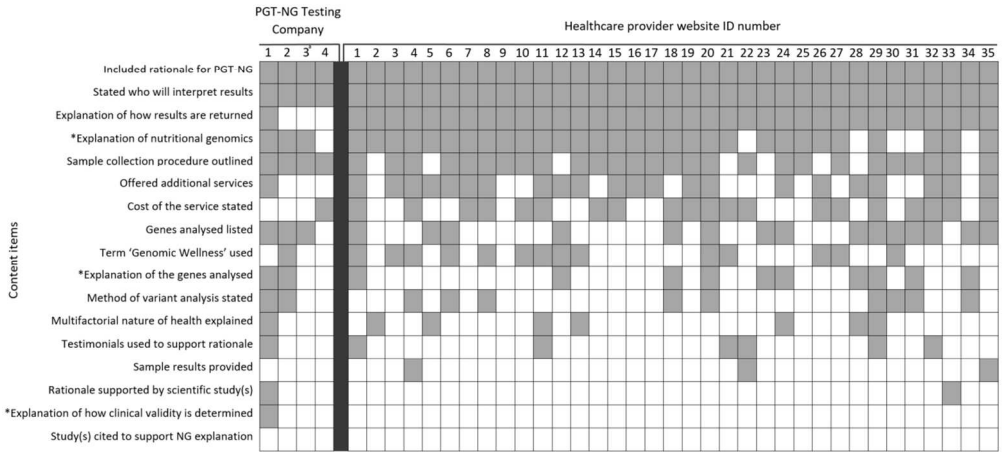
For websites that included these items, the explanations were rated on a Likert scale (1 = *not at all*, 2 = *somewhat*, 3 = *average,* 4 = *mostly,* 5 = *all the time)* across 5 dimensions[1]:

1. Depth
2. Accuracy
3. Exaggeration
4. Understandability
5. Credibility

Website text was also collected for each assessment category. Screenshots were taken following analysis.

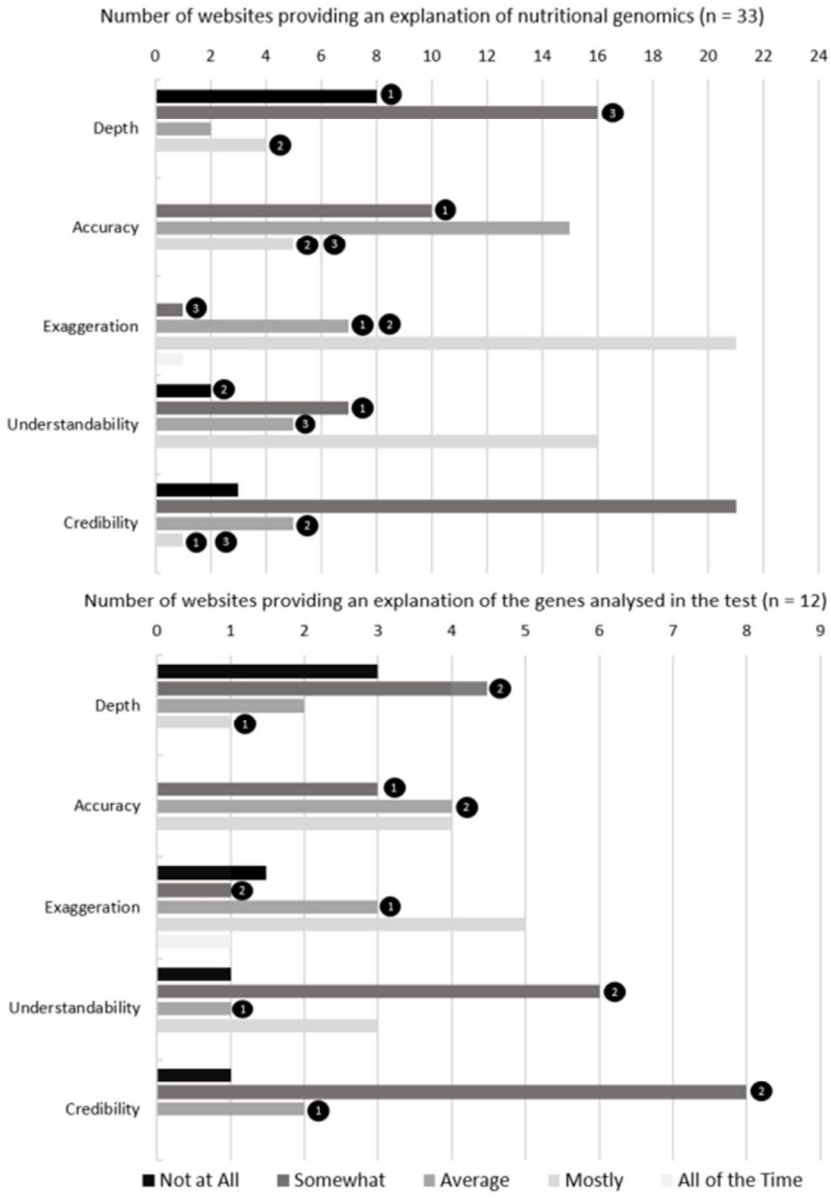
[1] Criteria for Assessing the Quality of Information:
Depth The detail provided in the information.
Accuracy The degree to which the information was correct, as validated by the current literature.
Exaggeration The extent to which the information was overstated or overemphasised.
Understandability How easy the text was to comprehend as a layperson. Encompassed the use of plain language and correct spelling and grammar. Aided by score from the Flesch Reading Easea Formula[a]a freely available online scoring program into which website text was copied.
Credibility The perceived trustworthiness of the information. Included the tone of language, use of scientific evidence and the professionalism of the website.
[a] Where 0-30.0 = Very difficult, 30.0-60.0= Difficult, 60.0-70.0= Plain English, 80.0-100.0= Easy

Table 1 Content of websites offering information about personal genomic testing for nutrition and wellness (N=39)




The 17 content items (see Figure 1) and in grey, the websites which included each item.

* Quality assessment item (see Figure 1)
[a] International company offering testing to Australians




The bars represent the scores for the healthcare provider websites, and the circles represent the scores for the testing companies (1, 2 and 3).

Note: Company 3 did not provide an explanation of the genes analysed in the test. None of the healthcare provider websites included the third quality assessment item, an explanation of how a genetic variant is considered clinically valid.