Gluten avoidance – trendy food fad, or insight into complex psycho-physiological interactions?

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Certificate of authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the award of any other degree or diploma at Charles Sturt University or any other educational institution, except where due acknowledgment is made in the thesis. Any contribution made to the research by colleagues with whom I have worked at Charles Sturt University or elsewhere during my candidature is fully acknowledged.

I agree that this thesis be accessible for the purpose of study and research in accordance with the normal conditions established by the Executive Director, Library Services or nominee, for the care, loan and reproduction of theses subject to confidentiality provisions as approved by the University.

Signature

Kyah Joan Hester

14 November 18
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Ethics

The research presented in this thesis was granted ethics approval by Charles Sturt University’s Faculty of Arts – Human Research Ethics Committee. This research conforms to the Declaration of Helsinki. Ethics protocol numbers and approval letters are supplied for qualitative and quantitative studies in Appendix A and Appendix E respectively.

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Abstract

Research indicates that there has been an increase in the adoption of gluten-free diets despite modest estimates of disorders that require this restrictive diet. To date, little is known about what motivates people to engage in gluten avoidance without a medical diagnosis that requires them to do so. This research was developed to examine this population in detail, in order to determine whether individuals who avoid gluten belong to a homogenous group that differs from gluten consumers.

This thesis adopted a sequential qualitative-quantitative mixed methods design, allowing for the integration of multiple data types. Each phase of the research informed the next, where qualitative interviews highlighted significant factors that needed to be included for subsequent analyses. In the qualitative phase, participants reported heavily relying on self-diagnosis, which was complicated by a sense of dissatisfaction with GPs, and the high levels of perceived discrimination participants felt from those around them. This paved the way for two subsequent quantitative research phases.

The second phase utilised a representative sample to examine prevalence rates of gluten avoidance behaviors, and the demographic variables that characterise them. Twenty percent of the sample reported participating in non-prescribed gluten avoidance behaviors, and a further 2% reported strict avoidance due to diagnoses of coeliac disease/wheat allergy. Non-prescribed gluten avoidance was more likely to be reported by females, who were under 35 years of age. These findings established a need for deeper quantitative investigation to assess if they are able to be further distinguished by additional variables.

The final research phase examined the physiological and psychological characteristics that were reported by participants avoiding gluten. Gluten avoiders were found to have a non-specific physiological response to all foods, not just to gluten alone. These trends extended to avoidance behaviours, and food perceptions as well. Further investigation of psychological variables revealed that gluten avoiders may be experiencing sensory issues that genuinely manipulate the experience of physical sensations in the body.

The research identifies gluten avoiders as a homogenous group of people who are attending to more, sensing more, feeling more and responding more strongly to a range of foods and their effects. This research helps to establish the unique set of needs of this population, and the considerations that need to be given in future treatment models.
GLUTEN AVOIDANCE

Chapter 1: Introduction

This chapter provides a background context for the research, and discusses dietary restriction and the way it relates to mental health and information seeking. This provides an overall framework for the thesis within the paradigm of health psychology and public health. The chapter also provides an overview of the research context, identifies the aims and objectives of the thesis, and discusses the likely significance of the research. The final sections of the chapter outline the chosen research design and the thesis structure.

1.1 Background

People manipulate their intake of food for a variety of reasons. Motivation for intake manipulation can be viewed in terms of both the social construction of desire for food, and the material consequences that food has on people’s lives (Caplan, 1996). One’s class, income and gender are all thought to impact food consumption behaviours, with those in Western countries facing issues of mass-choice that leads to over-consumption and increased health concerns. These growing health concerns have been paired with a myriad of public education campaigns aimed to improve the dietary choices being made by people in countries struggling with obesity. In light of these campaigns, people have developed an increased awareness of food, and the impacts that their diet has on their wellbeing. Dietary changes can occur either passively or actively, depending on the level of involvement that is required to maintain the change. People who have active involvement in their dietary change are often driven by an accumulation of evidence, a trigger to act, or a mixture of the two (Chapman & Ogden, 2009). These processes lead to the creation of dietary goals that are shaped by expected outcomes, and are often related to improved health or wellbeing in some way. Whilst the eating and manipulation of food is often linked with physical health, a large body of evidence also suggests that mental health is equally connected with the food we choose to eat.

1.1.1 The links between dietary restriction and mental health

The relationship between food and mental health is complicated and remains a topic of interest in modern day research. Poorly regulated diets that include low-quality foods have been shown to correlate with higher prevalence rates of mental health disorders, particularly in the earlier stages of the lifespan (O’Neil et al.,
2014). These findings are discussed in relation to specific nutritional deficiencies associated with both depression and anxiety disorders. One study examining the diet quality of Australian women found that following a western diet that included processed foods and refined sugars was more predictive of depressive and anxiety disorders than a more traditional diet of meat/vegetables/grains, even after controlling for other confounding variables (Jacka, Pasco, et al., 2010). This has also been found in Australian adolescents, with diet quality being associated to depression scores over and above the effects of other confounding variables (Jacka, Kremer, et al., 2010). Studies that observe changes in gut microbiota have also examined the impact that dietary changes have on stress reactivity and found that the oral administration of a probiotic can lead to decreased activity in the autonomic nervous system of rats, which mediates the stress response (Ait-Belgnaoui et al., 2014). Similar results have been modelled in human studies, although the mechanisms behind these results remain unclear (Messaoudi et al., 2011).

Although poor health is often associated with poor eating, the reverse has not been consistently found when observing the impact that healthy diets have on mental health and wellbeing. A systematic review of whole-of-diet interventions in 2015 found that of the eligible studies included in the review, only half (47%) observed significant effects on depressive scores following a dietary intervention (Opie, O’Neil, Itsiopoulos, & Jacka, 2015). The traditional healthy diet is also likely to be more expensive than one that is inclusive of less perishable items. Welfare dependent and low-income families can spend up to 40% of their disposable income maintaining healthy food habits, which also impacts the priority of their dietary choice (Kettings, Sinclair, & Voevodin, 2009). The stress that is associated with strict healthy eating protocols can also lead to the development of mood symptoms. This is demonstrated in the emergence of eating disorders termed orthorexia nervosa, which are triggered by worries about food purity. Sufferers of this condition are preoccupied with obsessive and anxious thoughts about their daily food intake, which are related to fears about the quality of the food they eat and the impact this has on their health (Brytek-Matera, 2012). Therefore, participation in a healthy diet is not in itself an adequate indicator of mental health. These findings have significant impacts on public health, and give rise to a growing need for adequate food education and diet treatments amongst the population.
1.1.2 The importance of health information seeking and health literacy

Studies showing a significant improvement in mental health after dietary change often have interventions that are delivered by fully qualified dieticians (Opie et al., 2015). Nutritional counselling services by a dietician have been shown to be more effective in reaching long-term health goals when compared to similar services being provided by a general practitioner (Willaing, Ladelund, Jørgensen, Simonsen, & Nielsen, 2004). General practitioners are often limited by time restraints and their capacity to develop holistic dietary plans for individual patients. Some have theorised that this inconsistency in expert advice fuels the anxiety around accurate dietary decisions (Rangel, Dukeshire, & MacDonald, 2012). The skill-mix amongst health care workers is driven by a variety of factors including available education and training for practitioners, which can ultimately impact both the coordination and the continuity of care that is provided to patients (Sibbald, Shen, & McBride, 2004).

Current models of health information seeking demonstrate that patients engage in a non-linear transfer of information based on their relationship with practitioners and their own levels of health literacy (Longo et al., 2010). These models suggest that they participate in information seeking as a form of stress management after experiencing health-threatening situations (Lambert & Loiselle, 2007). The acquisition of accurate health information is an important motivator in the decision to make changes to health practices, i.e. dietary restriction. There are also a variety of personal factors that contribute to the amount of information that is sought and the sources that are used to gather information, including personality, expectations, attitudes and emotions (Lambert & Loiselle, 2007). For example, patients who reported receiving dissatisfying services from their health care professionals were significantly more likely to rely on the internet as their main source of health information (Tustin, 2010), compromising health literacy and the appropriateness of their chosen diets. Low health literacy has been consistently associated with a range of poor health outcomes including hospitalisations, use of emergency care, misinterpretation of medication labels and higher mortality rates (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). The promotion of health literacy among persons considering dietary restriction is therefore a matter of public health interest, to ensure that accurate information is being shared amongst populations suffering from health concerns.
1.2 The current research problem

Over the last ten years or so, there has been an increased uptake of the gluten-free diet (GFD) within westernised cultures such as Australia and America (Allen, 2015). Typically, the adoption of a GFD is prescribed on the basis of having a gluten/wheat related disorder, which is believed to occur in approximately 1-2% of the population. This assists in the reduction of negative physiological effects that occur within the body, leading to malnutrition and poor overall health. However, incidence rates of coeliac disease (CD) and wheat allergy (WA) do not align with this sudden increase in gluten avoidance behaviours. Some of those engaging in gluten avoidance behaviours are believed to be suffering from a disorder called non-coeliac gluten sensitivity, however the mechanisms for this disorder and its links with gluten remain unclear. Despite the modest estimates of gluten sensitivity within the population, there is no clear indication of the number of people who are currently following non-prescribed GFDs due to the experience of gluten-related symptoms.

Research is yet to clarify the exact mechanisms that cause gluten-sensitivity, or the ways that it can be accurately identified in sufferers (Carroccio et al., 2012). To date, the only substantial means of establishing an accurate diagnosis of gluten sensitivity includes costly and complicated food challenges (Volta et al., 2015) that can only be made after the definitive exclusion of CD by a healthcare professional. This has caused many people to rely on self-diagnosis based on the health information they obtain online (Moore, 2014). Although dietary changes can be easily managed at home, diets that are particularly restrictive often pose a range of nutritional and health risks if implemented without the guidance of a medical professional. There is currently a lack of research exploring the factors that may influence the decision to engage in non-prescribed gluten avoidance, therefore the motivations for this dietary restriction remain unclear. This research has been developed to form a preliminary understanding of gluten avoidance behaviours, so that any unnecessary dietary restriction in the pursuit of symptom reduction might be avoided. By identifying alternative, and potentially more appropriate treatment avenues, this group will be able achieve their health goals without the complications and judgement that is often associated with medically unexplained symptoms.
1.3 The aim and scope of the research

1.3.1 Research aim

This thesis aimed to explore the factors that influence people to engage in non-prescribed gluten avoidance. The overall focus of this research was not to confirm or deny the presence of biological mechanisms that perpetuate these behaviours. Instead, it utilised pre-existing measures to explore the nature of the subjective experience reported by this population, utilised wide-scale representative surveys to establish an estimate of national prevalence rates, and identified additional features that characterise people who engage in this behaviour.

1.3.2 Research objectives and questions

Specific research objectives and questions were developed based on the existing knowledge base and the findings from prior phases of the current research. Each of the research objectives and questions are addressed within separate research phases noted throughout the thesis. In order to preserve this context, they have been discussed within their relevant research phases below.

1.3.2.1 Phase A

The main research objective of Phase A was to develop a comprehensive understanding of the subjective experience reported by non-prescribed gluten avoiders in Australia. In order to address this objective, the following research questions were posed:

1. What are the factors that influence the adoption of non-prescribed gluten avoidance in Australians?
2. What impacts does the decision to become a non-prescribed gluten avoider have on their lives?

1.3.2.2 Phase B

The main research objective of Phase B was to establish prevalence rates for non-prescribed gluten avoidance in Australia and ascertain the demographic variables that characterise this population. In order to address this objective, the following research questions were posed:

1. What are the prevalence rates of non-prescribed gluten avoidance in Australia?
2. What proportion of the Australian population is avoiding gluten on the basis of being diagnosed with coeliac disease or wheat allergy?
3. What demographic variables characterise non-prescribed gluten avoiders?

1.3.2.3 Phase C

The main research objective of Phase C was to identify the physiological and psychological factors that distinguish non-prescribed gluten avoiders from gluten consumers. In order to address this objective, the following research questions were posed across three separate thesis chapters:

Chapter 6: Symptomology and somatisation in gluten avoiders

1) What is the prevalence and type of gastrointestinal and extra-intestinal symptoms that are being experienced by gluten avoiders?
2) Is there a relationship between the symptoms being experienced by gluten avoiders and the frequency and intensity of gluten avoidance behaviours?
3) What is the prevalence of comorbid somatic symptoms amongst gluten avoiders?

Chapter 7: Food perceptions and cognitive influences on food choice

1) Do gluten avoiders report higher levels of perceived discrimination?
2) Do gluten avoiders score lower on measures of GP satisfaction, and what relationship does this have with gluten avoidance?
3) Do gluten avoiders have higher usage rates of online information sources/blogs and rate their trustworthiness higher than gluten consumers?
4) Do gluten avoiders prioritise health related factors when making food choices?
5) What food perceptions do gluten avoiders have, and are they related to avoidance behaviours?
6) Are gluten avoiders higher on measures of experiential thinking styles than gluten consumers?
7) Do gluten avoiders report high levels of ambiguity tolerance?

Chapter 8: The role of individual differences: A consideration of sensitivity dysfunction
1) Do gluten avoiders score higher on self-report pencil and paper tests of autonomic arousability?

2) Do gluten avoiders score higher on measures of stimulus amplification?

3) Do gluten avoiders score higher on the measures of neuroticism

1.3.3 Significance of the research

Despite reports of improved wellbeing, research has failed to establish any major health benefits that occur as result of gluten avoidance in those without a gluten-related disorder. The relationship between self-reported symptoms and gluten avoidance in non-medically diagnosed populations is yet to be captured within the literature. The current research will help to develop a better understanding of gluten avoidance by establishing whether the avoidance behaviours of this population are motivated solely by physiological concerns. These findings will have significant implications for health practitioners, informing best practice when responding to gluten-related symptoms reported by non-medically diagnosed individuals. This will also assist general practitioners in identifying appropriate referral channels for patients who require further investigation of their symptoms. By doing so, more appropriate symptom management strategies can be identified to help improve their health. Policy makers can also utilise these results to develop targeted education strategies to reduce the impact that poor health literacy has on the adoption of unnecessary gluten avoidance behaviours.

1.4 Research design

1.4.1 Methodology

A sequential qualitative-quantitative mixed methods approach was adopted for the research within this thesis. Teddlie and Tashakkori (2009) suggest that the most appropriate choice of methodology is one that is determined by the research questions rather than other superseding factors. In the case of the current thesis, a lack of pre-existing research meant that a well-designed quantitative questionnaire could not be developed without qualitative insight. Therefore, a qualitative phase was conducted first, and these findings were then used to inform the design of two wide-scale quantitative surveys. This design is adapted from the mixed-methods research models presented by Morse (2003), where the dominant project follows an initial exploratory phase. Conducting the research in this order resulted in the identification
of factors that may not have otherwise been considered if only the literature review was used to determine which measures were included. The mixed-methods approach also allowed for different types of data to be collected in order to address the research aims from multiple perspectives, resulting in a more comprehensive understanding of non-medically diagnosed gluten avoidance overall.

### 1.4.2 Research phases

This thesis includes three studies that form the basis of three distinct research phases, with the findings of each phase subsequently informing the design of the research in the phase that follows. These research phases are as described below:

#### 1.4.2.1 Phase A – Qualitative study

The initial research phase was designed with the aim to collect meaningful subjective experiences as reported directly by the population of interest. This was deemed appropriate to ensure that the research phases to follow included relevant variables that actually impacted the choices made by non-prescribed gluten avoiders. This allowed for a more balanced observation of variables that wasn’t solely dependent on the information, or lack thereof, available in the current literature base. A thematic analysis was used to explore the subjective experiences reported by 11 non-prescribed gluten avoiders. This allowed for a qualitative review of the reasons that influenced their initial decision to follow a gluten-free diet, and the factors that encouraged them to continue these behaviours over time.

#### 1.4.2.2 Phase B – Demographic characteristics of gluten avoiders

The second research phase utilised a wide scale quantitative survey that was designed specifically to capture prevalence rates of gluten avoidance behaviours in Australia. Without accurate estimates of the number of people engaging in the behaviour, there was no way to draw clear conclusions about the impacts that these behaviours could have. The data collected in this study was weighted against the most recent Census data (ABS, 2011) available for Australia to ensure that accurate and generalizable results could be reported. The demographic characteristics of each study group were captured and any notable differences were explored that may also help to explain their differences in behaviour.
1.4.2.3 Phase C – Physiological and psychological determinants of gluten avoidance

The study discussed in Phase C is broken down into several chapters based on their respective focus areas and the measures. Phase C is dedicated to the quantitative exploration of physiological and psychological variables that influence the adoption of non-prescribed gluten avoidance. A final sample of 1240 participants was used to compare non-prescribed gluten avoiders with gluten consumers. The symptoms being reported by gluten avoiders were explored via self-report measures. A complete investigation was carried out into the links symptoms held with perceptions, and the hypotheses for these that were developed from the insight relating to individual differences in sensitivity.

1.4.3 Thesis Structure

This thesis is presented in the above sequential design, and in conjunction with an introduction and literature review preceding the three research phases. A final discussion chapter follows these research phases, and is presented in the order described below:

Chapter 1 presented an overview of the research context on which the thesis was developed, including relevant gaps in the existing knowledge base, and the utility that the current research can provide in addressing these areas. It also outlined the aims and outcomes presented in the thesis, and considers the significance of the research. This is followed by a summary of the research design and the thesis structure.

Chapter 2 integrates the current literature exploring gluten-related disorders and the avoidance behaviours that occur as a result of the disorders increasing popularity, including the knowledge gaps that increase contestation of these illnesses. It also summarises the literature about non-medical drivers of food avoidance and dietary change, including a variety of psychological variables and how they can impact food choice. This literature review helps to identify key variables of interest within the population that were used to guide the development of subsequent phases of the research.

Chapter 3 provides an overview of the shared subjective experiences that are described by non-prescribed gluten avoiders, including the motives behind their
food choices and the factors that perpetuate their avoidance behaviours over time. A number of key themes were identified amongst the non-prescribed gluten avoiders that participated in the study. The results of this phase of the study study were used to inform the design of the following quantitative studies so that they relate directly to the reported experience of the population, and not confined to the limited coverage available in the current literature base.

Chapter 4 includes the results of a wide-scale population survey that was designed to accurately capture rates of prescribed and non-prescribed gluten avoidance behaviours in Australia. This representative sample provides insights into the demographic variables that characterise this population, such as age and gender distributions.

Chapter 5 details the method and design of the study presented in Phase C. The subsequent research questions for each section are presented within the context of the overall phase. This is followed by an overview of the recruitment strategy and the three-step participant selection process. A summary of all the measures that were employed is also included in this chapter, along with their reliability statistics. Finally, information about the chosen data analysis, ethical considerations, and limitations of Phase C are presented.

Chapter 6 focuses on the physical symptoms and avoidance patterns that are reported by non-prescribed gluten avoiders in regards to both gluten and non-gluten foods. The relationship between symptomology and avoidance behaviours is considered. Rates of somatisation amongst participants are also discussed in the context of non-prescribed gluten avoidance.

Chapter 7 discusses the findings from a range of variables that are presented alongside the qualitative findings from Chapter 3, in an effort to replicate the findings on a larger scale. This chapter also includes measures of additional cognitive characteristics that influence food choice, including health and risk perceptions, thinking styles and food choice preferences, as well as the factors that influence them.

Chapter 8 examines the role of individual differences in the decision to engage in non-prescribed gluten avoidance. Factors such as autonomic arousability,
stimulus amplification and personality characteristics are considered, and their relationship with gluten avoidance behaviours is discussed in detail.

Chapter 9 integrates the findings presented in the thesis in an overall discussion about non-prescribed gluten avoidance, and the conclusions that can be drawn from the research that has been conducted. The implications of these findings are also presented in the context of those who will be interacting with this population, or aiming to create products that are targeted towards them. A final conclusion to the thesis is presented following an overview of its limitations, and suggestions for future research.

1.4.4 Definitions and abbreviations

PGA: Prescribed gluten avoider
NPGA: Non-prescribed gluten avoider (see also GA)
GA: Gluten avoiders. **The term gluten avoider is used for simplicity throughout the thesis, adopted as an abbreviation following the elimination of non-relevant participants in the sample.
GA+: Gluten avoiders who present with self-reported symptoms following the consumption of gluten.
GA-: Gluten avoiders who do not report adverse symptoms following the consumption of gluten.
GC: Gluten consumers, or persons who deny actively avoiding gluten.
DA: Diagnosed avoiders. Encompasses the two main diagnoses that result in prescribed gluten avoidance (coeliac disease & wheat allergy).
GFD: Gluten-free diet
GRD: Gluten-related disorder
CD: Coeliac disease
WA: Wheat allergy
GP: General Practitioner
NCGS: Non-coeliac gluten sensitivity
IBS: Irritable bowel syndrome
ABS: Australian Bureau of Statistics
Chapter 2: Literature review

2.1 Introduction

Research that aims to capture drivers of non-prescribed gluten avoidance is in short supply and is plagued with ongoing contention surrounding the validity of the non-coeliac symptoms reported by this population. This chapter aims to provide an overview of this debate and explores how pre-existing food choice research may relate to the avoidance behaviours that characterise this population. This chapter was used to identify key variables of interest within the population that formed part of the study design discussed in later chapters.

2.2 Overview

Wheat and gluten proteins have been studied at length within the literature, and are accountable for two main disorders; coeliac disease (CD) and wheat allergy (WA). Coeliac disease is classified as an autoimmune response in the body that is triggered by the ingestion of gluten. In this response, the walls of the small intestine are damaged, preventing people from absorbing vital nutrients into the body. This leads to a variety of symptom presentations ranging from asymptomatic through to global malabsorption (Ontiveros, Hardy, & Cabrera-Chavez, 2015). Wheat allergy is defined as an allergic response to wheat, which results in the activation of antibodies within the digestive system leading to a range of atypical gastrointestinal symptoms. Both CD and WA can be clinically confirmed or excluded in a patient following a battery of medical and genetic tests that assist in the identification of physiological responses. Evidence-based treatment approaches suggest that total gluten/wheat avoidance is the best option for symptom management in both cases. Estimations of the prevalence rates for these disorders vary between studies, typically being reported around 1-2% of the total population.

2.2.1 Increasing popularity of gluten-free diet adoption

Research by US company Packaged Facts (2015) claims that between 2009 - 2014 the rising interest in gluten-free products resulted in a 34% compound growth rate in sales each year, equating to a multi billion dollar industry worldwide. Approximately 20% of the population was reported to be actively considering the gluten content of their foods when making a purchase. However, this trend was not reflective of the diagnostic rates for CD/WA at the time (Kim et al., 2016), indicating
that a large proportion of those choosing to restrict the amount of gluten in their diets did not meet diagnostic criteria for CD or WA.

Changing dietary behaviours among non-coeliacs occurred concurrently with the increasing focus on gluten within popular media formats, such as self-help books and celebrity diet plans. One of the most famous examples of these is the book written by licensed cardiologist and self-proclaimed health crusader, Dr. William Davis. The New York Times best seller *Wheat Belly* (Davis, 2011) claimed that gluten was the main contributing factor in modern health issues such as obesity, diabetes, rheumatoid arthritis, multiple sclerosis, fatigue, and glaucoma. The book ridiculed modern wheat varieties for the industry led genetic modification that he believed left consumers diseased and addicted to carbohydrate rich diets. The gluten myths outlined in Wheat Belly are debunked quickly, as it has been shown that the impact of wheat breeding has not increased the protein contents of wheat varieties enough to cater for the rise in perceived gluten related illnesses over time (Kasarda, 2013). Jones (2012) adds to these critiques by stating that the low-gluten diet presented by Davis (2011) is also in essence a low-carbohydrate diet leading to the avoidance of products such as breads, cakes, sauces, and processed foods, reducing overall caloric intake. These low-carbohydrate diets have been shown to be an equally, if not more effective alternative to low-fat diets at achieving weight loss and health improvements (Bueno, de Melo, de Oliveira, & da Rocha Ataide, 2013; Shai et al., 2008). However, if gluten-containing products are replaced by gluten-free alternatives, such as gluten-free breads and cakes - the opposite effect has been observed. When removing gluten from products, manufacturers often have to use additives to assist in the replication of foods in order to make them palatable for consumers (Gallagher, Gormley, & Arendt, 2004). Studies have shown people with CD who are effectively managing their diets with gluten-free substitutions can have a higher Body Mass Index due to these factors (Kabbani et al., 2012). The adoption of a gluten-free diet (GFD) alone is therefore an ineffective means of weight management, particularly for those whom are not medically required to avoid gluten and are forced to look for gluten-free alternatives.

Despite the risks that a major dietary change, such as the adoption of a GFD, can have on our bodies (Nash & Slutzky, 2014; Thompson, 1999), the diet continues to be popular amongst those without a diagnosis of CD. Rousseau (2015)
examines the role of these ‘quick fix’ diet solutions in society and notes that many people are drawn to their apparent efficacy due to the desire for a simple solution to a more complex problem. Those who experiment with diets can often misattribute weight loss or improvement in wellbeing to certain foods that are avoided as opposed to the overall impact that dieting can achieve. For example, the GFD is also by proxy low in carbohydrate rich foods that are often over consumed; for example, breads, pasta, and cakes. Low carbohydrate diets are known to improve symptoms and quality of life in certain patients with IBS, whose ailments can mimic those reported by gluten avoiders (Austin et al., 2009). Someone avoiding gluten could come to a false conclusion that their GFD is a catalyst for said improvements, reinforcing their behaviours and beliefs. Although the benefits for non-coeliacs following a GFD have been questioned in the literature, the diet continues to gain traction amongst television programs, websites, blogs and magazines. With television programs hosted by doctors becoming a common inclusion for daytime viewing, the separation between health professionals and health stars becomes complicated (Meijboom, 2007). Biswas, Biswas, and Das (2006) add that the success of these health claims is also based on the congruence between the celebrity used, and their association with the product.

The ambiguity and volume of information available about gluten makes consumers more vulnerable to misinformation. Increased cognitive loads are required to absorb multiple facets of information simultaneously (Lavie, Hirst, De Fockert, & Viding, 2004), especially when they involve specialised knowledge, such as that which is needed to understand autoimmune responses and dietary disorders. The busy lifestyles of consumers in the modern world only exacerbate the desire to reach a decision that is fast and ‘good enough’ (Schwartz, 2004). This lexicographic model of heuristics implies that consumers apply skewed weights to attributes that are most important to them (Goldstein & Gigerenzer, 2002). Decisions that are made using this process are often made fast, and can be utilised with limited cognitive resources in situations where the cost of making an error is low (Scheibehenne, Miesler, & Todd, 2007). The speed with which decisions are made is also correlated with higher levels of anxiety and energy, which impacts the quality of decisions and levels of risk aversion (Maule, Hockey, & Bdzola, 2000). In the context of seeking information about gluten, it is therefore likely that the number of conflicting messages complicates the decisions that consumers typically make about its consumption. This applies more
so to gluten than to a food item with less ambiguous messages such as carrots. In these situations, people may shift their thinking styles away from facts, relying more heavily on intuition derived from previous experience (Rousseau, 2015). These heuristics are often heavily influenced by the messages that consumers absorb from their trusted health information sources.

When observing the typical information sources used by non-prescribed gluten avoiders, Metchikoff (2014) found that the majority of their sample (55%, n = 71) had used the internet as their primary source of health information. This percentage rose to 78% when this range was broadened to include friends, family and other popular media sources, including books, magazines and support groups. These results are synonymous with findings within CD populations (Green et al., 2001), indicating that the majority of people avoiding gluten (both diagnosed and non-diagnosed) are getting a large proportion of their information from non-medical sources. The increasing use of the internet as a dominant health information channel has come with several issues, including manipulation of consumer acceptance, risk perception and accessibility of misinformation (Park, Chung, & Yoo, 2009). Moore (2014) found that non-prescribed gluten avoiders were also likely to engage in self-ascriptive behaviours, where they diverted away from medical diagnosis in favour of self-diagnosis. These diagnostic processes extended to include the identification of symptoms, and resulting quasi-diagnosis in family and friends of those avoiding gluten. This pattern of information consumption and sharing demonstrates how misinformation about gluten could fuel the ongoing desire to avoid it in those without a clear diagnosis of CD. Although a variety of misinformation has developed about gluten and its effects (Jones, 2012), a majority of the population remains avid consumers of gluten. Therefore, the increasing availability of popularized gluten information is only one of many factors that has been fueling the increase in gluten avoidance behaviours amongst non-diagnosed individuals.

### 2.2.2 Contention regarding gluten sensitivity

Recent publications have seen the introduction of a third gluten-related disorder following increased rates of CD-like symptoms being reported by patients who have failed either one or both diagnostic tests designed to identify the autoimmune disease. The term *non-coeliac gluten sensitivity* (NCGS) was thus adopted in the literature, and describes the experience of gastrointestinal and
neurological symptoms that are similar to those reported by patients with CD despite having no biomarkers that indicate the presence of the disease. It is therefore considered an entirely separate clinical condition that can only be accurately diagnosed following the exclusion of CD (Leonard, Sapone, Catassi, & Fasano, 2017), and positive responses to a strictly monitored gluten-challenge protocol (Catassi et al., 2015). The administration of such tests is often complicated and are particularly difficult to employ within the time restrictions encountered in general medical practice. This lack of diagnostic clarity has delayed an accurate estimation of prevalence rates for the condition. As there are currently no medical tests available to definitively confirm the existence of NCGS (Ludvigsson et al., 2013), identification typically occurs through self-report of symptoms and subsequent experimentation with exclusion diets and gluten challenges.

Many have speculated that gluten is the main trigger involved when experiencing non-coeliac symptoms due to the subsequent reduction in reported symptoms following a transition to a GFD, although this has been a matter of contention. Hadjivassiliou et al. (2010) conceptualised CD as one of a range of manifestations of gluten sensitivity, noting that a number of extra-intestinal presentations can also be linked back to gluten. These findings were not supported by the data presented in similar works, although there was some anecdotal support indicated for the links between gluten sensitivity and cerebellar function (Versino et al., 2010). Other factors were also considered important in the gut-brain connection observed in gluten consumption, including the presence of certain antibodies, specific genetic variations, and clinical responses to gluten withdrawal (Volta & De Giorgio, 2010). From this time, a significant amount of research was dedicated to the exploration of gluten-effects on non-coeliac patients, leading to a saturation of content.

Biesiekierski, Newnham, Muir, and Gibson (2012) were initially unable to confirm the existence of NCGS in non-coeliac patients, which they later deduced might be due to the role that other carbohydrates may play in the diagnosis (Biesiekierski, Peters, et al., 2013). In the following year, they established that the majority of people who were diagnosing themselves with NCGS had not adequately excluded CD, or engaged in the appropriate method in order to accurately establish a diagnosis, with just over 1 in 4 reported cases meeting the criteria for NCGS
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(Biesiekierski, Newnham, Shepherd, Muir, & Gibson, 2014). This study brought to light the significant complications that are associated with a diagnosis that relies heavily on self-reporting and co-operative diagnosis. Whilst there were a number of studies that have since established the presence of gluten effects in non-coeliacs (Caio, Volta, Tovoli, & De Giorgio, 2014), the atypical presentation that is associated with a diagnosis meant that a range of people also began to misattribute their general gastrointestinal upsets to gluten. One study suggested that this misattribution might occur in up to 86% of patients reporting gluten-related symptoms (Capannolo et al., 2015), significantly inflating the perceived scope of its effects amongst the general population on undiagnosed individuals.

The mechanisms behind NCGS and its prevalence rates are still a matter of debate, with recent research still suggesting alternative triggers for these effects. Through a double-blind crossover including three separate food challenges with gluten, fructans and a placebo, those with NCGS were found to be significantly more symptomatic to fructans (Skodje et al., 2017). In this study, the second highest symptom-inducing trigger was the placebo, which draws ongoing attention to the inconsistencies and complexities that are associated with this phenomenon. These mixed findings have fuelled the development of blogs and books discussed earlier, which are aimed at educating laypersons about gluten. As the information base is still being developed, and mechanisms are still being explored, these sources appear to be responsible for adding confusion to the already oversaturated coverage of gluten and its effects. This outlines the issues that can occur when trying to reach an accurate diagnosis regarding symptoms that are perceived to be associated with the consumption of gluten.

2.2.3 Risks associated with unnecessary restriction

Whilst there is unequivocal support for gluten avoidance in patients with CD as a direct method of repairing gluten-related damage, recommendations for those experiencing NCGS are less clear. Even after starting a gluten-free diet, those with villous atrophy associated with CD show a slow and sometimes incomplete recovery from damages caused (Peter, Jos, & Chris, 2002). If not properly followed, or only partially adhered to, CD patients can also inadvertently increase their risks of developing cancer (Holmes, Prior, Lane, Pope, & Allan, 1989). Those that are adopting a strict GFD need to consider whether the strict dietary change provides
benefits over and above the risks that follow. There is a lack of current data about risks associated with consuming a GFD in a non-coeliac population. However, a number of papers have explored the risks faced by populations with CD – marking it as a serious dietary choice for many, and one that comes with consequences that should be seriously considered before making the transition (Nash & Slutzky, 2014).

The adoption of a GFD is used as a management strategy to reduce symptoms for those with CD, and cannot lead to an elimination of the life-long disease itself. A study by Kabbani et al. (2012) found that the initiation of a GFD for coeliac patients resulted in a significant increase in their BMI across 39 months. Longitudinal examination of patients with CD have also found that there was a pattern of significantly poor vitamin status among this population (Hallert et al., 2002). Those with CD heavily encourage people adopting a GFD to assess their own vitamin needs with a health professional as they begin reduce their consumption levels of gluten. Shepherd and Gibson (2013) examined the inherent deficiencies present in a GFD and found that these dietary restrictions are often accompanied by inadequate intake of fibre, thiamine, folate, vitamin A, magnesium, calcium, iron and zinc. Nutritional issues have also been identified in gluten-free products, with studies showing that they are rarely enriched (Thompson, 1999) and often lack folate, iron and dietary fibre (Thompson, 2000a).

Gluten-free diets are also complicated due to a lack of understanding in the general population about the structure and definition of gluten, which is a major factor in diet adherence (Leffler et al., 2008). Even those diagnosed with CD struggle to comply with a GFD (Ciacci, Cirillo, Cavallaro, & Mazzacca, 2002), regardless of the physiological damage gluten consumption causes in these individuals. Despite the risk of malnutrition, and the complicated lifestyle impacts a dietary change such as this causes, Metchikoff (2014) found that only 14% of non-diagnosed gluten avoiders had employed the expertise of medical or dietary professionals into their diet plans. Although the study is small, and based on convenience sampling, these findings do allude to the risk of misinformation leading to poor health decisions based on minimal nutritional guidance. Coeliac Australia (2015) warns that people are at risk of misattributing the health improvements they experience following gluten avoidance to a self-diagnosis of NCGS without proper medical examination. This places them at greater risk of misdiagnosis, and perpetuates their fears about the poor capacity of
modern medical professionals in diagnosing conditions of this nature. Assumptions like this are dangerous, because doctors remain significantly more educated about general health than non-doctors and can provide additional access to testing that is otherwise unobtainable.

Moore (2014) explains that the above issues can cause people to question the motivations behind non-medically diagnosed individuals who choose to follow a GFD. This draws attention to the inconsistencies between biomedical advice and independent anecdotal choice, increasing social contestability of the issue. Paired with the ongoing spread of misinformation, this decreases the seriousness in which gluten-intolerances are considered by third parties, particularly when these intolerances require additional effort on the part of service providers i.e. making a dish gluten-free. Often this can lead to serious consequences where gluten-free requests are ignored or only partially adhered to in public establishments. This variance in attitudes promotes cross contamination in foods that are prepared and can lead to increased physiological reactions and discomfort for many genuine sufferers.

2.3 The psychological components of food choice

Any comprehensive understanding of food choice behaviours needs to include a review of the psychological components that influence these decisions. These become particularly pivotal in the context of food consumption, as this large industry of consumables often utilises manipulation of perceptions and emotions in the hopes of increasing purchasing behaviours. The main factors that influence food choices are reviewed below, including consumer perceptions, thinking styles and cognitions, emotions and personality.

2.3.1 Consumer perceptions

The perception of a given product’s healthiness is one of the many important factors that influence consumption. Each consumer has a different understanding of what health is, and how to identify the healthiness of certain products and nutrients (Laureati, Giussani, & Pagliarini, 2012). These perceptions are formed through an interpretation of available product information given to consumers, whether this be via word of mouth, online, or via the packaging provided on the product itself. This information has been shown to manipulate consumer perceptions based on its contents (Jones & Richardson, 2007). Labels often utilise language such
as *fat-free, organic, and natural* in an attempt to influence the perceived healthiness, and therefore attractiveness of a product. Food names and descriptors also prime consumers with certain expectations about a food, acting as a self-fulfilling prophecy (Wansink, van Ittersum, & Painter, 2005). This finding is based on the formation and engagement of heuristics, which are collected over time through the opinions and knowledge that consumers are exposed to (Schulte-Mecklenbeck, Sohn, de Bellis, Martin, & Hertwig, 2013). Heuristics act as cognitive shortcuts for consumers who are often lacking in time and mental resources when they are in situations where food choices need to be made.

Utilising heuristics when making a quick decision is often a flawed process, and can lead to errors when making judgements about foods. Most people are likely to immediately perceive a food to be more healthy if it is labeled as low fat (Carels, Harper, & Konrad, 2006). Carels, Harper and Konrad (2006) also showed that foods labeled as healthy, or foods linked to weight loss, were systematically seen to contain fewer calories than they actually did. This labeling (and therefore perception) is often manipulated in a way that places focus on certain food factors over others, and can sometimes be incongruent with the product being advertised. Obesity Australia (2014) hypothesized that it was these types of perceptions that were driving the overconsumption of fat in westernized populations, acting as a significant contributor to the increasing obesity epidemic. Provencher, Polivy, and Herman (2009) further investigated how heuristics could be triggered in an experimental study that manipulated product labeling. They gave their 99 participants the opportunity to taste an ambiguous cookie product after receiving targeted descriptions (either healthy or unhealthy) about its ingredients. Alarmingly, their findings indicated that foods paired with healthy messages were consumed at a rate of 35% more than those whom were given messages suggesting the product was unhealthy, despite being offered the same cookie. The extent to which these messages influenced the rate of consumption further supports the importance that consumer perceptions play in food choice, and demonstrates how the language chosen to describe a food can easily manipulate them.

Despite the effects shown in the above studies – there is a limit to the intensity and the scope of manipulation that can be achieved through labeling. This is demonstrated in a preliminary study that examined the effects of a nutrition logo on food consumption in a group of 36 women (Steenhuis et al., 2010). It was
hypothesised that the addition of a nutrition logo in the healthy group would influence greater consumption. In fact, the results of the study showed no significant difference between groups. Another study (Adams & Geuens, 2007), which employed a survey of 310 Belgian adolescents, found that health messages (healthy vs. unhealthy) were more effective when they were congruent with the foods with which they were paired. It was harder to prime consumers with health information regarding foods that were unambiguous, and for which they had pre-existing health beliefs such as cake being an unhealthy food. However, when a food product’s health status is ambiguous, consumers were much more vulnerable to the effects of messaging. In the case of gluten, an increasing number of negative messages is likely to sway ambiguous consumer beliefs towards a negative categorization. A review of the health perceptions held by non-prescribed gluten avoiders may therefore help shed light on the impact that these mixed messages could have on their resulting behaviours.

The decision to consume one food over another has also been linked with risk perceptions, and this can play a part in how consumers evaluate the foods that are available to them. Risk perceptions are closely associated with the tolerance that one has to ambiguous situations, where those with a higher tolerance to ambiguity have been found to accept higher levels of risk (Tymula et al., 2012). Ghosh and Ray (1997) note in their earlier work that this may be due to the fact that ambiguity is sometimes misperceived as risk in certain individuals, intimately linking the two concepts together. Risk perceptions are also influenced by the amount of trust that consumers place in food-safety information relating to foods (Lobb, Mazzocchi, & Traill, 2007) and this can ultimately influence the amount a consumer is willing to pay for a product (Angulo & Gil, 2007). Knox (2000) indicates that there is a substantial gap between the food risk perceptions held by experts, and the general opinions that exist within the lay public. This is facilitated by a lack of specialized knowledge, which prevents non-experts from understanding the complexity of processes involved with food modification and breeding. Therefore, the debate surrounding risk perceptions of gluten is uniquely placed so that consumers may make their own decisions based upon at-home experimentation. There is currently no research that quantifies the risk perceptions of non-prescribed gluten avoiders; however, it is possible that their avoidance behaviours are a reflection of the higher levels of perceived risk that they associate with its consumption.
2.3.2 **Thinking styles and cognition**

It is impossible for consumers to logically evaluate and consider every piece of available information when they engage in decision-making processes, due to the time restraints that are placed upon them in the busy lifestyles of the modern era. Petty, Schumann, Richman, and Strathman (1993) note that the *more arguments = more valid* heuristic can be triggered easily in individuals with limited cognitive resources, mirroring the phenomenon currently developing in gluten avoidance. When 56 participants had their choice processes tracked across a range of meal pairs, none were found to have utilised the traditional compensatory strategy that allows for complete weighting and summing of all relevant variables (Schulte-Mecklenbeck et al., 2013). Instead, participants employed a range of time saving processes to make quick decisions, where they either limited their searches, or limited their incorporation of weighting. These findings add to the preliminary work of (Scheibehenne et al., 2007) that showed both compensatory (weighing up the value of all factors to make an informed decision) and non-compensatory strategies (lexicographic approach where decisions are often based on one factor/reason that is valued the highest) to be equally as accurate at predicting food choice. It was concluded that the abundance of food decisions presented in the modern era has resulted in the refinement of choice heuristics relating to consumer preferences and values, resulting in attendance only to the information that matters most. In the case of gluten avoidance, the significant number of information sources available would serve to skew the judgements being made by consumers more so than for products which have clearly documented benefits/risks.

In order to combat the above limitations on cognitive resources, individuals are known to adopt certain information processing or thinking styles that they rely on to reach a decision that is best aligned with their values and beliefs. These styles can be categorized into more intuitive systems, which shows a preference for fast implicit processing, and the analytical systems, which show more conscious but slow efforts to make a judgement (Leikas, Lindeman, Roininen, & Lahteenmaki, 2007). These information-processing styles align effortlessly with Pacini and Epstein’s theory of rational and experiential thinking styles (1999). Pacini and Epstein (1999) found that experiential thinking shares similarities with those who prefer heuristic processing, where an automatic processing style is utilised to efficiently
make decisions on a broad range of factors. This is supported by the fact that those with the opposite (rational) thinking style are significantly less vulnerable to the impact of heuristics (Epstein, Pacini, Denes-Raj, & Heier, 1996). People who fall on the rational end of the spectrum adopt a more analytical approach to thinking, which means that their judgments are often less associated with affect. Leikas et al. (2007) proposed that those with a preference for analytical processing should therefore be less impacted by the affective tone of food risk information, an issue that is particularly apparent in the above debate regarding gluten. Therefore, differences in thinking styles could be responsible for the discrepancy between behaviour patterns in non-prescribed gluten avoiders, and gluten consumers.

### 2.3.3 Emotions

Emotions can be considered another driver of avoidance behaviours (for a full review, see Schifferstein, Fenko, Desmet, Labbe, & Martin, 2013). While packaging and sensory qualities can have some impact on choice, often it is the pre-existing attitudes that drive purchasing at the point of sales. This is not to say that consumers don’t use packaging to evaluate products, but simply that preconceived ideas about the product often come into play when choices are being developed. Some studies have drawn a clear distinction between the emotional responses of product users and non-users, noting that non-use is an independent process that is deserving of its own analysis (Gutjar et al., 2015). However, the lack of standardised measurements for emotion has been a consistent barrier in food-mood research. King and Meiselman (2010) attempted to ease this barrier in their study comparing users and non-users on a range of factors. When they compared the consumer’s emotional profile to food product usage, they found that non-users had a distinct negative profile compared to product users (having strong positive emotions towards the food). The more positive a consumer felt about the product, the more likely they were to use it, over and above acceptance values. These findings support the theory that consumers are only likely to invest time and money into a product that generates positive emotions for them (Schifferstein & Desmet, 2010). This may suggest that mood is an additional variable that impacts perception when making food choices, further validating its inclusion in the food choice model presented by Steptoe, Pollard, and Wardle (1995).
When consumers experience negative emotions and stress, their behaviours have been shown to shift regarding the types of foods they are drawn towards (Oliver, Wardle, & Gibson, 2000). A study of 34 undergraduate females found that when placed under stress, participants ate significantly more sweet snack foods, supporting the idea that these emotions cause disinhibition of previously imposed dietary beliefs about what should be avoided (Zellner et al., 2006). Stress and anxiety may also impact on food avoidance. The impacts of stress on eating behaviors are so profound that, even after patients are involved in a negative food challenge, a number of them continue to avoid their assumed trigger food due to the fears of the symptoms reoccurring (Eigenmann, Caubet, & Zamora, 2006). Food-related anxiety can also trigger avoidance behaviours in consumers who are particularly averse to risk taking. Meiselman (2015) explored the role of emotions in the context of perceived product risk, noting that higher probabilities of risk are associated with panic, reducing the likelihood of consumption. Therefore, if a consumer has a pre-existing assumption that gluten-free products are healthier, they would have likely already decided if they would be searching for these products. On the other hand, if a consumer has pre-existing negative expectations about a product, they are more likely to experience anxiety that can only be alleviated by avoidance of the product. This nocebo effect is most common in women and those who have negative knowledge about a food (Symon, Williams, Adelasoye, & Cheyne, 2015), and has been considered as an alternative explanation for the relief in symptoms experienced by some non-coeliacs after beginning a GFD (Biesiekierski, Muir, & Gibson, 2013).

Autonomic nocebo responses have been observed in a study which staged others discussing concerns about a placebo tablet in front of observers. These participants were found to report significantly more side effects and experience significantly more overall symptoms than the control group (Faasse, Grey, Jordan, Garland, & Petrie, 2015). Although self-reported rates of state anxiety remained constant, these participants were observed to experience symptoms of stress following the social modeling experiment. The authors hypothesized that participants’ attention may have been directed towards body monitoring after receiving cues from their external environment. This relationship has been confirmed in studies that target hypochondriasis whereby both attention and expectancy have been shown to
influence the reporting of symptoms (Schmidt, Wolfs-Takens, Oosterlaan, & van den Hout, 1994). Treatment options that include the re-direction of body-focused attention have been proven to be successful in these clinical populations, demonstrating long-term efficacy and an overall reduction in illness-related behaviours and cognition (Papageorgiou & Wells, 1998). The existence of anxiety and stress in relation to food-consumption can therefore impact consumers on a cognitive and a physiological level. Little is known about the role that such emotions play in the decisions made by non-prescribed gluten avoiders. An observation of their avoidance behaviours in the context of related symptoms and perceptions is required to explore the relationship between these variables for this specific population.

2.3.4 Personality

The literature exploring the links between personality and choice is extensive, including the influences traits have on political choice (Caprara, Schwartz, Capanna, Vecchione, & Barbaranelli, 2006), vocational choice (Osipow, Ashby, & Wall, 1966) and drug choice (Le Bon et al., 2004). An assessment of one’s personality provides the ability to predict the type of disposition someone would adopt in a certain situation, assisting in future predictions for their behaviours (Ickes, Snyder, & Garcia, 1997). In the context of food-choice, personality traits are thought to interact with food choice motives in order to determine whether a food is consumed or avoided. Personality traits have also been shown to significantly differ between groups with different tastes, including sweet-taste preference in wine (Saliba, Wragg, & Richardson, 2009) and tolerance for spicy foods (Byrnes & Hayes, 2013). These individual differences support a biological basis for taste preferences (Drewnowski, Henderson, & Barratt-Fornell, 2001), which could be mediated in part by psychological variables like personality and temperament. Previous research has established that one’s level of nutritional knowledge is not alone sufficient to predict their food consumption behaviours (Packman & Kirk, 2000). This has led some to propose that psychological variables may also be involved in the processes that effect consumption behaviours and dietary change (Richardson & Saliba, 2011). These factors can also impact cognitive variables, such as the perceptual distortions that are involved in perpetuating disordered eating behaviours (Heilbrun & Flodin, 1989).

Some researchers have considered the role that factors such as food-neophobia and food-involvement also play within this decision-making model, and
revealed a connection to food intake (Eertmans, Victoir, Vansant, & Van den Bergh, 2005). These results add weight to previous research (Marshall & Bell, 2004), which found that food involvement mediated food choices in military personnel. This military study also indicated that those with higher food involvement tended to make healthier food choices. Food-neophobia has been defined as a personality style in its own right, measuring the reluctance to experiment with new foods. Pliner and Hobden (1992) showed that food-neophobia was negatively associated with experience seeking, and is particularly useful when assessing dietary patterns in relation to the consumption of a novel food, or ingredient, such as gluten. In contrast, traits such as sensation seeking and sensitivity to rewards have both been associated with more adventurous consumption behaviours, such as the frequency of chilli consumption (Byrnes & Hayes, 2013). One explanation provided for this association was that persons higher on these traits might also possess a higher tolerance to risky consumption behaviours. In this context, those who are averse to risk would not consume foods that they associate with discomfort, including foods that are spicy.

Personality traits may also mediate the consumption rates of gluten due to the higher rates of confusion regarding its healthiness and risk, as stated earlier in the review. Some of the above studies adopted the Steptoe et al model of food choice to assess consumption behaviours in their respective research. Steptoe et al. (1995) predicted that personality traits such as neuroticism and openness to experience would both relate to food choice variables because of their demonstrated relationship with the emotional food experience, and the willingness to eat. The role that emotion plays within the context of food choice has been discussed above. It was confirmed that neuroticism correlated positively with the mood scale in men, and openness to experience correlated negatively with familiarity in both genders (Steptoe et al., 1995). This suggests that people who are preferring to eat familiar foods are often lower in openness, limiting their ability to try new foods without apprehension.

Other studies examining food choice have also nominated neuroticism to be an important mitigating factor due to its ability to moderate stress levels, and the consequential health practices that typically follow. Neuroticism has been identified as one of the main personality factors that influence rates of self-reported illness symptoms (Feldman, Cohen, Doyle, Skoner, & Gwaltney Jr, 1999), even when there is no physiological basis for these complaints. It remains unclear as to whether this
direct association is linked to attentional biases, or biases in the interpretation and recall of physical sensations. Carrillo, Prado-Gascó, Fiszman, and Varela (2012) found that neuroticism was significantly correlated with Steptoe’s health scale (Steptoe et al., 1995), deducing that it could also impact food choice indirectly by influencing food preferences and values. These associations have also been observed in a younger cohort (11-15 years) where neuroticism was found to be negatively associated with healthy eating/habits (MacNicol, Murray, & Austin, 2003). The findings related to neuroticism consistently identify emotional variability as a unique driver of food choice, which are likely shaped by the biological expressions of personality features. Personality variables therefore provide additional insights when attempting to characterise a specific set of food-choice behaviours, such as those observed by non-prescribed gluten avoiders.

2.4 Summary

The literature review presented in this chapter aimed to identify key variables of interest that should be considered when attempting to characterise the experience of non-prescribed gluten avoiders. Despite sharing similar symptoms with CD, the literature regarding emerging gluten-related illnesses such as NCGS continues to lack the identification of clear mechanisms that serve to adequately reach a diagnosis in contemporary GP settings. Self-diagnosed rates of gluten sensitivity have increased, with many individuals now being able to access information about gluten and its effects from popular sources. The fear caused by sensationalised gluten content has the potential to increase avoidance behaviours amongst those who obtain no physiological benefit from the diet. This population thus places themselves at risk of malnutrition and make health-altering decisions often without the assistance of trained medical professionals.

To date, there has been limited research conducted into the consideration of psychological factors that influence the decisions to engage in non-prescribed gluten avoidance. Factors such as perceptions, cognitions, emotions and personality have all been shown to influence behavioural patterns and food choice. These variables need to be further scrutinised specifically within the context of gluten avoidance, so that a comprehensive understanding of the phenomenon can be developed. In order to adequately design a large-scale quantitative survey that observes the impact of these variables, the feedback from non-prescribed gluten
avoiders themselves is required. Collecting the experiences of this population directly will assist in the identification of important factors that contribute to their behaviours, as well as those factors that are perhaps yet to be identified as important in the current body of literature. In this regard, qualitative experiences can adequately inform the subsequent inclusion of variables that would assist in the larger scale observations of these behaviours and their drivers. The qualitative study designed to address these aims is discussed in detail in Chapter 3.
Chapter 3: The subjective experiences of non-prescribed gluten avoiders

3.1 Introduction

There was a significant research gap identified within the literature review presented in Chapter 2, noting a lack of in-depth understandings related to the motivations behind non-prescribed gluten avoidance. A qualitative study was designed in an effort to begin addressing this gap within the scope of the current research. In addition, in order for future quantitative studies to be deemed as relevant and relatable for people who avoid gluten, they needed to be informed by the subjective experiences described by the people who engage in this behaviour. The research discussed in this chapter aimed to understand the subjective experiences of gluten avoiders, including the reasons that influenced their initial decision to follow a GFD, and the factors that encouraged them to continue these behaviours over time. This qualitative study design and findings will be presented in the current chapter.

3.2 Background

Currently there is a lack of diagnostic information and evidence-based treatment options available to non-prescribed gluten avoiders. In situations where there is ongoing contention around the development of symptoms, doctors are often reluctant to commit to diagnostic labels in the hopes to reduce rates of self-fulfilment amongst health-focused patients. This phenomenon was outlined in a study of chronic fatigue patients (Woodward, Broom, & Legge, 1995), where the absence of diagnostic labels resulted in negative effects for the patients themselves. Even when doctors suspect emerging illnesses, they are often difficult to verify with the existing testing options. Doctors are valued on their ability to make fast and accurate diagnoses, and so those illnesses that cannot be objectively identified are often not prioritised in the same way that diagnosable conditions are amongst contemporary health professionals (Åsbring & Närvänen, 2002). Thus, illnesses with unclear aetiologies can be stigmatised, leading to a number of negative experiences, including contestation and epistemic injustice.
3.2.1 Contested illness

A landmark study within the area of non-prescribed gluten avoidance in America was published by Moore (2014), and remains one of the only studies to adopt an in-depth qualitative perspective in order to explore the experience of this population. They found a range of common factors amongst gluten avoiders that perpetuated their ongoing dietary behaviours, such as their experiences with doctors and the disappointment that followed as a consequence. In this study, it was noted that gluten avoiders’ expectations of doctors were particularly impacted following the lack of diagnostic clarity available in the medical sphere. This led them to question the authority of doctors in the traditional sense, resulting in a significant increase in dependence on self-diagnosis and management of their food-related symptoms. Golley, Corsini, and Mohr (2017) proposed that this dissatisfaction with conventional medicine was also a major influence on the behaviours of symptomatic wheat avoiders, and was reminiscent of the contested illness experience found in a variety of health phenomena reporting medically unexplained physiological symptoms. Contested illnesses are defined as those health-conditions that are characterised by symptoms without clearly identified biological mechanisms, which often lead to contestation amongst doctors about the origins of said symptoms.

A comprehensive review by Maulterud (2000) outlines several issues with the way doctors traditionally approach treatment of medically unexplained physiological symptoms. They note in particular that the power relationships that exist in doctor-patient interactions often allow the doctors to decide which symptoms are real and valid, leaving little opportunity for the patient to engage in shared decision-making. These one-sided diagnostic experiences can result in the invalidation of suffering that occurs as a result of medically unexplained physiological symptoms regardless of their origins, and can influence future health-seeking behaviours in these individuals (Johansson, Hamberg, Lindgren, & Westman, 1996). This laborious pattern of diagnostic negotiation is not experienced in other chronic illnesses that are paired with clear biomarkers and testing options (Swoboda, 2006). Due to the perceived simplicity and lack of dangers associated with dietary manipulation, gluten avoiders are placed in a unique position, which allows them to manage their symptoms from home more readily than some other contested illnesses (Copelton & Valle, 2009). This however also places them at greater risk for
mismanagement of their symptoms, as a range of physiological issues cannot be observed externally, or without prior medical training (i.e. malnutrition).

### 3.2.2 Vernacular health theory and epistemic injustice

The tendency for gluten avoiders to undermine biomedicine has been associated with an increase in self-ascriptive looping (Moore, 2014), driven by the patients’ understanding of their own illness. McLaughlin (1996) describes this as vernacular health theory, where shared experiences influence the definition of emerging illnesses more so than the language used by doctors. This facilitates discussion amongst sufferers, whether this is in person, or in more recent times within online forums. Previous studies have already shown that gluten avoiders are more likely to utilise online sources for health information rather than seek out the guidance from trained medical professionals (Metchikoff, 2014). Sufferers therefore play a crucial role within the social construction of their illnesses, including the legitimacy of unexplained symptoms that are being reported (Swoboda, 2006).

The failure of doctors to validate symptoms for gluten avoiders can be considered as a form of epistemic injustice (Fricker, 2007). This notion considers the role that ethics play within epistemology, and the responsibilities held by healthcare professionals to include sufferers in the analysis of their health concerns. Without this joint participation in knowledge formation, patients can experience negative health consequences that further impact their wellbeing. For example, one study in Sweden identified that the stress associated with diagnostic interrogation during consultations resulted in more stress than was related to the initial health-trigger (Åsbring & Närvänen, 2002). Therefore, this epistemic injustice could also result in the perpetuation of symptoms based on the contestation that is often perceived by sufferers.

A qualitative follow up by Golley, Corsini, Topping, Morell, and Mohr (2015) found that wheat avoidance behaviours were driven by the perceived benefits associated with the avoidance, and perpetuated by a frustration with negative test results and a lack of diagnostic explanation for reported symptoms (Golley et al., 2017). The findings of these studies provide insight into the possible motivating factors for non-prescribed gluten avoidance, to the extent that it incorporates the avoidance of wheat-based products. However, the higher ratio of gluten/wheat
avoidance in comparable Western countries suggests that there remains a large proportion of gluten avoiders that are yet to be captured by studies that focus exclusively on wheat. There is a need to extend this understanding beyond behaviours relating specifically to wheat avoidance, as gluten avoidance is almost three times as prevalent in the population, and may be characterised as an entirely different construct. To date there are no studies specifically looking to document the qualitative experience of gluten avoiders in Australia. Considering the likely role that sufferers play in the construction and definition of their illness, a qualitative design was best suited to capture these experiences.

Therefore, this study aims to answer the following research question:

1. What are the factors that influence the adoption of non-prescribed gluten avoidance in Australians?
2. What impacts does the decision to become a non-prescribed gluten avoider have on their lives?

3.3 Method

3.3.1 Sample strategy and participants

Purposive sampling was used to recruit Australians 18 years and over who reported following a non-prescribed GFD. Eleven adult participants (10 females, one male) were recruited via a range of formats including: online advertisements, university forums, newsletters, and advertisements in local health stores. An example of the online format of this advertisement can be viewed in Appendix B. The consent of participants was inferred by their expression of interest and subsequent contact with the researcher (as outlined in the participant information sheet, see Appendix C). A point of saturation was reached after the ninth interview, when no new thematic information emerged (see Glaser, 1992). This assumption was confirmed by two final interviews, both yielding no further insights.

3.3.2 Role of the researcher

The collection and analysis of data in this study was influenced by both the researcher’s own personal experiences and their clinical background as a registered psychologist. The data should therefore be considered within the context of the interviewer’s ability to draw on emotional and psychological experiences,
impacting the responses collected and the analytical process that followed (Starks &
Brown Trinidad, 2007). Whilst the impact of these clinical skills is not thought to
have jeopardised the accuracy of the data collected, it is acknowledged that
researchers without formal clinical training may have probed responses differently,
and focused on alternative themes in their analysis.

3.3.3 Data collection and analyses

A semi-structured interview was composed of questions exploring the
choice to follow a GFD, the effects this choice had, the support that was received, and
the knowledge on which these decisions were based. A full interview schedule for this
research can be viewed in Appendix D. Following their expression of interest,
participants were interviewed through the online video-chat medium ‘Skype’,
allowing communication cues to be received and respond to by the researcher at a
distance (Sullivan, 2013). They were offered a $20 E-gift card as compensation. The
audio from interviews was recorded on a computer and transcribed verbatim
(excluding utterances and non-words) prior to analysis. Thematic analysis was used in
this study, as it has been used in previous research aimed at characterising similar
kinds of complex avoidance behaviour in relation to wine consumption (McIntyre,

Participants were considered to be actively engaged in the social
construction of their own experience, where perceptions about gluten were likely to
impact avoidance behaviours at the micro-level (Cruickshank, 2012). The role that
subjectivity plays in non-prescribed gluten avoidance has been previously noted in an
American study by Moore (2014) who adopted a similar qualitative approach to
capture the experience of people who avoid gluten. The purpose of the current
analysis was to utilise this social-constructionist epistemology to document the ways
in which participants developed their understanding of the world (Gergen, 1985)—
and the avoidance behaviours they chose to adopt within it. Inductive reasoning was
used to allow this subjectivity to be captured within the thematic analysis through the
identification of both explicit and implicit themes. The data analysis began during
transcription of the interviews, where a familiarisation with the data was achieved.
Data coding was conducted in NVivo 10, initially sorting individual interviews
according to themes identified within the data. The language used by participants in
each interview was scrutinised so that concepts of the self and the social experience
could be understood within the context of non-prescribed gluten avoidance. Each theme was reviewed in relation to other themes and refined to ensure that the overarching concepts captured in the analysis were fully supported by the data (Fade & Swift, 2011). Readings and coding of the data continued until a clear theme matrix emerged. Consultations with researchers in a related field resulted in maximum inter-coder agreement, where randomly selected quotations were associated with their corresponding themes at a 100% success rate.

3.4 Results

3.4.1 General findings

All participants reported following a self-managed GFD with varying degrees of adherence. However, none of the 11 participants reported following a strict 100% GFD, with most suggesting that this was particularly difficult to achieve. This became apparent following the conclusion of the interview phase, and suggested that those defining themselves as ‘gluten avoiders’ allowed for some gluten consumption either through error, or due to intentional eating. It also clarified the difficulties associated with maintaining a GFD, even with participants who self-reported as gluten sensitive/intolerant.

Some participants also appeared to be unclear about the definition of gluten, and what products it could be found in, with one participant stating gluten was the “gluggy substance in rice when it’s cooked – before it’s been washed…” and another stating “I think potatoes maybe have gluten in them”. Not all participants showed the same level of confusion about which products did, and did not contain gluten, with levels of knowledge varying widely amongst participants. Nevertheless, most reported using the Internet as their main source for information relating to gluten, which they then used to assist them in making a self-diagnosis of gluten sensitivity.

Participants reported experiencing a range of symptoms following the consumption of gluten, including but not limited to: “nausea”, “headaches”, “back pain”, “fatigue”, “digestive symptoms”, “constipation/diarrhoea”, “bloated-ness”, “abdominal pain”, “brain fog”, “depressed [mood]”, and “excessive tiredness”. Each participant’s experience post-gluten consumption was described very differently, took varying degrees of time to take effect, and was triggered by different levels of gluten intake. Each participant also reported positive improvements in their health following
the transition to a GFD, and deduced that gluten was therefore the cause of these symptoms.

JUNE: “...there have been occasions where one breadcrumb has made me sick...”

KELLY: “...if you give me a sandwich, I would not be well after that. And I’d feel it within the hour...”

MARY: “...I could probably get up right now and have a piece of bread and I’d be fine. But if I had a piece of bread every day, for four or five days, then I wouldn’t be feeling great...”

3.4.2 Primary themes

Three primary themes were identified in the analysis that helped capture the subjective experience of participants: 1) psychosocial isolation, 2) self-sufficiency, and 3) food consciousness.

3.4.2.1 Psychosocial isolation.

The current study found that participants typically suffered from multiple forms of perceived discrimination. Whilst managing their gluten-related symptoms, they described an ongoing perceived judgement from others regarding their choice to follow a GFD. Participants reported these criticisms coming from internal social networks (i.e. family and friends), as well as the external commercial environment (i.e. restaurateurs). One of the most overt, and seemingly most important forms of discrimination experienced by non-prescribed gluten avoiders was from their social network. Often, participants would discuss their choices with friends or family, only to have them be dismissed as part of a fad diet.

LILLY: “...Now that there is more gluten free options around, people are starting to think that it’s just a 'fad', and think you're over reacting...”

They explained how incorrect media portrayals of gluten sensitivity have resulted in a skewed public opinion about gluten related problems, leading them to feel pigeonholed as fad dieters. This ongoing prejudice about their motives led participants to become distressed and feel unsupported by their social network.
JESSICA: “...I told them that we were cutting down on gluten just by choice. And they kind of rolled their eyes, cause as you would know...at the moment for people to go ‘I’m gluten-free’—it’s almost trendy...”

Often these perceived social responses made participants feel that they were not being taken seriously by their peers and the wider community. Whilst these responses were not reported to be direct in nature, participants nonetheless felt the impacts of their weight when assessing their choices to remain gluten-free. Sally suggested that those who are medically diagnosed with CD do not receive the same type of discrimination that gluten avoiders do because their symptoms are taken more seriously:

SALLY: “...If you've got CD ...and you say you’ve got CD, people seem to take that with more authority...But if you're just intolerant, which seems to have exactly the same symptoms and [is] really unpleasant...you're apparently an idiot who doesn’t know what they are talking about. You're just a 'fool'...”

A number of participants, especially from non-urban areas, also explained that they became anxious when venturing out into the commercial sphere for food options. This anxiety was triggered by an inconsistent response from restaurants regarding their needs, which was often difficult to predict until they were committed to a venue. In some cases, if the manager of a food establishment was supportive of non-prescribed gluten avoidance, they described receiving respect and care during the commercial food preparation process. However, if those preparing food were doubtful of the necessity for gluten-free foods for people with non-coeliac gluten intolerance, the reception was often negative. Participants noted that it was difficult to find venues that made them feel welcome, and once these locations were found, they often returned there in order to avoid triggering a negative reaction at a new restaurant.

3.4.2.2 Food consciousness.

Participants reported that food took up a large portion of their focus throughout the day. They tended to regularly monitor food ingredients and cooking processes, demonstrating an elevated sense of food consciousness. The reading of labels was the main way participants screened which food products were safe for gluten-free consumption and which were not. Some participants agreed that their behaviours were overly cautious, but preferred this to the alternative state.
Participants also described being most comfortable consuming foods that they had produced themselves, as it alleviated risks of contamination, and allowed them to be less consumed by the monitoring of ingredients and additives. This sense of trust was linked to fears about hidden additives and preservatives that participants believed were found in more commercially available foods.

JUNE: “...Yes, I absolutely trust what I make myself...I find it's just so much easier and so much safer. I know exactly what I can put in...”

Participants explained that the security of their own homes allowed them to safely experiment with foods, without the added stress triggered by fears of contamination by additives and preservatives. It also became evident that home cooking was associated with the idea of consuming a more natural, and thus healthier, product.

RUBY: “...I guess instinctively as well I trust things that are closer to their natural state...”

Participants also became excited about using substitute food options that allowed them to continue cooking their favourite meals at home. These successes led them to feel like they were being actively involved in their diet management, and gave them a sense of normalcy in an otherwise isolating experience.

JESSICA: “...I personally have had a good experience...like a piece of bread underneath the egg—you don’t need it...there’s so many other things you can put underneath that that don’t have gluten in them...”

Participants were happy to continue putting this extra effort into the cautious consumption of foods, and regularly monitored food ingredients and cooking processes, demonstrating an elevated sense of food consciousness. This conscious pressure allowed participants to maintain a fairly adherent structure to their GFD and helped them to avoid consuming gluten in error.

3.4.2.3 Self-sufficiency

Participants in this study had confidence in their ability to make their own health decisions based on a mixture of knowledge and intuition. At times this included a higher level of perceived knowledge about the issue than they thought
general practitioners (GPs) could provide. They also reported basing their decisions on the biofeedback they received from their bodies, using this as a way to measure the effectiveness of dietary options.

LILLY: “...I know that when I do certain things I feel better. So that’s what I do. I rely on what my body is telling me...”

Participants regularly stated that they trusted their bodies over and above the facts available to them through medical sources. Despite some participants acknowledging that they had performed insufficient research into the issue, they continued to feel that they knew enough to make effective changes to their diets. This attitude appeared to be linked to the perceived lack of dangers they associated with restrictive food programs.

ZOE: “...I would usually do [research] with medical stuff, but I figured it’s a diet...If it doesn’t work then I’ll just stop in a week or two...”

Among many of the participants there was a clear lack of trust in the knowledge that GPs held about NCGS and diagnostic methods. These feelings were also used as justification for continued self-management of their diet without ongoing medical care. Some participants explained that doctors were blatantly stating they had no idea what was happening to their patient, and were failing to make appropriate referrals in order to clarify the issue, as illustrated by Mary:

MARY: “...When I did have...very excruciating stomach pain...I went to the doctor a few times and they were basically like ‘Hmm we don’t know what it is’. I wasn’t given a referral for an endoscopy, colonoscopy, nothing like that...”

Participants often reported feeling frustrated due to these encounters with their GP, as they had expected them to be able to provide helpful information due to their medical expertise. When doctors appeared unable to meet the expectations held by participants, they became agitated and either turned to other sources of information for help, or adopted a self-managed approach. They also justified their continued lack of medical support by stating that their GPs would not offer additional helpful information over what they were already aware of.
ZOE: “...I just found her to be very unhelpful, to the point where I didn’t want to go back to her. And...I started doing this [GFD]. And I almost want to go back to her and be like ‘look at what I’ve done, but it wasn’t thanks to any of your advice’...”

The descriptions of these doctors’ poor ability to involve the client in their own diagnostic process meant that patients walked out of the clinic feeling unheard, and often angry at their lack of answers. Participants were not only discouraged to seek additional support from their GPs regarding gluten-related issues, but also felt less likely to seek opinions regarding non-related issues too.

3.5 Discussion

This phase of the research aimed to explore the subjective experiences of people engaging in non-prescribed gluten avoidance in Australia in order to develop an understanding of their motives behind their choice to follow a GFD, and the consequences that followed. Participants reported that GFD’s were adopted in the hope of managing an array of negative symptoms that they felt were connected to the consumption of gluten. As a result of a thematic analysis, the researcher identified three major themes: psychosocial isolation, food consciousness, and self-sufficiency. These findings mirror previous research in America (Moore, 2014) where gluten-free dieters adopted the responsibility to self-diagnose because of frustration with the medical diagnostic process. This study also shared common findings with those found in observations of wheat-avoiders (Golley et al., 2017) including the role that symptoms played in diet adherence and the perceived health benefits associated with avoidance behaviours. However, gluten avoiders also reported a significant amount of perceived discrimination from others that is yet to be characterised in other research. This perceived discrimination fostered self-dependency attitudes that were not observed previously in the population of wheat-avoiders. Therefore, wheat-avoidance and gluten avoidance are believed to be influenced by different issues, and are likely to have significantly different impacts on the person’s wellbeing following the adoption of their respective diets.

This study found that gluten avoiders regularly experienced criticism about their chosen diets, and their process of self-diagnosis. Often self-diagnosis is viewed as less legitimate than medical diagnoses (Copelton & Valle, 2009), which
can cause sufferers to experience feelings of contested-illness (Moore, 2014). Like other forms of perceived discrimination, these attitudes about the validity of self-diagnoses can have negative effects on both physical and mental health. A meta-analysis by Pascoe and Richmond (2009) showed that these effects can be significant, and can lead to ongoing psychological and physiological stress responses, as well as encourage unhealthy behaviours. There have also been a number of individual differences that are associated with the ability to cope with discrimination-related stress including perceived personal control and self-esteem (Dion, Dion, & Pak, 1992). The findings in this research phase suggest that people avoiding gluten may be likely to experience lower levels of self-esteem due to the attitudes and behaviours of others in their social network, and in the wider community. Such treatment may also lead to the development of additional psychosomatic issues relating to anxiety that would further complicate their ability to identify gluten-specific responses in the gut.

In this chapter, people adopting a GFD were heavily focused on food consumption and food choices throughout their day. This overt consciousness regarding food intake allowed for the experience of a mixture of positive and negative emotions, often centred on the concept of trust. Alternative recipes and substitutions were readily adopted as an additional means of managing food intake in accordance with their diet. Several studies have shown that alternative health seeking behaviours (in this case alternative eating is a form of health treatment) can be exhibited in response to anxiety about health care concerns (McIntyre, Saliba, & Moran, 2015; van den Brink-Muinen & Rijken, 2006). Participants reported themselves as both in control of their diet (self-sufficiency) and out of control (due to the impact of others and through temptation), reflecting the complications associated with this food consciousness.

The findings presented in this chapter indicated that participants saw no harm in administering the transition to a GFD without the ongoing support of a health professional. These ideas were fuelled by a sense of self-sufficiency and the belief that they were best placed to monitor and assess the physiological concerns associated with dietary changes. Adopting a GFD, particularly without professional advice or support can be dangerous, as it can lead to several nutritional deficiencies (Shepherd & Gibson, 2013; Thompson, 2000b) that are generally undetectable through normal insight and bodily monitoring. There is a possibility that people avoiding gluten may
be underestimating potential risks, as they choose not to seek medical care for their symptoms. Golley et al. (2017) have recently proposed clinical guidelines to assist GPs in addressing patient concerns related to undetermined gastrointestinal symptoms, and advise to increase rates of referral to specialists (e.g. dieticians) in order to improve patient outcomes.

This choice to avoid gluten is further complicated by the use of the internet as a major health and diagnostic information source, which contains information of variable quality (Sørensen et al., 2012) and is potentially misleading. Participants in the current study consciously recognised their lack of knowledge about underlying mechanisms for NCGS, but still reported high levels of satisfaction in their ability to make informed treatment decisions. The shifting parameters of administering health care have been reported by Meijboom (2007), who notes that the availability of diagnostic and treatment information online has created an alternative avenue for those who have lost faith in their GPs and are seeking advice for self-managed treatments. Hardey (1999) suggests this blurs the boundaries between expertise and layperson, where the reader becomes responsible for the application of health information. Studies also show that trust in internet based sources varies across consumer segment groups according to the health beliefs that are adopted by the reader (Dutta-Bergman, 2003).

Whilst this study provides a unique insight into the experience of non-prescribed gluten avoiders, its findings are not without limitations. The use of qualitative methods was best suited to the exploration of subjective experiences; however, these findings offer limited generalisability to the wider population of people adopting a GFD. This is especially due to the individual nature of the experience itself. It was also difficult to initially obtain interest from potential participants, suggesting that those who volunteered their time may have possessed a personality type affiliated with helping (Saliba & Ostojic, 2014). While every effort was made to preserve the integrity and the context of the participants’ experiences, the impact of the author’s own professional experience and knowledge cannot be omitted from the thematic decisions made. Therefore, this study should be considered as a preliminary supplementation to future quantitative work examining gluten avoidance in greater depth.
3.6 Conclusion

This study discussed a range of common experiences that were described by non-prescribed gluten avoiders. The main themes captured within the thematic analysis included feelings of psychosocial isolation, a heightened level of food consciousness, and a lack of GP support that fosters attitudes of self-sufficiency. Therefore, the findings expand on previous research and add further insight into the experiences described by non-prescribed gluten avoiders. The participants reported similar issues to the contested illness experience noted by those with fibromyalgia (Armentor, 2017) and chronic fatigue syndrome (Clarke & James, 2003). They were also subject to negative doctor-patient relationships that impacted their future health-seeking behaviours, and their decision to seek validation from non-conventional sources (i.e. the internet and alternative health professionals). The lack of validation these participants perceive could place them at greater risk of developing anxiety-related symptoms, complicating their ability to discriminate between gluten-related issues and other physiological concerns.

A holistic understanding of the characteristics of gluten avoidance is needed to fashion targeted approaches to address these concerns and risk factors for reduced wellbeing. Information from a wider population will help capture the demographic characteristics that can assist in targeted research. Once these features are identified, quantitative research can help to identify any factors that may be involved in the experience of gluten-related symptoms amongst non-prescribed gluten avoiders. These findings may also aid in the creation of standardised and structured practice guidelines for people presenting with similar experiences, so that contemporary health professionals can effectively engage in shared decision-making without imparting judgement or invalidation amongst sufferers.
Chapter 4: Demographics and prevalence rates of gluten avoidance

4.1 Introduction

The qualitative study discussed in Chapter 3 revealed that non-prescribed gluten avoiders experience discrimination and negative stigma during their interactions with social networks and medical professionals. In order to explore these potential concerns, baseline data on prevalence rates and demographics of those adopting a GFD in Australia are needed. Results from previous American studies suggest that the rate of adoption for gluten-free diets (GFD's) exceed the expected rates of diagnosis for gluten-related disorders (GRD's; Kim et al., 2016). However, similar comparisons of prevalence rates in Australia are yet to be established in a large and representative sample. A confirmation of prevalence rates for specific gluten avoidance behaviours is needed to ensure that the population is accurately characterised in relation to those following medically prescribed gluten-free diets (GFD’s). The aim of this chapter is to examine the proportion of Australians choosing to engage in non-prescribed gluten avoidance, and identify any demographic variables that may help to further characterise this population.

4.2 Background

The main GRD’s associated with medically prescribed gluten avoidance are coeliac disease (CD) and wheat allergy (WA). Although a consensus has not been reached internationally, it is estimated that approximately 1% of the western population are diagnosed with CD (Elli et al., 2015). A recent meta-analysis reported a variation in CD rates of up to 10% between countries, and clear geographical differences were observed between European, Australasian and American countries (Kang, Kang, Green, Gwee, & Ho, 2013). There has been some suggestion that populations whose staple diet is wheat are more at risk of developing CD than those whose main agricultural crops do not include gluten (Kang et al., 2013). This trend is found to be even more pronounced for populations with a traditionally rice-based diet.
that are now introducing increasing amounts of wheat products into the market (Cummins & Roberts-Thomson, 2009). Prevalence studies conducted specifically in Australia (Hovell et al., 2001) and New Zealand (Cook et al., 2000) have shown that rates of CD in the respective populations were estimated at 0.4% and 1.2% respectively. Similar prevalence rates have been found for WA. A meta-analysis on plant food allergies found that wheat allergies were reported at less than 1% for oral food challenges, and 1.2% for studies that included self-reported symptoms and skin tests (Zuidmeer et al., 2008). These differences indicate a need to establish independent national rates of CD and WA, so that they can be accurately compared against rates of gluten avoidance behaviours.

Self-reported prevalence rates of non-coeliac gluten-sensitivity (NCGS) in the United Kingdom has been reported in up to 13% of the population (Aziz et al., 2014). Research exploring NCGS often relies on estimates that are established from these self-report measures due to the lack of simple diagnostic options currently in use (Branchi, Aziz, Conte, & Sanders, 2015). One study that observed rates of self-reported NCGS in Australia found that up to 75% of the population could have misdiagnosed themselves with the condition (Biesiekierski et al., 2014) due to these issues. The discrepancy between self-reported allergic reactions to foods and actual allergies as determined by food challenges has been reviewed by Sicherer (2011). They note that only 19-28% of all food-related complaints are confirmed through food challenges, and suggest that clinicians be cautious of the impact that perception plays when patients are reporting food-related symptoms. Findings such as these fuel the debate about the legitimacy of the self-reported symptoms experienced by those with non-coeliac gluten sensitivity (Moore, 2014), leading to similar challenges that were explained by participants in Phase A, including isolation and perceived judgement from peers. The underlying mechanisms that cause NCGS are still under investigation by researchers, and it is possible that some individuals who self-report issues are misattributing symptoms from interrelated conditions. In the United Kingdom, a population study found that individuals who reported having gluten-sensitivity were significantly more likely to meet the diagnostic requirements for irritable bowel syndrome than those without reported sensitivity issues (20 : 3.89; Aziz et al., 2014). Whilst efforts are being made to create standardised methods of testing and diagnosis for NCGS (Catassi et al., 2015), measuring rates of non-coeliac
gluten avoidance, rather than sensitivity, may provide a simple alternative to begin characterising this phenomenon at a national level.

More and more of the American adult population has been reported to actively avoid or reduce gluten intake in their daily meal regimes over time (King & Meiselman, 2010). These avoidance figures far exceed the proposed number of people diagnosed with conditions that would require them to follow a GFD for medical purposes. This continues to be the case even when the total number of people experiencing self-reported NCGS is added to this total. For example, one study that examined diagnoses of CD and NCGS in people with irritable bowel issues found incidence rates of 0.6% and 4.9% respectively. The same study found 8.2% of participants reported following a GFD (Herfarth, Martin, Sandler, Kappelman, & Long, 2014), clarifying that CD and NCGS diagnoses alone are not sufficient to account for the amount of people adopting a GFD (Tanpowpong, Broder-Fingert, Katz, & Camargo Jr, 2015). A recent Columbian population survey reported that general wheat/gluten avoidance rates were approximately 17%, and that these behaviours were significantly more likely to occur amongst respondents that were 38 years old or younger (Cabrera-Chavez et al., 2016). In the same study, 76.4% of participants avoiding gluten reported experiencing no adverse reactions to wheat and/or gluten containing foods. Notably, this study separated gluten avoiders from those specifically following a GFD, which may inflate these figures.

Information suggests that there continues to be a disproportionate number of people in Western countries who are avoiding gluten without being prescribed to do so by their doctors. To date, there is little information to confirm that this phenomenon is also being observed in Australian populations. One study by the CSIRO examining wheat (as opposed to gluten) avoidance in Australia, reported 5.7% having a diagnosed intolerance or allergy requiring them to follow a GFD (Golley et al., 2015). The research team found that wheat avoidance was positively correlated with dairy avoidance, and predicted by female gender. Those who avoided wheat were also less receptive to conventional medicines and treatment. However, the literature indicates that gluten avoidance is an independent construct, separate from wheat avoidance on account of the differences observed in health and risk information available for each. The current study was designed to capture the prevalence of non-prescribed gluten avoidance in Australia, in order to establish whether a
disproportionate amount of people were avoiding gluten compared to the rates of those who had been prescribed this diet by their doctor. The secondary research aim was to identify the demographic variables that characterise different gluten consumption/avoidance behaviours within a large and representative Australian sample. The following research questions were developed as a means of addressing the above aims:

1. What are the prevalence rates of non-prescribed gluten avoidance in Australia?
2. What proportion of the Australian population is avoiding gluten on the basis of being diagnosed with CD or WA?
3. What demographic variables characterise non-prescribed gluten avoiders?

4.3 Method

4.3.1 Recruitment and Participants

Study invitations were sent to an online database of more than 80,000 Australians registered to participate in research. A total of 1021 (n = 505 males, n = 516 females) participants successfully completed the survey, which provided a robust enough sample to generalise findings across the broader Australian population. The distribution of participants amongst age categories can be viewed in Table 4-1 below.

Table 4-1
Distribution of participants in each age cohort within the total study sample

<table>
<thead>
<tr>
<th>Age Cohort (years)</th>
<th>n</th>
<th>% of sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>122</td>
<td>12%</td>
</tr>
<tr>
<td>25-34</td>
<td>209</td>
<td>20%</td>
</tr>
<tr>
<td>35-44</td>
<td>218</td>
<td>21%</td>
</tr>
<tr>
<td>45-54</td>
<td>200</td>
<td>20%</td>
</tr>
<tr>
<td>55-64</td>
<td>118</td>
<td>12%</td>
</tr>
<tr>
<td>65 or over</td>
<td>155</td>
<td>15%</td>
</tr>
</tbody>
</table>

Note: N = 1021
4.3.2 Procedure

Questionnaires were distributed to participants over the span of a week in June 2016. The online questionnaire consisted of 14 items, which took participants approximately 5 minutes to complete. Items collected responses to demographic questions and gluten avoidance as discussed in the following section.

4.3.3 Measures

Demographics: Demographic questions were included to capture the following variables amongst participants: gender, age group, location of residence, total household income, and level of education.

Gluten avoidance item: A logical approach was adopted by the researcher in the development of a single survey item designed to capture self-reported rates of gluten consumption/avoidance. The design was followed by a pilot of the item as recommended by Rattray and Jones (2007), run with a convenience sample (n = 7) to ascertain participant responses to formatting and word choice. Item options designed to capture rates of medically prescribed gluten avoidance were also included to allow for further classification and comparison between avoiders with different motivations. With this addition, the gluten avoidance item was able to capture a full spectrum of gluten avoidance behaviours within the large representative Australian sample. Participant feedback from this pilot allowed for the question to be refined, leading to a minimisation of confusion and error during responding. The gluten avoidance item required participants to respond to the following instructions on a 5-point item: *Please indicate which best describes your situation:* a) I strictly avoid gluten and have been diagnosed with a Wheat Allergy or Coeliac Disease by my doctor, b) I strictly avoid gluten, however have NOT been diagnosed with a Wheat Allergy or Coeliac Disease by my doctor, c) I regularly avoid gluten, d) I occasionally avoid gluten or e) I don't avoid gluten at all. Those who endorsed a) were classified as prescribed gluten avoiders (PGA). Participants who endorsed items b), c) or d) were classified as non-prescribed gluten avoiders (NPGA) and those who endorsed e) were classified as gluten consumers (GC).

4.3.4 Data Analysis

The dataset was organised and analysed using IBM SPSS Statistics version 22. The most recent Australian Census data (ABS, 2011) was used to apply
weights to the variables location x gender x age and location x region (see Table 4-2 for weighting values). The applied weightings transformed the data to mirror distributions found within the Australian population, and helped to maximise the representativeness of the dataset.

Frequency statistics were calculated to determine the overall prevalence of each behaviour type, as indicated through responses to the above avoidance item. A group of non-prescribed gluten avoiders was formed through an aggregation of participants who endorsed options b), c) and d) to the above item, hereafter referred to as the non-prescribed gluten avoiders (NPGA). Participants endorsing option a) were classified as prescribed gluten avoiders (PGA), and participants endorsing option e) were classified as gluten consumers (GC).

No missing items were present in the dataset, and a review of the box plots revealed no major outliers in the data. Normal distributions were confirmed via a check of the histograms and skew/kurtosis information for each variable. Descriptive statistics were used to calculate frequencies and percentages for study groups and demographic groups. Chi-square tests were also used to identify significant differences between groups for related demographic variables. Where significant Chi-square tests were found, a post-hoc test based on contingency tables was applied as per the methods recommended in (Beasley & Schumacker, 1995). This method includes calculating adjusted residuals for each cell in the contingency table, and then observing the chi-squares for each against the adjusted p-values. Adjusted p-values were calculated via the Bonferroni method (# of chi-square tests divided by .05). Effect sizes were calculated with Cramer’s V and reported according to the guidelines proposed by Cohen (1988). The findings for these analyses are presented in the results section below.
### Table 4-2
Weighting values applied to sample as per ABS Census 2011 data

<table>
<thead>
<tr>
<th>State</th>
<th>Gender</th>
<th>Age Group</th>
<th>Target %</th>
<th>State</th>
<th>Region</th>
<th>Target %</th>
</tr>
</thead>
<tbody>
<tr>
<td>QLD</td>
<td>Males</td>
<td>18-34</td>
<td>0.032046947</td>
<td>QLD</td>
<td>Metro</td>
<td>0.089224496</td>
</tr>
<tr>
<td></td>
<td></td>
<td>35-54</td>
<td>0.039196894</td>
<td>Rural</td>
<td>0.106641702</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>55-75</td>
<td>0.025859693</td>
<td>NSW/ACT</td>
<td>Metro</td>
<td>0.226533479</td>
</tr>
<tr>
<td></td>
<td>Females</td>
<td>18-34</td>
<td>0.032271293</td>
<td>Rural</td>
<td>0.119044485</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>35-54</td>
<td>0.040806792</td>
<td>VIC/TAS</td>
<td>Metro</td>
<td>0.194400339</td>
</tr>
<tr>
<td></td>
<td></td>
<td>55-75</td>
<td>0.025684580</td>
<td>Rural</td>
<td>0.079178714</td>
<td></td>
</tr>
<tr>
<td>NSW/ACT</td>
<td>Males</td>
<td>18-34</td>
<td>0.056527548</td>
<td>SA/NT</td>
<td>Metro</td>
<td>0.061692396</td>
</tr>
<tr>
<td></td>
<td></td>
<td>35-54</td>
<td>0.068941599</td>
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<td>0.024313310</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>55-75</td>
<td>0.045211905</td>
<td>WA</td>
<td>Metro</td>
<td>0.073533811</td>
</tr>
<tr>
<td></td>
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<td>0.056896004</td>
<td>Rural</td>
<td>0.025437267</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>35-54</td>
<td>0.071515626</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>55-75</td>
<td>0.046485282</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>VIC/TAS</td>
<td>Males</td>
<td>18-34</td>
<td>0.044482671</td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>35-54</td>
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<tr>
<td></td>
<td></td>
<td>55-75</td>
<td>0.035341021</td>
<td></td>
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<tr>
<td></td>
<td>Females</td>
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<td>0.044877251</td>
<td></td>
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<td></td>
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<tr>
<td></td>
<td></td>
<td>35-54</td>
<td>0.057239127</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>55-75</td>
<td>0.037078450</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SA/NT</td>
<td>Males</td>
<td>18-34</td>
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<td></td>
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<td></td>
</tr>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>55-75</td>
<td>0.011509058</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Females</td>
<td>18-34</td>
<td>0.013448154</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>35-54</td>
<td>0.017856425</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>55-75</td>
<td>0.011942823</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WA</td>
<td>Males</td>
<td>18-34</td>
<td>0.016377935</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>35-54</td>
<td>0.020462245</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>55-75</td>
<td>0.012610551</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Females</td>
<td>18-34</td>
<td>0.016063807</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>35-54</td>
<td>0.020900388</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>55-75</td>
<td>0.012556151</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: QLD – Queensland, NSW – New South Wales, ACT – Australian Capital Territory, VIC – Victoria, TAS – Tasmania, SA – South Australia, NT – Northern Territory, WA – Western Australia.
4.4 Results

4.4.1 Prevalence rates and types of gluten avoidance in Australia.

The prevalence rates for different types of gluten avoidance/consumption behaviours can be viewed in Figure 4-1. More than three quarters of participants in the study reported making no attempts to avoid gluten. The remaining 22% participants engaged in gluten avoidance behaviours (either prescribed or non-prescribed). Non-prescribed gluten avoidance exceeded prescribed avoidance rates by more than 15%, with a total prevalence rate for CD/WA of 2% found in the study. As the data in the study was weighted to ABS statistics by gender, age and location, it can be assumed that these prevalence estimates represent actual rates of avoidance within the Australian population.

Figure 4-1 Prevalence of avoidance behaviours within study sample, PGA – prescribed gluten avoiders, NPGA – non-prescribed gluten avoiders, GC – gluten consumers, N = 1021.

4.4.2 Frequency of avoidance amongst non-prescribed gluten avoiders.

The frequency of avoidance behaviours varied amongst non-prescribed gluten avoiders from occasional to strict (see Figure 4-2). The majority of NPGA endorsed the least frequent avoidance option, indicating that they only occasionally avoided gluten. Fewer people were inclined to endorse the more severe dietary behaviours, with the smallest percentage of NPGA adopting strict avoidance behaviours.
Figure 4-2 Frequency of gluten avoidance reported by NPGA. NPGA – non-prescribed gluten avoiders (n = 204).

4.4.3 Gender distribution

A chi-square test for independence revealed that there was a significant difference in gender distributions found across study groups, \( \chi^2(2, N = 1021) = 6.27, p < .05 \), Cramer’s \( V = .078 \), showing a small effect size (see Figure 4-3). The distribution of females across the overall study sample was 51%. The distribution of females found within the gluten consumers group was the most similar to the rates that reflected the overall sample. There was an overrepresentation of females in the group of non-prescribed gluten avoiders, exceeding males by 16%. Pairwise comparisons completed post-hoc confirmed that the different distributions of females in the NPGA group and the GC group were statistically significant (\( \chi^2 = 6.11, p = .013 \)). This significant overrepresentation of females was not replicated in the prescribed gluten avoider group, where females were typically underrepresented in comparison to the overall sample distribution.
Figure 4.3 Distribution of females across study groups. PGA – prescribed gluten avoiders \((n = 24)\), NPGA – non-prescribed gluten avoiders \((n = 204)\), GC – gluten consumers \((n = 793)\).

### 4.4.4 Age distribution

A chi-square test for independence revealed that there was a statistically significant difference in age distributions across study groups, \(X^2(5, N = 1021) = 39.57, p < .001\), Cramer’s \(V = .139\). Participants aged 25-34 years were found to be significantly overrepresented in PGA. This cohort exceeded the sample distribution of prescribed gluten avoidance, reported an extremely high diagnostic rate of 6% for CD/WA, which was notably higher than in any other age group (see Figure 4.4).

Figure 4.4 Prevalence rates of self-reported CD/WA diagnoses reported across age cohorts \((N = 1021)\).
The prevalence of non-prescribed gluten avoidance was also found to be disproportionately higher in the younger age groups, trending down as age increased (see Figure 4-5). Again, the age cohort of 25-34 years was found to be significantly overrepresented in the group of non-prescribed gluten avoiders. Post-hoc pairwise comparisons of the age groups confirmed that the 25-34 cohort showed significantly higher than expected values in PGA ($X^2 = 17.2, p < .001$) and NPGA ($X^2 = 14.0, p < .001$), and significantly lower than expected scores in GC ($X^2 = 26.0, p < .001$).

![Figure 4-5 Rates of non-prescribed gluten avoidance across age cohorts \(N = 1021\).](image)

### 4.4.5 Residential location

A chi-square test for independence revealed no significant differences in residential location for the different groups; $X^2(14, N = 1019^1) = 23.59, p > .05$. Findings showed that a disproportionately larger amount of prescribed gluten avoiders (more than 75%) were living in Sydney, Melbourne or Brisbane. However, these findings were not mirrored when observing rates of non-prescribed gluten avoidance. In general, non-prescribed gluten avoidance rates from each location were reflective of the overall prevalence rate for the population. Similar non-distinct trends were also observed for gluten consumers leading to the conclusion that residential location is not a major determinate of gluten avoidance behaviours.

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1 Two responses were missing from the final dataset, making up 0.2% of the total sample.
4.4.6 Total household income

A Chi-square test for independence revealed that there were significant differences found between the amount of total household income reported by each group; \( X^2(6, \, n = 884^2) = 19.43, \, p > .01 \), Cramer’s \( V = .105 \). Prescribed avoiders were overrepresented in the highest income bracket, at a rate more than three times what was expected. A total of 35% of all prescribed avoiders fell within a total household income bracket of $3000+ per week. This difference was confirmed as significant through pairwise comparisons completed post-hoc; \( X^2 = 14.49, \, p < .001 \). Proportions of each income bracket per study group can be viewed in Figure 4-6. These same trends were not as pronounced in any other study group. Non-prescribed gluten avoiders showed a slight over-representation among the higher income brackets, and gluten consumers were observed to have the opposite relationship with income. However these trends did not reflect substantial differences in income between groups overall, and were not found to be significant.

![Figure 4-6 Distribution of total household income across study groups. PGA – prescribed gluten avoiders (n = 23), NPGA – non-prescribed gluten avoiders (n = 181), GC – gluten consumers (n = 680).](image)

\[^2\] Of note – a total of 8% of prescribed gluten avoiders, 11% of non-prescribed gluten avoiders, and 14% of gluten consumers chose not to provide their incomes, or reported negative incomes. Therefore they were excluded from this specific analysis.
4.4.7 Levels of education

A chi-square test for independence revealed significant differences between the education levels reported across the different study groups; \( X^2(6, n = 1019^3) = 13.44, p > .05 \). Both prescribed gluten avoiders and non-prescribed gluten avoiders showed similar rates of over-representation in higher levels of education (bachelor or postgraduate qualifications, see Figure 4-7). This difference was most pronounced when observing the Bachelor/Honours qualifications held by gluten avoiders (both prescribed and non-prescribed) compared to gluten consumers. However, a post hoc analysis revealed that none of the pairwise comparisons met significance once the p-value was adjusted using the Bonferroni method. In this case, the difference in group sizes is likely to have resulted in a type 1 error occurring.

![Figure 4-7 Distribution of education levels across study groups. PGA – prescribed gluten avoiders (n = 24), NPGA – non-prescribed gluten avoiders (n = 205), GC – gluten consumers (n = 790).](image)

4.5 Discussion

The aim of this chapter was to determine the prevalence of gluten avoidance in Australia, and to characterise the demographics of this group as a whole.

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3 A total of three participants chose not to provide information about their education levels. A further seven chose the ‘other’ option, and then provided an open response which allowed their educations to be categorised within the options shown above.
These aims were achieved through the implementation of a sophisticated data weighting process that allowed accurate conclusions about the Australian population to be drawn from the study sample.

The prevalence rate of participants avoiding gluten due to diagnoses of CD and WA was observed to be 2%. These rates are comparable to previous estimations of 0.4-1.2% for CD (Cook et al., 2000; Hovell et al., 2001) and 1.0-1.2% for WA (Zuidmeer et al., 2008), totalling anywhere from 1.4-2% for both conditions. Due to the similarities amongst reported diagnosis rates and previous estimates, the use of self-report measures in the absence of medical records appears to be relatively appropriate for this context. It also indicates that total rates of CD/WA diagnoses in Australia have not substantially increased over time, reflecting similar rates that were reported almost a decade ago. It is important to note that some believe CD to be under-diagnosed due to issues with diagnosis and atypical symptoms (Castillo, Theethira, & Leffler, 2015), and therefore some additional people with CD may have been captured within the group of non-prescribed gluten avoiders due to these complications.

The results indicated that 20% of participants were engaging in non-prescribed gluten avoidance behaviours to varying degrees. These findings suggest that Australia is experiencing similar gluten avoidance trends as those observed in Italy (Capannolo et al., 2015) whereby a disproportionate amount of people are avoiding gluten compared to the number of people able to be accurately diagnosed with gluten-related disorders. This disproportion confirms that some people are avoiding gluten for reasons other than prescribed symptom management. If avoidance frequency can be taken as an indicator of the intensity of the motivation behind food choice, a preliminary estimation of symptom strength may be possible in the absence of supplementary medical records. People who experience significant adverse effects from the consumption of gluten would be more likely to integrate strict avoidance as a regular strategy for self-management. Less frequent avoidance behaviours could therefore indicate the existence of certain psychological motivators in the absence of physiological ones, i.e. perceived health benefits.

As the majority of non-prescribed gluten avoiders reported occasional avoidance, it is possible that their behaviours are less driven by strong physiological
responses to gluten. This is supported by previous research showing up to 76.4% of people avoiding gluten do not experience adverse symptoms following its consumption (Cabrera-Chavez et al., 2016). The 2-7% of participants in this chapter that reported partaking in strict non-prescribed avoidance could represent a population experiencing more frequent symptoms (including those with gluten sensitivity), which is similar to estimated prevalence rates for NCGS reported for other countries (6.88%; Capannolo et al., 2015). The relationship between symptom frequency and gluten avoidance frequency is yet to be captured within the literature. Further research into this area could help to establish the utility of using these self-report measures as a practical screening tool for doctors to quickly identify additional medical needs in patients. It is noted however that screening tools directly asking questions about gluten avoidance may trigger responses that are skewed by bias that wasn’t observed in the current study due to its non-specific design.

Gender was also found to have a statistically significant association with non-gluten avoidance behaviours. The results indicated that there was an over-representation of females in the non-prescribed group compared with expected rates found in the total population (approx. 51%), consistent with an avoidance study conducted in Italy (Volta, Bardella, Calabrò, Troncone, & Corazza, 2014). The Italian findings revealed that females were greater than five times more likely to report gluten-related symptoms than men, which they suspected to be associated with sensitivity to gluten. Other studies have found a more conservative ratio of females to males experiencing what they term ‘gluten intolerance’ (2.3:1; Bardella et al., 2005), but still concluded that gluten-related symptoms are expressed differently in men and women. There has been some suggestion that women are typically predisposed to experience more intense and more frequent non-specific bodily symptoms, which is linked with differences in the socialisation process and the sex prevalence of anxiety (Barsky, Peekna, & Borus, 2001). More exploration is therefore needed into this phenomenon before conclusions can be made about the gender specificity of gluten-related symptoms versus the sex prevalence of general sensation intensity/frequency.

A statistically significant association between age and gluten avoidance was also found in the current study, with both prescribed and non-prescribed gluten avoidance found to be negatively associated with age. In particular, the 25-34 years cohort showed unexpectedly high rates for each. This group reported diagnostic rates
of CD/WA that were more than three times higher than any other cohort, with more than 6% of the group indicating they were participating in strict gluten avoidance following the receipt of a diagnosis by a doctor. Whilst prescribed avoidance behaviours trended down as age increased, these findings were likely biased by the outlying diagnostic rates reported by the 25-34 years cohort. The same 25-34 years cohort also reported the highest prevalence of non-prescribed gluten avoidance behaviours amongst all the age groups in the study. Prevalence rates in this group were reported at 29%, which was 8% higher than any other cohort. A much more consistent trend was observed for non-prescribed gluten avoidance in regards to its relationship with age. Prevalence of these behaviours was observed to steadily decline across the cohorts, indicating a more consistent relationship between the variables. The clinical picture described by Volta and De Giorgio (2012) suggests that the mean onset for gluten sensitivity in Italy occurs around age 40. If this is the case, the younger cohorts may be engaging in non-prescribed gluten avoidance for reasons other than those directly related to physiological reactions following its consumption. It is unknown whether these results are reflective of an increasing rate of gluten sensitivity over time, discrepancies in reporting rates, or additional factors that vary between cohorts. Older studies capturing onset age are also likely to be impacted by the difficulties associated with obtaining an accurate diagnosis, as these procedures and methods continue to improve over time.

Location, income and education levels of participants were not found to significantly impact non-prescribed gluten avoidance, suggesting that they do not directly influence the choice to engage in these behaviours. However, there were slight trends observed for those reporting gluten avoidance due to medical prescription. Those who reported a doctor’s diagnoses of CD/WA were found to be more likely to be based in capital cities such as Sydney, Melbourne, or Brisbane. They were also found to be significantly over-represented in the highest income bracket at a rate more than three times what was expected, making up 7% of the entire population earning over $3000 in total weekly household income. Prescribed gluten avoiders were observed to have similar over-representation in education levels as was seen in non-prescribed gluten avoiders, with the majority (36%) of the group holding at least a Bachelors/Honours qualification. It may be that those with higher levels of education, and higher incomes, have more access to treatment services, which allows
them to thoroughly investigate their illnesses until a diagnosis is reached. This process was noted to be lengthy and place particular strain on sufferers, as captured in the experiences discussed in Chapter 3. In New Zealand, lower income was associated with the delaying of medical enquiry, which at times jeopardised the state of participant’s health until the issue was more developed (Barnett, 2000). Treatment clinics and doctors with more resources may also be a feature better found within the capital cities that prescribed avoiders were found to frequent. Therefore income is not likely to be a trigger in the development of CD/WA; rather it could simply provide more opportunities for diagnosis.

The above results provide meaningful considerations for future research to explore. It is possible that there are a proportion of people who are avoiding gluten for reasons other than direct symptom management, due to the majority of non-prescribed avoiders adopting lower frequency behaviours. More research is therefore required to clarify whether there is an association between the frequency of gluten avoidance and the intensity of gluten-related symptoms. If avoidance frequency is indicative of symptom frequency, this may serve as a simple measure for use in further research examining this population. Such research would also allow further exploration into the non-physiological motives behind less frequent non-prescribed gluten avoidance.

Whilst the current study is considered to be highly generalisable across the Australian population, there remain some limitations that need to be considered in the context of these findings. The current study purposely excluded a specific measure relating to gluten sensitivity diagnoses. The diagnostic processes for establishing the presence of this new gluten-disorder continue to be developed. It was assumed that the inclusion of such an option would serve to confuse participants who have self-diagnosed themselves with gluten sensitivity due to the lack of medical clarity available at the time of their investigations. This limitation can be addressed once the medical community reaches a consensus on NCGS processes.

4.6 Conclusion

This chapter has allowed for the calculation of accurate prevalence rates for different types of gluten avoidance behaviours (prescribed and non-prescribed), and the demographic variables that characterise them. Rates of non-prescribed gluten avoidance are occurring at a rate of 20%. Typically, non-prescribed gluten avoiders in
Australia are more likely to be female, and aged between 18-35 years. It is important that the characteristics of this specialised population be known so that the risk factors that have been associated with this behaviour (see Chapter 3) can be applied at a policy and healthcare level. Previous findings indicate that at least some people avoiding gluten are doing so for reasons other than those directly related to the experience of symptoms following its consumption. This is beyond the scope of the research detailed in this chapter. However, the literature reviewed in Chapter 2 indicates that avoidance can be driven by both physiological and psychological variables. The links between gluten avoidance behaviours and symptom frequency will be examined in the next phase of research to clarify whether these findings apply to an Australian context. Such investigations will facilitate the development of a comprehensive profile for non-prescribed gluten avoiders, and the variables that contribute to their dietary choices.
PHASE C

Chapter 5: Design and methodology

5.1 Introduction

Qualitative data reported in Chapter 3 (Phase A) of the research unveiled a range of experiences amongst GA. Several experiences were found to impact their choice to both start, and continue, avoiding gluten without being directed to by their medical doctor, including the ongoing perceptions of healthcare and knowledge about gluten that they accrued over time. The findings discussed in Chapter 4 (Phase B) confirmed that 20% of the Australian population are excluding gluten from their diet to a degree. The complexity of their experiences and their impacts were identified as factors needing further exploration at a wider population level. These recommendations form the basis of Phase C of the research, which encompasses four chapters (5-8) dedicated to the quantitative exploration of physiological and psychological variables that influence the adoption of non-prescribed gluten avoidance. The chapter explains the study design and methodology that was created in order to achieve the above research objective.

5.2 Design and research questions

This study was designed to capture and explore the physiological and psychological variables that influence the adoption of non-prescribed gluten avoidance. A quantitative methodology was chosen to allow for the complex analyses of data at a population level. The results from this study are presented in Chapters 6 to 8, and aims to answer the research questions as indicated below:

Chapter 6: Symptomology and somatisation in gluten avoiders

1) What is the prevalence and type of gastrointestinal and extra-intestinal symptoms that are being experienced by gluten avoiders?

2) Is there a relationship between the symptoms being experienced by gluten avoiders and the frequency and intensity of gluten avoidance behaviours?

3) What is the prevalence of comorbid somatic symptoms amongst gluten avoiders?
Chapter 7: Food perceptions and cognitive influences on food choice

1) Do gluten avoiders report higher levels of perceived discrimination?
2) Do gluten avoiders score lower on measures of GP satisfaction, and what relationship does this have with gluten avoidance?
3) Do gluten avoiders have higher usage rates of online information sources/blogs and rate their trustworthiness higher than gluten consumers?
4) Do gluten avoiders prioritise health related factors when making food choices?
5) What food perceptions do gluten avoiders have, and are they related to avoidance behaviours?
6) Are gluten avoiders higher on measures of experiential thinking styles than gluten consumers?
7) Do gluten avoiders report high levels of ambiguity tolerance?

Chapter 8: The role of individual differences: A consideration of sensitivity dysfunction

1) Do gluten avoiders score higher on self-report pencil and paper tests of autonomic arousability?
2) Do gluten avoiders score higher on measures of stimulus amplification?
3) Do gluten avoiders score higher on the measures of neuroticism?

5.3 Recruitment and participant groups

A purposive sampling method was used to recruit 1521 adult Australians from a sample of more than 200,000 research participants. These participants had previously registered interest on a research participation platform. Individual email invitations were sent to people who had registered interest with a research participation database, giving them the opportunity to be involved in the study. This invitation included information about the study’s purpose and general design (see participant information sheet, Appendix F), and directed participants to an online Colmar Brunton survey tool where they could complete the survey from any computer or device. An online collection method was chosen to maximise the chances of recruiting a representative sample of non-prescribed gluten avoiders (hereafter termed GA for pragmatic purposes) within the cost and time restraints of the study.
This facilitated the collection of data from people all over the country, so that future results may be easily generalised across the population.

Participants who indicated their consent to participate were asked to confirm if they had been diagnosed with any of the following by a doctor/GP; wheat allergy, coeliac disease, egg allergy, dairy intolerance, diabetes, or none. This question acted as a screening tool to ensure those who endorsed the wheat allergy or coeliac disease items were not included in the study. Those who indicated diagnoses of egg allergy, dairy intolerance, and diabetes could participate in the study, and these responses were added to future analyses. The survey consisted of 283 items, and took approximately 30 minutes to complete. A full list of survey questions is available in Appendix G. A total of 91.5% of participants finalized their survey in under an hour. A small concession was offered to participants in the form of online spending credits to the value of approximately $10 in return for their time spent completing the survey. Eligible participants who successfully completed their surveys were then categorized into study groups via a three-step coding process, as outlined below:

5.3.1 Step 1 – Collecting a sample representative of the Australian population

Participants were allocated to categories determined by their gender, gender x age (e.g. Males, 18-24 years) and primary residence location. A target number of participants were allocated to these demographic categories based on the population distribution reported for Australia in the Census 2012 (See Table 5-1 for a full overview of the collection quotas used in the study). Once the collection quota for each demographic category was filled, no more participants in the category were accepted into the category. This collection method allowed an accurate sampling of the Australian population to be achieved at the sample level, ensuring that no specific category was over/under represented. If the category they met remained unfilled, they were selected and forwarded for secondary allocation into study groups.
Table 5-1  
Study collection quotas as determined by demographic distributions in ABS Census 2011

<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>Category</th>
<th>Collection Quotas</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Males</td>
<td>+/- 10% Nat Rep (Target n=735, Min n=662)</td>
</tr>
<tr>
<td>Gender</td>
<td>Females</td>
<td>+/- 10% Nat Rep (Target n=765, Min n=688)</td>
</tr>
<tr>
<td>Gender x Age</td>
<td>Males 18 - 24 years</td>
<td>+/- 10% Nat Rep (Target n=95, Min n=85)</td>
</tr>
<tr>
<td>Gender x Age</td>
<td>Males 25 - 34 years</td>
<td>+/- 10% Nat Rep (Target n=135, Min n=121)</td>
</tr>
<tr>
<td>Gender x Age</td>
<td>Males 35 - 44 years</td>
<td>+/- 10% Nat Rep (Target n=142, Min n=128)</td>
</tr>
<tr>
<td>Gender x Age</td>
<td>Males 45 - 54 years</td>
<td>+/- 10% Nat Rep (Target n=127, Min n=114)</td>
</tr>
<tr>
<td>Gender x Age</td>
<td>Males 55+</td>
<td>+/- 10% Nat Rep (Target n=240, Min n=216)</td>
</tr>
<tr>
<td>Gender x Age</td>
<td>Females 18 - 24 years</td>
<td>+/- 10% Nat Rep (Target n=92, Min n=83)</td>
</tr>
<tr>
<td>Gender x Age</td>
<td>Females 25 - 34 years</td>
<td>+/- 10% Nat Rep (Target n=136, Min n=122)</td>
</tr>
<tr>
<td>Gender x Age</td>
<td>Females 35 - 44 years</td>
<td>+/- 10% Nat Rep (Target n=141, Min n=126)</td>
</tr>
<tr>
<td>Gender x Age</td>
<td>Females 45 - 54 years</td>
<td>+/- 10% Nat Rep (Target n=130, Min n=117)</td>
</tr>
<tr>
<td>Gender x Age</td>
<td>Females 55+</td>
<td>+/- 10% Nat Rep (Target n=263, Min n=237)</td>
</tr>
<tr>
<td>Location</td>
<td>Sydney</td>
<td>+/- 10% Nat Rep (Target n=303, Min n=273)</td>
</tr>
<tr>
<td>Location</td>
<td>Regional NSW/ACT</td>
<td>+/- 10% Nat Rep (Target n=202, Min n=182)</td>
</tr>
<tr>
<td>Location</td>
<td>Melbourne</td>
<td>+/- 10% Nat Rep (Target n=274, Min n=247)</td>
</tr>
<tr>
<td>Location</td>
<td>Regional VIC/TAS</td>
<td>+/- 10% Nat Rep (Target n=144, Min n=130)</td>
</tr>
<tr>
<td>Location</td>
<td>Brisbane</td>
<td>+/- 10% Nat Rep (Target n=144, Min n=130)</td>
</tr>
<tr>
<td>Location</td>
<td>Regional QLD</td>
<td>+/- 10% Nat Rep (Target n=144, Min n=130)</td>
</tr>
<tr>
<td>Location</td>
<td>Adelaide</td>
<td>+/- 10% Nat Rep (Target n=87, Min n=78)</td>
</tr>
<tr>
<td>Location</td>
<td>Regional SA/NT</td>
<td>+/- 10% Nat Rep (Target n=43, Min n=39)</td>
</tr>
<tr>
<td>Location</td>
<td>Perth</td>
<td>+/- 10% Nat Rep (Target n=115, Min n=104)</td>
</tr>
<tr>
<td>Location</td>
<td>Regional WA</td>
<td>+/- 10% Nat Rep (Target n=43, Min n=39)</td>
</tr>
</tbody>
</table>

Note: Above quota figures were supplied in the Colmar Brunton collection proposal.

5.3.2  **Step 2 – Distinguishing gluten avoiders from gluten consumers**

Collection quotas for the two study groups were also supplied, allowing participants to be categorised based on their response to a 5-point item measuring gluten avoidance frequency (see Figure 5-1).
Quotas were filled on a first-come first-served basis, where the first appropriate participants were allocated to each category. The first group, termed gluten avoiders (GA, \( n = 1021 \)) reported actively avoiding the consumption of gluten in their diets without a diagnosis of coeliac disease or wheat allergy. This group captured a varying degree of gluten avoidance, as detailed in later analyses. The second group, termed gluten consumers (GC, \( n = 500 \)), was used in the study as a control group and reported making no attempts to moderate their gluten consumption. The quota for the control group was calculated to ensure that meaningful conclusions could be drawn from the findings, with GC making up approximately 33% of the total study sample. Following this initial categorisation of participants, it was identified that some gluten avoiders were avoiding gluten without experiencing any symptoms following its consumption. As the aims of this research centred predominantly around unnecessary dietary restriction in the pursuit of symptom reduction, further analyses were employed to ensure that their inclusion in this group was statistically appropriate.

5.3.3 Step 3 – Refining study groups based on symptomology

Preliminary analyses revealed there to be deviation within experiences reported by gluten avoiders in the sample, with a total of 28% reporting having never experienced symptoms following the consumption of gluten. The following analyses were completed to ensure that these differences would not impact the ability to draw meaningful conclusions from the data, whilst still satisfying the overall research aims and objectives.

Gluten avoiders were divided into subgroups: those that reported experiencing adverse symptoms following the consumption of gluten (GA+, \( n = 740 \)) and those who were experiencing no gluten-related symptoms (GA-, \( n = 281 \)). A Chi-
square test for independence showed that there was a significant difference in the frequency of gluten avoidance behaviours amongst the groups, \(X^2(3, n = 1021) = 52.88, p < .001\), Cramer’s \(V = .228\). A larger proportion of GA- reported total avoidance of gluten (18%), as compared to the 11% reported in GA+. However, the majority of GA- reported gluten avoidance at a lower frequency than GA+, as can be seen in Figure 5-2. Post-hoc analyses confirmed that GA+ were significantly underrepresented in the lowest avoidance frequency (\(\chi^2 = -29.3, p < .001\)), and significantly overrepresented in the second highest avoidance frequency group (\(\chi^2 = 26.8, p < .001\)).

![Figure 5-2 Frequency of gluten avoidance behaviours between symptomatic and non-symptomatic gluten avoiders](image)

**Figure 5-2** Frequency of gluten avoidance behaviours between symptomatic and non-symptomatic gluten avoiders. GA+ = symptomatic gluten avoider, \(n = 740\), GA- = non-symptomatic gluten avoider, \(n = 281\).

The frequency of non-gluten food avoidance was also compared amongst the subgroups, using Chi-square tests of independence to determine any significant differences (see Table 5-2 for results). Gluten avoiders without gluten-related symptoms typically reported less avoidance of non-gluten foods than was reported by GA+, with the largest difference observed for the avoidance of dairy products. This difference in dairy avoidance was substantially larger than the other avoidance behaviours, with an effect size approaching medium, indicating it was a characteristic of gluten-symptomatic avoiders only.
Table 5-2
Chi-square statistics for non-gluten food avoidance behaviours amongst GA subgroups

<table>
<thead>
<tr>
<th>Food Avoided</th>
<th>Gluten Avoiders (%)</th>
<th>$X^2$</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GA-</td>
<td>GA+</td>
<td></td>
</tr>
<tr>
<td>Dairy</td>
<td>53.4</td>
<td>77.3</td>
<td>63.08**</td>
</tr>
<tr>
<td>Eggs</td>
<td>38.8</td>
<td>46.5</td>
<td>14.56*</td>
</tr>
<tr>
<td>Carbohydrates</td>
<td>74.4</td>
<td>79.3</td>
<td>11.35*</td>
</tr>
<tr>
<td>Fats</td>
<td>86.5</td>
<td>84.1</td>
<td>3.39</td>
</tr>
<tr>
<td>Preservatives</td>
<td>90.4</td>
<td>92.6</td>
<td>4.44</td>
</tr>
</tbody>
</table>

Note: ** = $p < .001$, * = $p < .05$, GA- = Gluten avoidance without gluten-related symptoms ($n = 281$), GA+ = Gluten avoidance with gluten-related symptoms ($n = 740$).

Similar analyses were conducted to observe the differences in the number of adverse symptoms experienced by the subgroups. Gluten avoiders without gluten-related symptoms also reported significantly lower frequencies of symptoms from the consumption of non-gluten foods (see Table 5-3). Again, the biggest difference observed between the two groups was found for dairy, with 58.3% more GA+ reporting the experience of adverse symptoms following the consumption of dairy. This effect size was large, supporting the premise that GA+ are reporting significantly different experiences to GA- in relation to non-gluten foods.

Table 5-3
Chi-square statistics for symptom frequency after the consumption of non-gluten foods in GA subgroups.

<table>
<thead>
<tr>
<th>Non-gluten food</th>
<th>Gluten Avoiders (%)</th>
<th>$X^2$</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GA-</td>
<td>GA+</td>
<td></td>
</tr>
<tr>
<td>Dairy</td>
<td>22.1</td>
<td>80.4</td>
<td>303.95**</td>
</tr>
<tr>
<td>Eggs</td>
<td>11.7</td>
<td>46.2</td>
<td>104.83**</td>
</tr>
<tr>
<td>Carbohydrates</td>
<td>17.1</td>
<td>71.2</td>
<td>243.37**</td>
</tr>
<tr>
<td>Fats</td>
<td>24.2</td>
<td>73.8</td>
<td>210.43**</td>
</tr>
<tr>
<td>Preservatives</td>
<td>28.1</td>
<td>82.4</td>
<td>281.61**</td>
</tr>
</tbody>
</table>

Note: ** = $p < .001$, GA- = Gluten avoidance without gluten-related symptoms ($n = 281$), GA+ = Gluten avoidance with gluten-related symptoms ($n = 740$).
Gluten avoiders without gluten-related symptoms adopted food avoidance behaviours that were significantly different to those of GA+ (both gluten and non-gluten related), and reported significantly different patterns of symptoms. It was determined that GA- should be excluded from the overall group of GA for the data analyses included in Chapters 6-8, as the findings indicated they are unique and distinguishable from GA+. The subgroup of GA- could be reminiscent of a “fad

Table 5-4
Demographic details of final sample chosen for Phase C

<table>
<thead>
<tr>
<th>Variable</th>
<th>Gluten Avoiders</th>
<th></th>
<th>Gluten Consumers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-30</td>
<td>174</td>
<td>23.5</td>
<td>95</td>
<td>19.0</td>
</tr>
<tr>
<td>31-40</td>
<td>171</td>
<td>23.1</td>
<td>92</td>
<td>18.4</td>
</tr>
<tr>
<td>41-50</td>
<td>126</td>
<td>17.0</td>
<td>105</td>
<td>21.0</td>
</tr>
<tr>
<td>51-60</td>
<td>132</td>
<td>17.8</td>
<td>92</td>
<td>18.4</td>
</tr>
<tr>
<td>&gt;60</td>
<td>137</td>
<td>18.5</td>
<td>116</td>
<td>23.2</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>249</td>
<td>33.6</td>
<td>219</td>
<td>43.8</td>
</tr>
<tr>
<td>Female</td>
<td>491</td>
<td>66.4</td>
<td>281</td>
<td>56.2</td>
</tr>
<tr>
<td>State</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NSW</td>
<td>210</td>
<td>28.4</td>
<td>145</td>
<td>29.0</td>
</tr>
<tr>
<td>VIC</td>
<td>195</td>
<td>26.4</td>
<td>130</td>
<td>26.0</td>
</tr>
<tr>
<td>QLD</td>
<td>175</td>
<td>23.6</td>
<td>114</td>
<td>22.8</td>
</tr>
<tr>
<td>SA</td>
<td>62</td>
<td>8.4</td>
<td>38</td>
<td>7.6</td>
</tr>
<tr>
<td>WA</td>
<td>68</td>
<td>9.2</td>
<td>39</td>
<td>7.8</td>
</tr>
<tr>
<td>TAS</td>
<td>15</td>
<td>2.0</td>
<td>18</td>
<td>3.6</td>
</tr>
<tr>
<td>ACT</td>
<td>14</td>
<td>1.9</td>
<td>15</td>
<td>3.0</td>
</tr>
<tr>
<td>NT</td>
<td>1</td>
<td>0.1</td>
<td>1</td>
<td>0.2</td>
</tr>
<tr>
<td>Education Level</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Year 10 or equivalent</td>
<td>84</td>
<td>11.4</td>
<td>59</td>
<td>11.8</td>
</tr>
<tr>
<td>Year 12 or equivalent</td>
<td>116</td>
<td>15.7</td>
<td>107</td>
<td>21.4</td>
</tr>
<tr>
<td>TAFE/apprenticeship</td>
<td>109</td>
<td>14.7</td>
<td>66</td>
<td>13.2</td>
</tr>
<tr>
<td>Diploma, certificate etc.</td>
<td>134</td>
<td>18.1</td>
<td>97</td>
<td>19.4</td>
</tr>
<tr>
<td>Undergraduate degree</td>
<td>201</td>
<td>27.2</td>
<td>111</td>
<td>22.2</td>
</tr>
<tr>
<td>Post-graduate qualification</td>
<td>91</td>
<td>12.3</td>
<td>57</td>
<td>11.4</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>0.7</td>
<td>3</td>
<td>0.6</td>
</tr>
</tbody>
</table>

Note: N = 1240. Due to the specific participant selection process, the above groups may not accurately represent a traditional Australian population. Instead, this represents natural distributions present in GA and GC populations only. For an examination of demographic variability within a representative Australian population, please refer to Chapter 4. These groups are used in Phase C in order to determine any specific characterizing features of gluten avoiders.
dieters” group, where levels of dietary avoidance may not correlate with rates of actual symptoms experienced. The behaviours of GA- could also be driven by other legitimate reasons (i.e. family member with CD), although this is unlikely due to the generalised avoidance patterns reported towards all foods. The scope of the current research did not allow for a thorough investigation of these motivators. Therefore, 281 GA- were excluded from the group of gluten avoiders included in the research sample, reducing the total number of participants from $N = 1521$ to $N = 1240$. It is believed that the above group revisions allow for a more accurate investigation of gluten avoiders within the confines of the current research. The demographics of this revised sample can be viewed below in Table 5-4.

5.4 Measures

The measures used in Phase C reflected the themes of health concerns, discrimination, and self-education, as discussed in the qualitative interviews with GA. Due to the lack of pre-existing measures relating to gluten-specific behaviours and perceptions, a number of items were developed specifically for use in this study. These questionnaires were developed to capture self-reported responses about: 1) frequency of avoidance, 2) frequency of symptoms, 3) food perceptions and 4) information use/trust. These questionnaires were measured on a 5-point Likert scale and included simple wording to minimise participant confusion. The literature review (Chapter 2) revealed various additional factors that may influence the decision to avoid gluten, and were consequently chosen based on their alignment with these factors. These established measures have demonstrated acceptable reliability scores for use in this study (see Table 5-5 for comparison of reliability scores). These variables are discussed below in the order they are presented in the chapters:

5.4.1 Demographics and health questionnaire

Questions regarding age, gender, income, education and location of participants were all collected to identify demographic variables. Participants were also required to indicate the presence of other health conditions (unrelated to gluten) including egg allergies, dairy intolerances, and diabetes. These conditions were chosen as some of the more common conditions that are associated with food consumption behaviours, and can be managed with diets that require the at-home manipulation of food consumption.
5.4.2 Food avoidance and symptoms questionnaire

Participants were asked to rate the frequency of avoidance, their behaviours, and the symptoms they experienced after consuming six different food ‘types’, including gluten, eggs, dairy, carbohydrates, fats and preservatives. The choice to include additional food types was made for two reasons. Firstly, the collection of additional food perceptions allowed for baseline measures of food attitudes to be established outside of any possible gluten-specific biases that existed. Second, the inclusion of a variety of food categories helped to minimize the focus of the study, and thus any emotional responses (both positive and negative) that may be connected to individual opinions held about gluten and its effects. Participants were required to respond to the following on a 5-point Likert scale, ranging from 1 (never) to 5 (always), for each of the six food types:

1. How often do you avoid ….
   [gluten/dairy/eggs/carbohydrates/fats/preservatives]?

2. How often do you experience negative symptoms after eating
   [gluten/dairy/eggs/carbohydrates/fats/preservatives]?

5.4.3 Gluten symptomology questionnaire

A 12-item questionnaire was adapted from the Patient Health Questionnaire (PHQ-15 outlined below; Han et al., 2009), to assess the experience of physiological symptoms after the consumption of gluten specifically. The response options were presented in an identical 3-point Likert scale that replicated response options for the PHQ-15. The symptom items were chosen from the most common adverse experiences shared between reports of gluten avoiders outlined in Chapter 3 and in previous studies examining gluten symptomology (see Catassi et al., 2015). Each item corresponded to a single symptom, and required a self-report rating from 0 (not bothered at all) to 2 (bothered a lot) regarding their experience of the symptom after eating products containing gluten.

5.4.4 Patient Health Questionnaire (PHQ-15)

The PHQ-15 is a measure of somatization that observes the frequency with which a variety of somatic symptoms occur in a person (Han et al., 2009). Each item corresponds to a single somatic symptom, and requires a self-report rating from
0 (not bothered at all) to 2 (bothered a lot) regarding their experience of the symptom within the previous 4 weeks.

5.4.5 Food perceptions questionnaire

Participants were asked about their perceptions of six food types, including gluten. These six food types mirrored those included in the aforementioned questionnaire, and were measured along a 5-point Likert scale. Items were designed to assess the way participants perceived the healthiness of foods from 1 (not healthy at all) to 5 (very healthy), and the risks associated with consuming them from 1 (none at all) to 5 (high risk). Participants were required to respond to the following:

1. How healthy do you think [dairy/eggs/carbohydrates/fats/preservatives] is?
2. How much risk do you believe is associated with eating [dairy/eggs/carbohydrates/fats/preservatives]?

Participants were considered to perceive a food as unhealthy if they answered either 1/2 out of 5 along the Likert scale. Participants were noted to perceive food consumption as higher risk if they answered either 4/5 out of 5 along the Likert scale. These distinctions allowed for simplified analytics amongst a large number of individual Likert items detailed in Chapter 7.

5.4.6 The Care and Relational Empathy (CARE) – revised measure

The CARE questionnaire (Mercer, Maxwell, Heaney, & Watt, 2004) was adapted to measure participant satisfaction levels for their general practitioners and the rapport that they had established with them. This revised questionnaire identified key features of a successful professional medical alliance with health providers. Seven original items were taken from the measure that assessed independent aspects of patient-doctor communication and rapport levels. Three additional items that were developed by the researcher were also included to assess the frequency with which each participant visited their GP, their overall ratings of GP consultations, and the GP’s ability to offer helpful advice. These three features were considered to be of additional importance, and were considered appropriate to include given the findings discussed in Chapter 3. Participants were required to rate on a 7-point Likert scale their experience with GPs from 1 (poor) to 7 (outstanding), and how often they visited the doctor from 1 (not much at all) to 7 (all the time).
5.4.7 Everyday Discrimination Scale (EDS)

The Everyday Discrimination Scale (EDS; Williams, Yu, Jackson, & Anderson, 1997) was utilised in the study in an effort to capture the perceived levels of discrimination experienced by participants, as the qualitative study found that perceived discrimination was a major theme amongst GA (Chapter 3). This measure is known to have good psychometric properties and is often used for its brevity (Krieger, Smith, Naishadham, Hartman, & Barbeau, 2005). It has also been shown to have convergent validity with the Kessler Distress Scale (Gonzales et al., 2016). Although this measure was originally targeted at racial discrimination, it was used in the context of the current study to identify indicators of perceived discrimination that mimic those seen in the racism literature (Vega & Rumbaut, 1991) that may contribute to greater health issues and lower wellbeing scores in other minority groups. The 9-item scale requires participants to report the frequency with which they experienced various types of mistreatment or daily hassles. These responses are captured on a 4-point Likert scale from 1 (never) to 4 (often). Higher scores on the EDS indicate a higher frequency of perceived discrimination.

5.4.8 Information consumption questionnaire

The use and perceived trustworthiness of a range of information sources, including print articles, online articles, written blogs, journal articles, books, television programs and government guidelines were measured via 5-point Likert scales. Items required participants to rate their frequency of use for each source from 1 (never) to 5 (all the time), and their level of trust for each source from 1 (not at all trustworthy) to 5 (always trustworthy). Participants were asked to rate their usage of sources first in order to minimise their answer to the trust item biasing their answer on the usage item. Participants were noted to be a frequent user of a source if they answered either 4/5 out of 5 along the Likert scale. Participants were noted to consider a source as trustworthy if they answered either 4/5 along the Likert scale. These distinctions allowed for simplified analytics amongst a large number of individual Likert items detailed in Chapter 7.

5.4.9 Multiple Stimulus Types Ambiguity Tolerance Scale (MSTAT-I)

This scale assesses perceptions of ambiguity on an individual level, and one’s tolerance to a lack of information about a stimulus/context. A total of 22 items were developed by McLain (1993) to assess how strongly participants agreed to
statements regarding their tolerance for ambiguous situations from 1 (strongly disagree) to 7 (strongly agree). A review of the literature identified a range of conflicting/ambiguous messages about gluten and its effects, which has been shown to amplify psychological influences on choice in vulnerable individuals (Eubank, Collins, & Smith, 2002; C. MacLeod & Cohen, 1993). This measure was therefore chosen to identify if there was a difference in the way that GA interpret and respond to ambiguous situations, and if this is an important factor in their choice to avoid gluten.

5.4.10 Rational Experiential Inventory (REI-40)

The REI 40 was developed by Pacini and Epstein (1999) as a measure of individual information-processing preferences. Responses are coded into four subscales, as determined by rational or experiential preferences. Those with a rational cognitive style tend to be more analytical, whilst those with a preference for experiential thinking tend to largely rely on intuition when making decisions. Participants were required to rate how much they agreed with a range of statements about their thinking styles from 1 (completely false) to 5 (completely true). The 40-item version of the questionnaire was chosen over the 10-item version due to its ability to be broken down into four subscales rather than simply the two cognitive styles.

5.4.11 Food Choice Questionnaire - Revised (FCQ-R)

This 24-item questionnaire by Fotopoulos, Krystallis, Vassallo, and Pagiaslis (2009) assesses the importance placed on certain food elements when consumers choose to purchase a certain food. It is a revised version of the Food Choice Questionnaire originally developed by Steptoe et al. (1995). The variables in the questionnaire include factors such as health, convenience, and price. Participants were required to respond on a 7-point Likert scale as to how important (1 = extremely unimportant, 7 = extremely important) it is for their food to have a particular characteristic. The FCQ-R is a comprehensive way of assessing the motives behind food selection for participants (Fotopoulos et al., 2009). Alongside the eight subscales developed in the revised edition of the FCQ, an additional measure of “Total food choice” was calculated. It was theorized that if the scores on each subscale indicated a rating of singular importance, with higher scores equating to higher importance placed on a certain characteristic, then a “Total food choice” score could be calculated.
by summing these subscales. This total food choice score would represent how much total importance consumers are placing on their food decisions, emulating characteristics that symbolize the food consciousness described by GA (Chapter 3). This is a novel measure developed by the researcher for the purpose of the current study.

5.4.12 *Food Neophobia Scale (FNS)*

The Food Neophobia Scale consists of 10 items aimed at measuring one’s aversion to new or novel foods, and is considered distinctly different from other measures that would impact food avoidance, such as *finickiness* (Pliner & Hobden, 1992). This measure was included in the study as a means of accounting for any gluten avoidance behaviours that were due to an overall aversion to novel foods/ingredients. Participants were asked to indicate how much each of the 10 statements reminded them of themselves, from 1 (*strongly disagree*) to 7 (*strongly agree*). Positive and negatively worded items were included in the scale, focusing on the responses to new/unknown foods.

5.4.13 *Somatosensory Amplification Scale (SASS)*

This questionnaire consists of 10 items that are used to measure one’s tendency to amplify a range of symptoms, thought to be an indicator of somatization (Barsky, Wyshak, & Klerman, 1990). Items required participants to indicate how characteristic each of the 10 statements were for them, from 1 (*not at all*) to 5 (*extremely*). Subscales of external and internal stimulus amplification were also calculated from responses to determine if participants favoured one over the other. Previous research suggests that the SASS is not significantly correlated with any socio-demographic variables, but is thought to correlate highly with DSM-III-R hypochondriasis (Barsky et al., 1990). This measure was therefore considered for its ability to add additional value to the analysis in regards to the contested illness experiences described by GA in previous work (Moore, 2014).

5.4.14 *Arousability Predisposition Scale (APS)*

This 12-item scale (Coren, 1990) was designed to measure individual differences in autonomic arousal. This self-reported measure of autonomic arousability has been correlated with the electrodermal activity that reflects changes in arousal (Coren & Mah, 1993) of the sympathetic nervous system. Therefore, this
scale of arousability provides a simple and non-invasive solution to allow the measurement of autonomic arousal within an online format. Respondents are required to rate each statement based on the frequency of their experience on a 5-point Likert scale from 1 (never) to 5 (almost always). Scale scores are calculated as a total of these responses.

5.4.15 Big Five Inventory (BFI)

The Big Five Inventory was inspired by Goldberg’s (1993) dimensions of personality: extraversion/introversion, agreeableness/antagonism, conscientiousness/lack of direction, neuroticism/emotional stability, and openness/closed to experience. It consists of 44-items that measure an individual on each of the five dimensions based on their response to a variety of statements (John & Srivastava, 1999). Each statement is rated from 1 (strongly disagree) to 5 (strongly agree). Reverse-scored items are also included in the questionnaire.

5.5 Reliability Analysis

Reliability statistics were calculated for each questionnaire included in the survey, and compared with the expected alphas that were reported in their originating publications (See Table 5-5). Both Cronbach’s alpha and MacDonald’s omega were provided, so that any flaws within the estimates of one would be captured with the other. The use of MacDonald’s omega over the alpha has been recommended by Peters (2014) due to the problems that they propose are associated with the calculation. In this instance, both calculations were similar. It can be determined therefore that the statistics reported in the below table accurately reflect the reliability of each scale. The majority of questionnaires produced alphas higher than those expected, or in line with the expected reliability scores. All reliability alphas fell above 0.75 with the exception of the Food Neophobia Scale, which still produced a higher alpha than that in its original publication.

5.6 Data Analysis

IBM SPSS Version 22 was utilised for all data analyses in Phase C. No missing items were found and no statistical assumptions were violated when reviewing skew and kurtosis variables. The dataset was scrutinized prior to analyses in order to identify any patterns of responding that indicated the participant was not engaged with the questionnaire. Randomised checks were also completed on
dichotomous question pairs to ensure that attitudes and responses on both showed a general consensus. Variable calculations were captured in syntax files to ensure that scale/subscale scores were accurate. These included the re-coding of negatively worded items, and the aggregation of relevant scores.

Table 5-5
Comparing the reliability of measures between original studies and the current study.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Author</th>
<th>Year</th>
<th>Items (n)</th>
<th>Original α</th>
<th>Current α</th>
<th>Current ω</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHQ15</td>
<td>Han et al.</td>
<td>2009</td>
<td>15</td>
<td>.80</td>
<td>.87</td>
<td>.87</td>
</tr>
<tr>
<td>SASS</td>
<td>Barsky et al.</td>
<td>1990</td>
<td>10</td>
<td>.82</td>
<td>.77</td>
<td>.77</td>
</tr>
<tr>
<td>FCQ-R Health</td>
<td>Foutopoulos et al.</td>
<td>2009</td>
<td>4</td>
<td>.78</td>
<td>.86</td>
<td>.87</td>
</tr>
<tr>
<td>FCQ-R Mood</td>
<td></td>
<td></td>
<td>4</td>
<td>.74</td>
<td>.86</td>
<td>.86</td>
</tr>
<tr>
<td>FCQ-R Convenience</td>
<td></td>
<td></td>
<td>3</td>
<td>.79</td>
<td>.85</td>
<td>.85</td>
</tr>
<tr>
<td>FCQ-R Sensory Appeal</td>
<td></td>
<td></td>
<td>3</td>
<td>.71</td>
<td>.77</td>
<td>.77</td>
</tr>
<tr>
<td>FCQ-R Natural Content</td>
<td></td>
<td></td>
<td>3</td>
<td>.78</td>
<td>.88</td>
<td>.89</td>
</tr>
<tr>
<td>FCQ-R Price</td>
<td></td>
<td></td>
<td>2</td>
<td>.78</td>
<td>.80</td>
<td>.81</td>
</tr>
<tr>
<td>FCQ-R Weight Control</td>
<td></td>
<td></td>
<td>3</td>
<td>.82</td>
<td>.81</td>
<td>.81</td>
</tr>
<tr>
<td>FCQ-R Familiarity</td>
<td></td>
<td></td>
<td>2</td>
<td>.63</td>
<td>.68</td>
<td>.69</td>
</tr>
<tr>
<td>FNS</td>
<td>Pliner &amp; Hobden</td>
<td>1992</td>
<td>10</td>
<td>.88</td>
<td>.84</td>
<td>.85</td>
</tr>
<tr>
<td>MSTAT-I</td>
<td>McLain</td>
<td>1993</td>
<td>22</td>
<td>.86</td>
<td>.85</td>
<td>.85</td>
</tr>
<tr>
<td>REI-40</td>
<td>Pacini &amp; Epstein</td>
<td>1999</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>REI-NFC</td>
<td></td>
<td></td>
<td>20</td>
<td>.90</td>
<td>.89</td>
<td>.89</td>
</tr>
<tr>
<td>REI-FI</td>
<td></td>
<td></td>
<td>20</td>
<td>.87</td>
<td>.88</td>
<td>.89</td>
</tr>
<tr>
<td>BFI-44</td>
<td>John &amp; Srivastava</td>
<td>1999</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BFI-Extraversion</td>
<td></td>
<td></td>
<td>8</td>
<td>.88</td>
<td>.84</td>
<td>.84</td>
</tr>
<tr>
<td>BFI-Agreeableness</td>
<td></td>
<td></td>
<td>9</td>
<td>.79</td>
<td>.79</td>
<td>.80</td>
</tr>
<tr>
<td>BFI-Conscientiousness</td>
<td></td>
<td></td>
<td>9</td>
<td>.82</td>
<td>.83</td>
<td>.84</td>
</tr>
<tr>
<td>BFI-Neuroticism</td>
<td></td>
<td></td>
<td>8</td>
<td>.84</td>
<td>.85</td>
<td>.85</td>
</tr>
<tr>
<td>BFI-Openness</td>
<td></td>
<td></td>
<td>10</td>
<td>.81</td>
<td>.77</td>
<td>.80</td>
</tr>
<tr>
<td>EDS</td>
<td>Williams et al.</td>
<td>1997</td>
<td>9</td>
<td>.88</td>
<td>.90</td>
<td>.90</td>
</tr>
<tr>
<td>APS</td>
<td>Coren</td>
<td>1990</td>
<td>12</td>
<td>.83</td>
<td>.88</td>
<td>.88</td>
</tr>
</tbody>
</table>

Note: PHQ15 = Patient Health Questionnaire, SASS = Somatosensory Amplification Scale, FCQ-R = Food Choice Questionnaire Revised, FNS = Food Neophobia Scale, MSTAT-1 = Multiple Stimulus Types Ambiguity Tolerance Scale, REI-40 = Rational Experiential Inventory, BFI-44 = , EDS = Everyday Discrimination Scale, APS = Arousability Disposition Scale.

Univariate descriptive statistics were then calculated to observe frequencies, means and standard deviations. These allowed for the initial identification of major differences between groups. Due to the power of the sample size, even small deviations in variables resulted in statistical significance. These additional observations of the data allowed for a finer scrutiny of variables – which
were later included in the secondary analyses. For all non-linear survey items, the chi-square test for independence was used to explore differences between gluten avoiders and gluten consumers\(^4\). For significant comparisons amongst more than 2 groups, post-hoc testing was completed as per the process described by Beasley and Schumacker (1995). This process involved the conversion of adjusted residuals into separate chi-square statistics, which were then contrasted with relevant p-values. In order to reduce the chance of committing a Type I error, a Bonferroni adjustment (see Bland & Altman, 1995) was made to these p-values so that they were not confounded by the number of analyses completed in the comparison. For linear scales, independent samples t-tests were employed to compare the means of both groups. Pearson correlation coefficients were also calculated for a range of variables to explore the strength of relationship between variables of interest. Effect sizes were calculated with Cramer’s V and reported according to the guidelines proposed by Cohen (1988).

5.7 Ethical Considerations

In Chapter 3, GA reported experiencing distress and feeling discriminated against when being asked questions that required them to justify their behaviours to others. Care was taken to ensure that the study remained focused on a variety of food types in an effort ensure that participants did not feel targeted by repetitive questions pertaining only to gluten. Participants were also not allocated a specific time to complete the survey (as long as they completed it in one sitting) in order to reduce feelings of pressure when responding. Some outlying participants took upwards of 8 hours to complete the total survey over the span of a single day. De-identification of the data prevents the researcher from exploring reasons for these, but it is presumed that these participants completed their surveys amongst other daily duties – as was allowed in the flexibility of the survey format.

5.8 Limitations of Phase C

In order to preserve the honesty of participants included in the survey, a direct question pertaining to gluten-sensitivity diagnoses was not asked. The existence or accuracy of such diagnoses was not a focus of the current study. It was considered

\(^4\) Differences are communicated within tables using selective group percentages, so that the groups can be visually compared. However, Chi-square and Cramer’s V statistics represent an analysis based on the full Likert comparison (either 3, 5 or 7 point). See Section 5.4. for relevant measures and item structure.
that the presence of a diagnosis may not directly translate to gluten avoidance behaviours, and likewise participation in gluten avoidance behaviours does not directly relate to the presence of a gluten-sensitivity diagnosis. Until the diagnostic process for non-coeliac gluten sensitivity becomes more refined for GP administration in biomedical settings, any existing records of these diagnoses would be limited to those who have the capacity to conduct the standard process outlined in Catassi et al. (2015).

The measures included in the study were all dependent on the participants’ ability to accurately and honestly self-report symptoms, behaviours and perceptions. This is noted to be both an advantage and a limitation in Phase C. Self-report measures provide unprecedented access to the thought processes of participants that cannot be captured by other forms of data i.e. medical/GP records or biomedical testing. However, varying degrees of expertise about gluten (as discussed in Chapter 3) could confound the reported effects that occur because of its consumption. The participant’s ability to accurately self-report clinical symptoms was also taken into consideration when making the decision to target questions at a broader food consumption level. The design of the questionnaire is therefore entirely dependent on self-report measures, most of which are not directly related to gluten.

The scope of this study did not allow for the collection of supplementary data from medical sources or health professionals, although it is acknowledged that such data may have aided in the identification of additional relevant medical information. It is also noted however that such data would be both difficult to capture, and to operationalize due to the ongoing issues medical professionals are facing with diagnostic validity. Therefore, the findings presented in the Phase C should be considered as a preliminary exploration into GA as based on the limited understanding of non-prescribed gluten avoidance provided by the literature, and the qualitative work in Chapter 3.

5.9 Conclusion

This chapter provides a comprehensive overview of the design and method used in Phase C, which is dedicated to the quantitative exploration of non-prescribed gluten avoidance. Study groups were established based on the three-step collection process outlined in 5.3, resulting in a final sample of 1240 participants.
This final phase aims to provide a preliminary exploration of the phenomenon so that a greater understanding of its components may be achieved. The data collected during this phase is discussed in the following three chapters and covers physiological and psychological variables of interest. Chapter 6 will examine the symptomology reported by GA, and how this relates to their avoidance behaviours. Chapter 7 then identifies relevant perceptions and cognitive influences on food choice, and Chapter 8 follows with a comprehensive review of individual differences that are likely to perpetuate gluten avoidance behaviours.
Chapter 6: Symptomology and somatisation in gluten avoiders

6.1 Introduction

Chapter 6 is the first of several chapters dedicated to the quantitative analyses of Phase C. This chapter will address the research gaps identified in Phase B where a proportion of gluten avoiders (GA) were found to be avoiding gluten without a medical diagnosis that required them to do so. This chapter will build on the findings presented in Chapter 3, which suggested that GA typically chose to avoid gluten due to the physiological symptoms they perceived it to cause. This chapter will therefore explore the individual symptom experience at a quantitative level and observe how this relates to avoidance behaviours in order to gain a better understanding of the relationship between these important variables.

6.2 Background

In the absence of a simple and accurate diagnostic measure of gluten sensitivity, doctors and researchers alike have relied on patients’ self-reported experience to gain a better understanding of their symptoms. Most people with gluten sensitivity tend to report the existence of two or more simultaneous symptoms following the consumption of gluten, including extra-intestinal symptoms such as fatigue, muscle or joint pain and a type of lethargy termed foggy mind (Volta & De Giorgio, 2012). However, more data is needed to establish the actual prevalence of these symptoms due to the ongoing issues surrounding accurate diagnoses of non-coeliac gluten sensitivity. These symptoms are similar to the complaints of those who report symptomatic wheat avoidance, with bloating and cramps being by far the most endorsed symptoms amongst this group (Golley et al., 2015). Although the symptoms of these wheat avoiders mirror those reported by patients with gluten sensitivity, only 14.9% of the symptomatic wheat-avoiders nominated an intolerance or allergy as their main reason for avoiding wheat. Several other diagnoses were also reported by wheat avoiders, such as irritable bowel syndrome (IBS, 3.4%), diverticulitis (2.3%), and unspecified allergy (2.3%). The broad nature of these presentations makes it particularly difficult to distinguish between symptoms relating to wheat, symptoms relating to gluten, and symptoms that are related to other health disorders affecting the gut.
A study by Tavakkoli, Lewis, Tennyson, Lebwohl, and Green (2014) showed that up to 30% of self-identified wheat avoiders were exhibiting symptoms that could be linked to diagnoses other than gluten sensitivity. Irritable bowel syndrome (IBS) is one of the major diagnoses that exhibit markedly similar symptoms to those reporting sensitivities to gluten (De Giorgio, Volta, & Gibson, 2016; Makharia, Catassi, & Makharia, 2015). Research suggests that up to 50% of those with gluten sensitivity (Volta, Caio, Tovoli, & De Giorgio, 2013), and 30% of those avoiding wheat (Tavakkoli et al., 2014) may also be experiencing IBS or other food intolerances. Patients who have been diagnosed with IBS also have a significantly greater chance of reporting issues with food hypersensitivity, as indicated by reactions to several different proteins (Carroccio et al., 2012). This overlap in symptomology can create added confusion to an already difficult diagnostic process, for both patients and health clinicians (Elli et al., 2015). It also highlights the difficulties associated with accurate diagnoses of these conditions, especially when there is a preference for self-diagnoses over evidence-based medical examination.

Research shows that non-prescribed gluten avoidance in adults is often associated with nonspecific gastrointestinal complaints such as abdominal pain, discomfort, bloating and diarrhoea/constipation (Tanpowpong et al., 2015). The participants in Chapter 3 reported that the abatement of these symptoms following the adoption of a gluten free diet led them to believe they were suffering from a sensitivity to gluten. However, the substantial symptom overlaps discussed above increases the likelihood that these presumptions could be made in error for a number of gluten avoiders. These issues are mirrored in a range of other syndromes that exhibit medically unexplained physical symptoms (MUPS, Burton, 2003), including IBS. To date, non-prescribed gluten avoidance has not been categorised alongside these other disorders, despite the clear commonality between the symptoms they present with.

High rates of medically unexplained symptoms in patients has been identified as a key indicator of somatoform disorder (Steinbrecher, Koerber, Frieser, & Hiller, 2011), where emotions tend to express themselves through physical means. For example, one of the greatest predictors of IBS symptoms is the visceral sensations that accompany anxiety (Hazlett-Stevens, Craske, Mayer, Chang, & Naliboff, 2003), highlighting the significant role that emotions play in the expression of IBS.
Symptoms. Studies have shown that negative emotions can disrupt one’s ability to distinguish between an increased sensitivity driven by medical triggers, and psychological symptoms driven by hypochondrial thoughts (S. Cohen et al., 1995). Strong rates of anticipatory symptomatic responses following gluten-challenges (Biesiekierski, Peters, et al., 2013) indicate that gluten avoiders are experiencing negative emotions in response to their perceived symptoms as a consequence of consuming gluten. The reporting of adverse physiological symptoms after the ingestion of gluten therefore is not in itself a sufficient way to identify gluten sensitivity. More information is needed to confirm if the symptoms of gluten avoiders are being influenced by similar patterns of somatisation observed to those with diagnoses of IBS.

Considering the aforementioned overlap between the symptomology of diagnoses, and the possible confounding nature of somatic symptoms, it is important to develop a distinction between gluten-specific symptoms and other symptoms that may be misattributed to gluten. A comprehensive understanding of gluten avoidance and its physiological drivers is yet to be established to this degree, particularly in relation to extra-intestinal symptoms. This chapter therefore aimed to quantify the experience of gluten avoiders through an examination of food avoidance behaviours, and the way these are associated with physiological symptoms. The nature of this work is explorative due to the lack of pre-existing research in this area for this specific population, and as such no specific hypotheses are tabled. The following research questions were posed:

1) What is the prevalence and type of gastrointestinal and extra-intestinal symptoms that are being experienced by gluten avoiders?
2) Is there a relationship between the symptoms being experienced by gluten avoiders and the frequency and intensity of gluten avoidance behaviours?
3) What is the prevalence of comorbid somatic symptoms amongst gluten avoiders?

6.3 Method

For a comprehensive overview of the method used to collect and analyse this data and the method used to categorise participants, see Chapter 5. A three-step process was used to categorise participants into two study groups; 1) gluten avoiders,
representing those who report avoiding gluten, and experiencing symptoms following gluten consumption, 2) gluten consumers, representing the control group reported no conscious attempts to avoid gluten. For pragmatic reasons, gluten avoiders will hereafter be referred to as GA, and gluten consumers as GC.

The current chapter will discuss the findings relating to the following measures:

- Demographics and health questionnaire – measuring prevalence rates of non-gluten health conditions amongst participants (see 5.5.1).
- Food avoidance and symptoms questionnaire – measuring reported rates of food avoidance behaviours and symptoms following the consumption of foods (see 5.5.2).
- Gluten symptomology questionnaire – measuring reported experience of particular symptoms following the consumption of gluten specifically (see 5.5.5).
- Patient Health Questionnaire (PHQ15) – validated scale developed to measure frequency of somatic symptoms in participants (see 5.5.4)

6.4 Results

6.4.1 Gluten symptomology

Chi-square tests for independence were used to assess the symptoms that were being experienced by participants following the consumption of gluten. There was a significantly greater proportion of GA that reported experiencing negative symptoms following the consumption of gluten, as compared to GC; \( \chi^2(4, N = 1240) = 1107.64, p < .001 \), Cramer’s \( V = .945 \). This effect size was large. This difference in the symptomology of GA also extended through to the analyses completed on specific symptom types. Further exploration showed that a larger proportion of GA reported experiencing bloating, fatigue, stomach cramps, weight gain, headaches, brain fog, inflammation, diarrhoea, mood changes, skin rash/sores, dizziness, and hormone issues following the consumption of gluten. A visualisation of the symptoms reported by each group can be viewed in rank-order in Figure 6-1, shown on the next page.
Figure 6-1 Prevalence of symptoms reported following the consumption of gluten. GC – Gluten consumers (n = 500), GA – Gluten avoiders (n = 740). All differences between groups are statistically significant to the \( p < .001 \) level.

Bloating, fatigue and stomach cramps were the three most frequent gluten-related symptoms reported by GA. These were also the symptoms with the greatest differences reported between groups, with all three comparisons resulting in large effect sizes, or effects just under this threshold (see Table 6-1). Fatigue, bloating and weight gain were also the most frequent symptoms reported by GC after consuming gluten. Gluten consumers were least likely to report experiencing brain-fog after the consumption of gluten, although GA ranked it as the 6th most experienced symptom. Therefore, there were subtle differences in the expression of symptoms of GA and GC following the consumption of gluten. Overall, GC were less likely to endorse the item relating to negative symptoms being experienced after the consumption of gluten. However, an observation of the above symptom breakdown
shows that up to 20% of GC are experiencing at least one symptom (fatigue) after gluten-consumption. This finding could indicate that GC do not necessarily perceive these as negative symptoms per se, and this would be reflected in their overall perceptions of risk.

Table 6-1
*Chi-square tests for symptom frequency following consumption of gluten*

<table>
<thead>
<tr>
<th>Symptom</th>
<th>GC</th>
<th>GA</th>
<th>$\chi^2$</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Experienced after gluten consumption (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bloating</td>
<td>16.8</td>
<td>78.6</td>
<td>468.97**</td>
<td>.615</td>
</tr>
<tr>
<td>Fatigue</td>
<td>20.4</td>
<td>70.5</td>
<td>301.07**</td>
<td>.493</td>
</tr>
<tr>
<td>Stomach cramps</td>
<td>13.6</td>
<td>62.6</td>
<td>296.67**</td>
<td>.489</td>
</tr>
<tr>
<td>Weight gain</td>
<td>15.4</td>
<td>61.5</td>
<td>260.99**</td>
<td>.459</td>
</tr>
<tr>
<td>Headaches</td>
<td>14.6</td>
<td>47.2</td>
<td>142.74**</td>
<td>.339</td>
</tr>
<tr>
<td>Brain fog</td>
<td>5.8</td>
<td>43.2</td>
<td>207.87**</td>
<td>.409</td>
</tr>
<tr>
<td>Inflammation</td>
<td>6.8</td>
<td>42.8</td>
<td>191.40**</td>
<td>.393</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>6.8</td>
<td>41.8</td>
<td>183.89**</td>
<td>.385</td>
</tr>
<tr>
<td>Mood changes</td>
<td>9.4</td>
<td>40.7</td>
<td>145.83**</td>
<td>.343</td>
</tr>
<tr>
<td>Skin rash/sores</td>
<td>7.2</td>
<td>30.5</td>
<td>99.34**</td>
<td>.283</td>
</tr>
<tr>
<td>Dizziness</td>
<td>5.8</td>
<td>29.5</td>
<td>106.12**</td>
<td>.293</td>
</tr>
<tr>
<td>Hormone issues</td>
<td>6.2</td>
<td>27.7</td>
<td>91.73**</td>
<td>.272</td>
</tr>
</tbody>
</table>

Note: ** = $p < .001$, GC – Gluten consumers (N = 500), GA – Gluten avoiders (N = 740)

A Pearson’s correlational analyses showed that the frequency of negative symptoms after the consumption of gluten was positively correlated with the frequency of gluten avoidance ($r = .864$, $p < .001$). The strength of this relationship was very large, indicating that the more symptoms someone experiences following the consumption of gluten, the more likely they are to avoid it. A full correlation matrix between symptoms and gluten avoidance can be viewed in Table 6-2. Bloating, cramps and fatigue were the three symptoms that had the strongest relationship with gluten avoidance behaviours. There was also a strong relationship noted between the experience of cramps and bloating occurring simultaneously after the consumption of gluten.
Table 6-2
Correlations between specific symptoms following the consumption of gluten and the frequency of gluten avoidance behaviours amongst participants.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Bloating</td>
<td>1</td>
<td>0.73</td>
<td>0.59</td>
<td>0.44</td>
<td>0.62</td>
<td>0.37</td>
<td>0.46</td>
<td>0.46</td>
<td>0.50</td>
<td>0.36</td>
<td>0.37</td>
<td>0.51</td>
<td>0.60</td>
</tr>
<tr>
<td>2 Cramps</td>
<td>1</td>
<td>0.57</td>
<td>0.53</td>
<td>0.53</td>
<td>0.42</td>
<td>0.49</td>
<td>0.50</td>
<td>0.48</td>
<td>0.40</td>
<td>0.40</td>
<td>0.50</td>
<td>0.50</td>
<td></td>
</tr>
<tr>
<td>3 Fatigue</td>
<td>1</td>
<td>0.57</td>
<td>0.55</td>
<td>0.40</td>
<td>0.52</td>
<td>0.39</td>
<td>0.59</td>
<td>0.43</td>
<td>0.43</td>
<td>0.52</td>
<td>0.48</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Headaches</td>
<td>1</td>
<td>0.44</td>
<td>0.47</td>
<td>0.55</td>
<td>0.40</td>
<td>0.53</td>
<td>0.51</td>
<td>0.50</td>
<td>0.47</td>
<td>0.36</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Weight gain</td>
<td>1</td>
<td>0.44</td>
<td>0.54</td>
<td>0.39</td>
<td>0.49</td>
<td>0.42</td>
<td>0.43</td>
<td>0.50</td>
<td>0.45</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Rash/sores</td>
<td>1</td>
<td>0.59</td>
<td>0.44</td>
<td>0.52</td>
<td>0.54</td>
<td>0.51</td>
<td>0.53</td>
<td>0.27</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Mood changes</td>
<td>1</td>
<td>0.43</td>
<td>0.61</td>
<td>0.52</td>
<td>0.58</td>
<td>0.55</td>
<td>0.34</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Diarrhoea</td>
<td>1</td>
<td>0.47</td>
<td>0.47</td>
<td>0.41</td>
<td>0.49</td>
<td>0.38</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 Brain fog</td>
<td>1</td>
<td>0.59</td>
<td>0.57</td>
<td>0.63</td>
<td>0.43</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 Dizziness</td>
<td>1</td>
<td>0.60</td>
<td>0.58</td>
<td>0.28</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 Hormone</td>
<td>1</td>
<td>0.58</td>
<td>0.29</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 Inflammation</td>
<td>1</td>
<td>0.40</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 Gluten avoidance</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: $N = 1240$, all correlations at or above $r = 0.27$ were statistically significant at the $p < .001$ level.
6.4.2 Non-gluten related health conditions

Chi-square tests for independence were used to assess the difference in self-reported prevalence rates of non-gluten health conditions amongst participants. There was a significant difference in the number of non-gluten health conditions that were reported, with GA indicating higher rates of both egg allergy and dairy intolerance (see Table 6-3). Gluten avoiders were more likely than GC to report having a dairy intolerance. This was also the non-gluten health condition with the greatest difference between groups, although this effect size was small. Gluten consumers were more likely to report having diabetes than any other non-gluten condition, although these prevalence rates were still lower than those reported by GA. In 2013, the prevalence of diabetes for the Australian population was recorded to be 10% (Guariguata et al., 2014). This is similar to the rates that were found for participants in the study, further supporting the overall representativeness of the sample collected.

Table 6-3
Chi-square tests for the prevalence of non-gluten health conditions

<table>
<thead>
<tr>
<th>Health condition</th>
<th>GC Prevalence (%)</th>
<th>GA Prevalence (%)</th>
<th>( \chi^2 )</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td>Egg Allergy</td>
<td>0.8</td>
<td>3.9</td>
<td>11.21**</td>
<td>.095</td>
</tr>
<tr>
<td>Dairy Intolerance</td>
<td>3.0</td>
<td>15.8</td>
<td>51.48**</td>
<td>.204</td>
</tr>
<tr>
<td>Diabetes</td>
<td>9.0</td>
<td>10.0</td>
<td>0.34</td>
<td>.017</td>
</tr>
<tr>
<td>None of these</td>
<td>87.6</td>
<td>73.6</td>
<td>35.35**</td>
<td>.169</td>
</tr>
</tbody>
</table>

Note: ** = \( p < .001 \), GC – Gluten consumers (n = 500), GA – Gluten avoiders (n = 740).

6.4.3 Avoidance of non-gluten foods

Chi-square tests of independence were used to assess the frequency with which participants in the study avoided non-gluten foods\(^5\). There was a significant difference found in the amount of non-gluten foods that were avoided between participants, with a consistently higher rate of GA reporting actively avoiding dairy, eggs, carbohydrates, fats and preservatives in their diets (see Table 6-4).

\(^5\) Non-gluten foods assessed in the study included: dairy, eggs, carbohydrates, fats and preservatives. Behaviours toward and symptoms reported from consumption of non-gluten foods were utilized as a control in order to discriminate between gluten-specific avoidance behaviours, in contrast to the adoption of a generally restrictive diet that involved avoidance of various food types.
Table 6-4

Chi-square tests for non-gluten food avoidance amongst participants

<table>
<thead>
<tr>
<th>Non-gluten food</th>
<th>GC (Reported avoidance (%))</th>
<th>GA (Reported avoidance (%))</th>
<th>$\chi^2$</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dairy</td>
<td>15.4</td>
<td>77.3</td>
<td>459.2**</td>
<td>.609</td>
</tr>
<tr>
<td>Eggs</td>
<td>13.0</td>
<td>46.5</td>
<td>152.4**</td>
<td>.351</td>
</tr>
<tr>
<td>Carbohydrates</td>
<td>33.6</td>
<td>79.3</td>
<td>276.2**</td>
<td>.472</td>
</tr>
<tr>
<td>Fats</td>
<td>58.0</td>
<td>84.1</td>
<td>120.0**</td>
<td>.311</td>
</tr>
<tr>
<td>Preservatives</td>
<td>62.2</td>
<td>92.6</td>
<td>220.9**</td>
<td>.422</td>
</tr>
</tbody>
</table>

Note: ** = $p < .001$, GC – Gluten consumers ($n = 500$), GA – Gluten avoiders ($n = 740$).

More than half of all GA chose to avoid dairy, carbohydrates, fats and preservatives, demonstrating persistently higher rates of reported avoidance. The most sizable difference in behaviours between groups was observed for the avoidance of dairy products, where the proportion of GA avoiding dairy exceeded rates reported by GC by 62%. A large effect size was found for this comparison, signifying a particularly strong difference in the behaviours between the two groups. There was also a significant difference found between the proportion of participants avoiding carbohydrates, with GA exceeding the rates reported by controls by 46%. Gluten avoiders were also substantially more likely to report simultaneous avoidance of preservatives. The majority of avoidance amongst GC was typically reported for fats and carbohydrates, with the majority of controls reporting having never made attempts to avoid dairy, eggs or carbohydrates.

A Pearson’s correlational analyses revealed that gluten avoidance was significantly correlated with the avoidance of all non-gluten foods measured (see Table 6-5), with a particularly strong positive relationship shown for the avoidance of dairy. These findings mirror those discussed in non-gluten food symptoms (6.4.3), where dairy-symptoms were shown to have the strongest relationship with gluten symptoms.
Correlations between symptomology and avoidance of non-gluten foods showed consistently strong and positive relationships for each. The avoidance of dairy was strongly associated with the number of reported symptoms following its consumption \( r = .78, p < .001 \). The same trend was found for eggs \( r = .70, p < .001 \), carbohydrates \( r = .66, p < .001 \), fats \( r = .56, p < .001 \) and preservatives \( r = .61, p < .001 \). The strength of these relationships were all large, indicating that the more symptoms someone experiences following the consumption of non-gluten foods, the more likely they are to avoid them. These findings are similar to those found between gluten symptoms and gluten avoidance, indicating that this relationship between symptoms and avoidance is not specific to gluten.

### 6.4.4 Non-gluten food symptoms

Chi-square tests for independence revealed that there was a significant difference in the number of negative symptoms experienced by participants following the consumption of non-gluten foods (see Table 6-6). Non-gluten food symptoms were rated in similar rank-orders amongst both groups. However, a significantly greater proportion of GA reported experiencing symptoms for each food, with medium to large effect sizes for all analyses. The most prominent of these differences were again related to dairy. This trend was also found to be similar for symptoms relating to carbohydrates and preservatives.
GLUTEN AVOIDANCE

Table 6-6
Chi-square tests for symptoms frequency following the consumption of non-gluten foods

<table>
<thead>
<tr>
<th>Non-gluten food</th>
<th>GC</th>
<th>GA</th>
<th>( \chi^2 )</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dairy</td>
<td>20.4</td>
<td>80.4</td>
<td>443.98**</td>
<td>.598</td>
</tr>
<tr>
<td>Eggs</td>
<td>8.2</td>
<td>46.2</td>
<td>202.23**</td>
<td>.404</td>
</tr>
<tr>
<td>Carbohydrates</td>
<td>11.6</td>
<td>71.2</td>
<td>430.73**</td>
<td>.589</td>
</tr>
<tr>
<td>Fats</td>
<td>25.4</td>
<td>73.8</td>
<td>290.12**</td>
<td>.484</td>
</tr>
<tr>
<td>Preservatives</td>
<td>24.6</td>
<td>82.4</td>
<td>429.45**</td>
<td>.588</td>
</tr>
</tbody>
</table>

Note: ** = \( p < .001 \), GC – Gluten consumers \((n = 500)\), GA – Gluten avoiders \((n = 740)\)

A Pearson’s correlational analysis revealed that the experience of gluten-related symptoms was significantly correlated with non-gluten food symptoms (see Table 6-7). There was a large positive relationship found between the frequency of gluten-related symptoms reported and the frequency of dairy symptoms reported. Similarly sized relationship were found for the experience of symptoms following consumption of carbohydrates, and preservatives.

Table 6-7
Correlation between gluten-symptomology and symptoms following the consumption of non-gluten foods

<table>
<thead>
<tr>
<th>Food type</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>1 Gluten</td>
<td>1.00</td>
</tr>
<tr>
<td>2 Dairy</td>
<td>1.00</td>
</tr>
<tr>
<td>3 Eggs</td>
<td>1.00</td>
</tr>
<tr>
<td>4 Carbohydrates</td>
<td>1.00</td>
</tr>
<tr>
<td>5 Fats</td>
<td>1.00</td>
</tr>
<tr>
<td>6 Preservatives</td>
<td></td>
</tr>
</tbody>
</table>

Note: \( N = 1240, \) all correlations at or above \( r = 0.38 \) were statistically significant at the \( p < .001 \) level.

Only a very small proportion of participants reported experiencing symptoms following the consumption of gluten without also experiencing symptoms after eating non-gluten foods. This group made up only 2% of the total study sample \((n = 24)\). These specific symptoms and avoidance patterns are indicative of someone experiencing a clear and isolated issue with gluten, and would likely benefit from further testing in relation to possible
diagnoses and treatment options. The avoidance behaviours of this group were characteristically different to the majority of gluten avoiders. Over 90% of this group indicated never avoiding dairy or eggs, and more than 60% reported never avoiding carbohydrates. Gluten symptomatic individuals were most likely to report avoidance of preservatives, with the majority of the group reporting a low frequency of avoidance only.

6.4.5 Experience of somatic symptoms

An independent samples t-test was performed comparing the mean PHQ-15 scores of GA (\(M = 10.0, SD = 5.8\)) and GC (\(M = 6.2, SD = 4.8\)); and GA were found to experience significantly higher somatisation scores; \(t(1238) = -12.22, p < .001\), Cohen’s \(d = 0.71^6\). Chi-square tests of independence were used to complement these findings in order to assess the frequency with which participants experienced each specific somatic symptom (see Table 6-8).

### Table 6-8

<table>
<thead>
<tr>
<th>Somatic symptom</th>
<th>GC Experienced (%)</th>
<th>GA Experienced (%)</th>
<th>(\chi^2)</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling tired</td>
<td>64.0</td>
<td>80.3</td>
<td>52.68**</td>
<td>.206</td>
</tr>
<tr>
<td>Stomach pain</td>
<td>40.4</td>
<td>74.6</td>
<td>160.79**</td>
<td>.360</td>
</tr>
<tr>
<td>Back pain</td>
<td>59.8</td>
<td>72.8</td>
<td>28.70**</td>
<td>.152</td>
</tr>
<tr>
<td>Trouble sleeping</td>
<td>54.4</td>
<td>71.2</td>
<td>47.46**</td>
<td>.196</td>
</tr>
<tr>
<td>Gas/indigestion</td>
<td>35.4</td>
<td>69.9</td>
<td>158.62**</td>
<td>.358</td>
</tr>
<tr>
<td>Headaches</td>
<td>54.8</td>
<td>68.8</td>
<td>40.18**</td>
<td>.180</td>
</tr>
<tr>
<td>Pain in limbs/joints</td>
<td>49.8</td>
<td>65.0</td>
<td>28.84**</td>
<td>.153</td>
</tr>
<tr>
<td>Constipation/diarrhoea</td>
<td>35.4</td>
<td>60.4</td>
<td>84.60**</td>
<td>.261</td>
</tr>
<tr>
<td>Dizziness</td>
<td>25.2</td>
<td>40.1</td>
<td>37.00**</td>
<td>.173</td>
</tr>
<tr>
<td>Heart pounds/races</td>
<td>20.4</td>
<td>39.5</td>
<td>52.43**</td>
<td>.206</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>22.8</td>
<td>38.1</td>
<td>33.26**</td>
<td>.164</td>
</tr>
<tr>
<td>Menstrual cramps/problems</td>
<td>19.8</td>
<td>29.2</td>
<td>14.94*</td>
<td>.110</td>
</tr>
<tr>
<td>Chest pain</td>
<td>18.2</td>
<td>28.5</td>
<td>17.50**</td>
<td>.119</td>
</tr>
<tr>
<td>Pain/problems during sex</td>
<td>8.2</td>
<td>21.1</td>
<td>38.79**</td>
<td>.177</td>
</tr>
<tr>
<td>Fainting spells</td>
<td>6.8</td>
<td>18.0</td>
<td>33.12**</td>
<td>.163</td>
</tr>
</tbody>
</table>

Note: * = \(p < .01\), ** = \(p < .001\), GA - Gluten avoiders (\(n = 740\)), GC - Gluten consumers (\(n = 500\)).

---

6 A p-value of less than .001 was observed in the Levene’s test of equality of variances, violating the assumption of equal variances, therefore the t-statistic was adjusted.

7 Reported symptoms were experienced within the previous 4 weeks prior to testing.
Gluten-avoiders typically experienced more stomach pain, back pain, other joint pain, headaches, chest pain, dizziness, fainting spells, menstrual cramps, heart palpitations, shortness of breath, pain during sex, bowel issues, gastrointestinal issues, low energy levels and sleeping difficulties within the four weeks prior to testing than GC did. Both groups ranked tiredness and back pain within their top three symptoms experienced. However, GA reported distinctly different experiences of gastrointestinally-based symptoms, such as stomach pains, gas/indigestion and constipation/diarrhoea (see Figure 6-2).

![Graph showing prevalence of somatic symptoms reported by participants. GC – Gluten consumers (n = 500), GA – Gluten avoiders (n = 740). All differences between groups are statistically significant to the p < .001 level with the exception of menstrual cramps reaching a significance level of p < .01.]

**Figure 6-2** Prevalence of somatic symptoms reported by participants. All differences between groups are statistically significant to the p < .001 level with the exception of menstrual cramps reaching a significance level of p < .01.

## 6.4.5.1 Comparison of somatic symptoms between total and partial gluten avoiders

Gluten avoiders reported somatic symptoms despite their attempts to moderate consumption of the suspected trigger (gluten). In order to rule out the possibility of gluten contamination as a reason for the above trend, a further comparison of somatic symptoms was performed between those reporting total gluten avoidance (i.e. those eliminating the potential trigger from their diet), and those that reported only partial avoidance of gluten (i.e.
may still be consuming some goods containing gluten, and therefore not maintaining a strict GFD. An independent samples t-test completed on somatisation scores for partial gluten avoiders (PGA, $M = 9.6, SD = 5.67$) and total gluten avoiders (TGA, $M = 11.5, SD = 7.16$) revealed that there was a significant difference; $t(738) = -2.38, p = .018$, Cohen’s $d = .28$, two tailed, with TGA reporting more somatic symptoms overall, although the effect size was small. The differences in the experience of individual somatic symptoms was observed through the chi-square tests for independence and can be seen below in Table 6-9.

Table 6-9
Chi-square tests for frequency of somatic symptoms reported by partial and total GA

<table>
<thead>
<tr>
<th>Somatic symptom</th>
<th>PGA Experienced (%)</th>
<th>TGA Experienced (%)</th>
<th>$\chi^2$</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling tired</td>
<td>79.8</td>
<td>84.3</td>
<td>1.13</td>
<td>0.039</td>
</tr>
<tr>
<td>Stomach pain</td>
<td>74.6</td>
<td>74.7</td>
<td>4.55</td>
<td>0.078</td>
</tr>
<tr>
<td>Back pain</td>
<td>72.1</td>
<td>78.3</td>
<td>3.22</td>
<td>0.066</td>
</tr>
<tr>
<td>Trouble sleeping</td>
<td>70.6</td>
<td>75.9</td>
<td>1.35</td>
<td>0.043</td>
</tr>
<tr>
<td>Gas/indigestion</td>
<td>70</td>
<td>68.7</td>
<td>2.96</td>
<td>0.063</td>
</tr>
<tr>
<td>Headaches</td>
<td>69.1</td>
<td>66.3</td>
<td>15.00*</td>
<td>0.142</td>
</tr>
<tr>
<td>Pain in joints/limbs</td>
<td>65</td>
<td>65.1</td>
<td>7.32*</td>
<td>0.099</td>
</tr>
<tr>
<td>Constipation/diarrhoea</td>
<td>60.3</td>
<td>61.4</td>
<td>6.99*</td>
<td>0.097</td>
</tr>
<tr>
<td>Dizziness</td>
<td>39.6</td>
<td>44.6</td>
<td>4.92</td>
<td>0.082</td>
</tr>
<tr>
<td>Heart pound/race</td>
<td>39.3</td>
<td>41</td>
<td>4.53</td>
<td>0.078</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>37</td>
<td>47</td>
<td>4.79</td>
<td>0.08</td>
</tr>
<tr>
<td>Menstrual cramps/problems</td>
<td>29.8</td>
<td>24.1</td>
<td>1.27</td>
<td>0.041</td>
</tr>
<tr>
<td>Chest pain</td>
<td>27.7</td>
<td>34.9</td>
<td>4.38</td>
<td>0.077</td>
</tr>
<tr>
<td>Pain/problems during sex</td>
<td>19.8</td>
<td>31.3</td>
<td>11.71*</td>
<td>0.126</td>
</tr>
<tr>
<td>Fainting spells</td>
<td>16.9</td>
<td>26.5</td>
<td>5.26</td>
<td>0.084</td>
</tr>
</tbody>
</table>

Note: * = $p < .05$, PGA – Partial gluten avoider, $n = 657$, TGA – Total gluten avoider, $n = 83$.

There were only four significant differences found between PGA and TGA in relation to individual somatic symptoms, with all showing small or very small effect sizes. Only one of these four symptoms appears to relate to food sensitivity (constipation/diarrhoea), providing the smallest effect size amongst those that reached significance. A slightly larger proportion of PGA experienced stomach pains and headaches,
which may or may not be indicators of gluten-contamination. However, as the observed effect sizes were small, these findings provide limited capacity to confirm the existence of cross-contamination effects. In general, there were no major indications of gluten-related somatic symptoms occurring within PGA that would suggest gluten-contamination is significantly inflating the higher somatisation scores reported by gluten avoiders.

6.5 Discussion

This chapter aimed to quantify the food avoidance behaviours that characterise people who avoid gluten without a diagnosis, and identify the type and frequency of their associated symptomology. Results show that GA are not only typified by their gluten-specific behaviours but by a general tendency to avoid a variety of foods including dairy, eggs, carbohydrates, fats and preservatives. Gluten-avoiders were found to report significantly higher incidence rates of non-gluten health conditions. They were also found to experience a higher frequency of all physiological symptoms, including those that were linked to the consumption of non-gluten foods, and somatic symptoms that were unrelated to food consumption. These findings suggest that the experience of non-prescribed gluten avoiders involves complex mechanisms and symptoms that may not be appropriately captured by the examination of gluten-based triggers in isolation.

The frequency of gluten avoidance behaviours varied amongst participants, where the majority of GA reported only avoiding gluten some of the time. This suggests that most GA diets are not managed on a zero-gluten basis, which replicates previous findings regarding the difficulty in adhering to a strict gluten free diet for both non-coeliacs (Golley et al., 2015) and coeliacs (Leffler et al., 2008) alike. Gluten avoiders were also significantly more likely to report experiencing adverse symptoms following the consumption of gluten compared to GC, with the prevalence of symptoms being reported by GA exceeding rates of controls by 37%. These findings are important for two reasons. Firstly, the confirmation of this relationship suggests that there are cross-correlations amongst the self-report measures used in the study, adding to the internal consistency of the chosen questions. The second, and perhaps more valuable conclusion is that non-prescribed gluten avoiders appear to be avoiding gluten based on the symptoms they are experiencing following its consumption. This study is the first to establish this connection so clearly within the undiagnosed populations. Bloating, fatigue and stomach cramps were the most common symptoms reported by GA following the consumption of gluten. Together, the prevalence of these symptoms within the group exceeded rates reported by GC by 49-62%. These findings match
the previous symptom-rankings reported by wheat avoiders in Australia (Golley et al., 2017). Wheat-avoiders reported extremely high rates of bloating compared to the 78.6% present in GA captured in the current study. However, the symptom options provided in the wheat-avoidance study paired bloating with fullness/flatulence, rather than considering them as separate symptoms. This could account for the higher rates of endorsement amongst wheat-avoiders compared to GA. The choice to engage in wheat-avoidance is also quite specific, and is likely made by those with a higher prevalence of pre-existing wheat allergies/intolerances – a separate condition to that of gluten intolerance/sensitivity.

A strong positive correlation was found between the number of gluten symptoms reported and the frequency with which participants indicated they avoided gluten. This suggests that physiological responses following the consumption of gluten should be considered as a motivating factor. However, the same trends were also observed for GA in relation to non-gluten foods. It is therefore unlikely that the experience of negative symptoms alone is sufficient as an indicator of gluten-sensitivity – and additional factors should be considered when trying to map the underlying drivers of these responses in GA to rule out additional complicating factors e.g. hypersensitivity. There was also a strong link between the experience of bloating and the experience of cramps following the consumption of gluten, which may suggest some crossover between the symptoms that needs to be clarified before they can be considered entirely separate symptom responses.

Gluten avoiders reported additional, and somewhat unexpected symptom experiences following the consumption of non-gluten foods as well. To date, little has been done to explore the non-gluten responses reported by GA, due to the focus that is often placed on gluten as the primary trigger. A significantly higher proportion of GA reported experiencing adverse symptoms following the consumption of dairy, eggs, carbohydrates, fat and preservatives. More than 50% of GA reported experiencing adverse symptoms after consuming these non-gluten foods, meaning the majority of cases are responding to both gluten and non-gluten foods simultaneously. Findings like these suggest that GA are unlikely to be characterised by an isolated response to gluten. Instead, their broad responses to all foods mimic those seen in some patients with IBS, where a response to wheat, milk and egg proteins lead to alternative diagnostic considerations of food hypersensitivity (Carroccio et al., 2010). Sensitivity across a range of foods is also linked to individual differences that determine higher order sensitivities in the central nervous system that are fuelled by overactive autonomic responses (Yunus, 2008). The similar rank-order of symptoms reported
for both GA and GC goes on to further support this notion, suggesting that GA may only be distinguished by the intensity of the symptoms they experience after consuming foods, rather than a unique set of symptoms triggered by gluten. Gluten symptoms were also significantly correlated with non-gluten food symptoms, again indicating that suspected sensitivity issues relating to gluten should be considered within a larger context that considers a range of possible trigger foods. The largest difference in non-gluten symptoms reported by the groups was found for dairy, with 16% reporting an intolerance and 64% reporting symptoms following its consumption. Unfortunately, dairy products are among those with the largest discrepancy between self–reported symptoms and actual immunological reactions (Woods, Abramson, Bailey, & Walters, 2001), which may impact the capacity to use these rates as a reflection of actual symptoms. The study compared the results of skin prick tests against self report and found that although 12.3% of participants identified themselves as having a dairy intolerance, only 0.7% showed a response that warranted such a label.

Gluten avoiders were found to report significantly greater prevalence rates of egg allergies or dairy intolerances than GC were. Milk and eggs are both common food allergens that are typically managed by the adoption of avoidance diets. Previous links have already been drawn between the villous atrophy caused in CD and its tendency to produce secondary lactose intolerance issues in patients (Ojetti et al., 2005). Milk and milk-products have also been shown to have high levels of FODMAPs (Gibson & Shepherd, 2012), which have been identified in the past as one of many variables that could be contributing to the symptoms people associate with gluten sensitivity (Biesiekierski, Peters, et al., 2013). Similar complications have arisen in the identification of ‘trigger’ foods for IBS, whereby a range of foods and their digestive responses are still being investigated in relation to mechanism theories (De Giorgio et al., 2016). These findings tend to support the notion that the title of ‘gluten-sensitivity’ may be too narrow to capture the complex experience of GA, who have indicated a more broad response to foods in general. This may also complicate their ability to distinguish between issues relating to gluten specifically, and issues related to other food triggers without the guidance of trained medical professionals in health and nutrition.

Gluten avoiders were found to avoid significantly more dairy, eggs, carbohydrates, fats and preservatives than those who made no efforts to avoid gluten in their diets. While these food-avoidance rates were lower than gluten avoidance specifically, it indicates that the narrow definition of GA based on gluten-focused behaviours may be misleading. Instead, GA were seen to adopt more generalised food-avoidance attitudes across
the range of food behaviours measured in the study. Preservatives were the most frequently avoided non-gluten food, where 92.6% of GA reported avoiding its consumption to varying degrees. Preservatives are often considered to be artificial, and their consumption has been linked to dangerous side effects in some instances (Anand & Sati, 2013). However, there are also times in which man-made “unnatural” compounds can provide proven health benefits (i.e. preserving/stabilising medicines). Fears associated with the consumption of unnatural additives such as these have been linked to the concept of naïve thinking styles (see Gelman, 2006). People who are more vulnerable to these cognitive biases would be more likely to assume that the healthiness of products is directly associated with its natural content. Similar thought processes may be adopted by GA, whom avoid preservatives almost as much as they avoid gluten despite lower rates of reported symptoms relating to the intake of preservatives.

The largest difference observed amongst groups existed for the avoidance of dairy – indicating that a significantly greater proportion of GA are choosing to reduce their intake of dairy products. The relationship between gluten and dairy avoidance was confirmed through a correlation, adding further weight to the potential for GA to be experiencing simultaneous issues with foods that don’t contain gluten. There was also a substantial number of GA who also reported avoiding carbohydrates, and so their efforts, and the reported improvements that they may have are possibly due to the accumulated effects of generally restrictive diets, as opposed to a specific response to gluten. Low-carbohydrate diets have also been shown to be significantly effective when attempting to manage the effects of diarrhoea-predominant IBS, where symptom relief is followed by substantial improvements in quality of life for patients (Austin et al., 2009).

There was a significant difference found in somatisation scores between GA and GC, with a larger proportion of GA reporting the experience of somatic symptoms. These symptoms are often considered manifestations of psychological distress, indicating that a person is more likely to confuse the physiological effect of emotions as the signs of a more clinical condition such as a food allergy (Berstad, Arslan, Lind, & Florvaag, 2005). The greatest difference observed between groups was found for the experience of stomach pain, gas/indigestion and constipation/diarrhoea, which suggests that they are more characteristic of GA than GC. These three symptoms are all related to the symptoms reported in CD (Ontiveros et al., 2015), NCGS (Catassi et al., 2015) and in food sensitivity responses (Turnbull, Adams, & Gorard, 2015). Subsequent analyses showed that cross-contamination amongst partial gluten avoiders was unlikely to be inflating these somatisation rates. Gluten
avoiders are therefore likely to be characterised by higher overall rates of somatisation, with a particularly significant presentation of somatisation through gastrointestinal symptoms.

Somatisation scores are strongly correlated with IBS severity (Creed et al., 2008) and have been shown to occur alongside anxiety diagnoses (Steinbrecher et al., 2011). The symptoms of IBS can be perpetuated by gastrointestinal-specific anxiety, which is defined as the fear of GI sensations and the context in which these occur (Labus, Mayer, Chang, Bolus, & Naliboff, 2007). This specific form of anxiety is believed to play a role in the maintenance of symptoms for this and other chronic conditions (Labus et al., 2004). These catastrophising attitudes towards minor ailments have been correlated with general difficulties associated with symptoms (Kroenke, Spitzer, & Williams, 2002). One study even suggested that the stress relating to gastric dysfunction is mediated by somatic symptoms (Van Oudenhove & Aziz, 2009), indicating that GA should, at the very least, be considered ‘at risk’ for the manifestation of emotional stressors as physical ones. These types of emotion-processing deficits have already been captured in the literature for females with diagnosed eating disorders, who have trouble identifying and describing their own emotions (Bydlowski et al., 2005) mediating attentional biases related to their eating behaviours (Harrison, Sullivan, Tchanturia, & Treasure, 2010).

One limitation of the above findings is that the measures rely solely on the participant’s abilities to accurately self-report physiological issues occurring. Due to the preliminary nature of the study, and the lack of medical assessment measures, it also considers the self-reporting of symptoms to represent the perceived experience of symptoms amongst participants. Considering the possible role that somatisation plays in the experience of GA, participants in the avoidance group may be less able to distinguish between clinically related responses, and those that are driven by food-related anxieties or other non-gluten sensitivity issues. However, since the perception of symptoms appears to create similar physiological effects as those that are biologically based, this distinction was considered to be less important in the context of these exploratory analyses – it was instead investigated in later chapters (see Chapter 7 & Chapter 8). There were also limitations in the depth to which non-gluten symptomology questions could be covered within the current study, as it did not fit within the scope of the project. It would be advantageous for future research to consider examining the specific types of symptoms that are reported by GA after consuming non-gluten foods to assess whether further issues relating to symptom crossover become apparent.
6.6 Conclusion

Gluten avoiders have been found to avoid more of, and experience a greater number of adverse symptoms after consumption of the following: gluten, dairy, eggs, carbohydrates, fats and preservatives. They also reported a greater incidence of non-gluten health conditions, and experienced higher rates of somatisation than GC. Together, these findings indicate that the behaviours of GA are likely to be driven by more than an isolated response to gluten alone. Although GA identify with gluten avoidance behaviours typically driven by gluten-triggered symptoms, studies have yet to capture the additional complications GA experience with non-gluten symptoms and subsequent avoidance patterns. This is particularly important for health practitioners to consider both in the diagnosis and treatment phase of these individuals. Higher levels of somatisation in GA is also likely to impact their health and risk perceptions due to the complications that may arise from the transference of emotions and stress into physiological issues. Confirmation of negative health and risk perceptions would clarify the role that catastrophising thoughts play in the perpetuation of gastrointestinal-specific anxiety, and the confounding symptoms it may cause in GA. These factors are measured and compared with avoidance behaviours in the following chapter, leading to a greater understanding of the cognitive features that influence gluten avoidance behaviours.
Chapter 7: Food perceptions and cognitive influences on food choice

7.1 Introduction

The findings in Chapter 6 demonstrated that gluten avoidance behaviours are likely to be driven by more than an isolated response to gluten, as originally described in the qualitative work discussed earlier (see Chapter 3). Chapter 6 showed that participants who avoided gluten also reported higher rates of symptoms after eating non-gluten foods, as well as higher rates of somatic symptoms unrelated to food consumption. Despite the lack of gluten specific symptomology, gluten avoiders still nominated gluten as the food they consciously attempted to avoid the most. There were also a percentage of gluten avoiders who reported experiencing no adverse symptoms following the consumption of gluten whatsoever. Therefore, additional cognitive influences need to be considered as an important factor in the decision to avoid gluten rather than defining it as a reactionary behaviour based on specific physiological sensitivities. The lack of gluten-specificity found in Chapter 6 introduces the need to explore additional factors when attempting to develop a clear understanding of the drivers of gluten avoidance. Therefore, the aim of this chapter is to explore the role that food perceptions and cognitive influences may play when making the decision to avoid gluten without a diagnosis.

7.2 Background

The relationship between health and food has gained increased attention in recent years, fuelling the growing demand for functional foods and personalised diets (Meijboom, 2007). Diets are now being adopted to assist in the treatment and prevention of illnesses, and foods are being successfully advertised based on the health benefits they provide. Studies that explore perceptions about food have shown that the fear of consuming unhealthy foods is already being prioritised over fears about the exposure to diseased or poisoned foods (Yeung & Morris, 2001), a reflection of the improved food-handling and storage procedures being utilised across the modern world. These consumer perceptions about food health are particularly useful when exploring consumption and purchasing patterns. Health perceptions manipulate the initial caloric estimations that consumers make about a product (Carels et al., 2006) and effect consumption rates directly by determining how much of a portion size is deemed to be appropriate/acceptable (Provencher et al., 2009). When attempting to develop theories about the avoidance of a product, these food perceptions are likewise important.
The adoption of dietary change in the pursuit of increased health has been enhanced by the virtually unlimited access that consumers have to health information via mediums such as the Internet. Preliminary studies conducted on gluten avoiders shows that they tend to consume a large amount of health information from online sources for the purpose of making their dietary decisions (Metchikoff, 2014). This phenomenon was also captured in Chapter 3, where gluten avoiders reported adopting experimental diets to manage their symptoms based on information they had mostly collected online. This allowed them to view a range of other people’s opinions and experiences in light of a lack of clarity provided by the medical professionals they approached in person. The information obtained from online sources can directly influence purchasing behaviours, regardless of the quality or reliability of information (D. A. Cohen & Babey, 2012). It can also facilitate the production of false memories, where consumers identify with the symptoms they see reported by others in the absence of clear physiological triggers (Bernstein, Laney, Morris, & Loftus, 2005). In these situations, beliefs and negative expectations are considered to be a powerful driver of behavioural choice (Hahn, 1997). The health belief model was developed on this premise (Rosenstock, Strecher, & Becker, 1988), where perceptions relating to risk and symptom severity are used to explain the adoption of behaviour changes at the level of the individual.

The decision to consume food is also impacted by the type of risk perceptions that are held about the product itself, or the ingredients contained within it (Leikas et al., 2007). These risk perceptions can increase significantly when the food item is associated with negative beliefs (Chaudhuri, 1998), such as the health effects that have been linked to gluten. The lack of consistent messaging about gluten safety for people without coeliac disease and the lag in scientific explanation regarding symptoms is likely to exacerbate fears of this nature. A range of pseudo-scientific sources also utilise far-reaching claims and emotive language to drive dietary change in their readership based on fears of the risk associated with current consumption trends (see Jones, 2012). Being exposed to such sources can lead to confusion about the true risks associated with gluten, and may influence the heuristics that are developed about the products in which it is contained. Lindeman (1998) states that these pseudoscientific claims are often adopted in the face of disputing evidence because they provide a simplistic solution to a complicated problem that is otherwise difficult to control. They suggest that this occurs in those with a preference for experiential thinking styles, where quick everyday decisions are determined by intuitions based on previous information and experiences.
The dependence on heuristics intensifies when the available information is unclear or ambiguous, as is currently the case within the literature regarding gluten qualities and health risks. Ambiguity tolerance was first conceptualised by Frenkel-Brunswik (1949) as a variable related to both emotional ambivalence and cognitive ambiguity rooted within one’s personality. Someone who is intolerant to ambiguity is said to experience anxiety and conflict when presented with ambiguous situations. Intolerance to ambiguity has since been studied in the context of decision-making, and been shown to interact with risk attitudes to jointly determine choice behaviours (Ghosh & Ray, 1992). If gluten avoiders are more intolerant to the ambiguity surrounding their reported symptoms and the lack of diagnostic clarity provided, they may be more vulnerable to the effects of heuristics when making decisions about gluten and its effects.

Negative expectations have been shown to impact health, during both the course of diseases, and the associated patient response to targeted treatments (Benedetti, Lanotte, Lopiano, & Colloca, 2007). These expectations have also been shown to play a role in the perpetuation of intolerance symptoms, where fear about the consumption of a product can lead to the experience of a nocebo effect (Vernia, Di Camillo, Foglietta, Avallone, & De Carolis, 2010). The associated anticipation about consuming a food can lead to the production of ambiguous symptoms that are mistakenly linked to the food itself. In some studies, the stress associated with this nocebo effect has been shown to mimic abdominal issues that cause people to falsely report issues such as a lactose intolerance (Vernia et al., 2010). Similar mechanisms could explain the experience of medically unexplained physiological symptoms reported by gluten avoiders.

The confusion between perceived and medically observable symptoms is often a focus in those categorised with a contested illness, where a set of symptoms has yet to reach a socially acceptable definition. Individuals with these ailments struggle to assert the legitimacy of their claims to medical professionals, resulting in feelings of stress and vulnerability when seeking treatment for their symptoms (Swoboda, 2006). After multiple dissatisfying experiences with GPs, those with a contested illness are often driven to seek affirmation amongst support groups of those suffering from similar symptoms (Goldstein, 2004a). These investigations can lead to an oversaturation of information about the associated risks, which can exacerbate any pre-existing nocebo effects at play (Symon et al., 2015; Wells, 2012). Gluten avoiders described similar experiences in Chapter 3, whereby unmet
expectations of the medical system drove them to adopt a self-education strategy in order to better understand their symptoms.

Although preliminary information has been collected about the information sources utilised by gluten avoiders in general, little is known about the relationship between their perceptions, beliefs and avoidance frequency. In addition, it is important to understand how these perceptions and beliefs are influenced by social factors (such as interactions with their GP, and with their wider social network) and cognitive factors (such as ambiguity tolerance, thinking styles and food choice preferences). Themes relating to GP satisfaction, discrimination and information consumption were identified in the qualitative work presented in Chapter 3 but are yet to be confirmed through large-scale quantitative research. The role that perceptions and cognitive influences play in the choice to avoid gluten without a medical prescription to do so is also yet to be characterised, due to both the evolving nature of the literature, and the limited focus on non-physiological factors. Therefore, the current chapter seeks to understand the cognitive characteristics that influence decision-making relating to food choice, and the factors that influence these cognitive characteristics. The following research questions were posed in order to assist with this preliminary characterisation:

1) Do gluten avoiders report higher levels of perceived discrimination?
2) Do gluten avoiders score lower on measures of GP satisfaction, and what relationship does this have with gluten avoidance?
3) Do gluten avoiders have higher usage rates of online information sources/blogs and rate their trustworthiness higher than gluten consumers?
4) Do gluten avoiders prioritise health related factors when making food choices.
5) What food perceptions do gluten avoiders have, and are they related to avoidance behaviours?
6) Are gluten avoiders higher on measures of experiential thinking styles than gluten consumers?
7) Do gluten avoiders report high levels of ambiguity tolerance?

7.3 Method

For a comprehensive overview of the method used to collect and analyse this data and the method used to categorise participants, see Chapter 5. A three-step process was used to categorise participants into two study groups; 1) gluten avoiders, representing those whom report avoiding gluten, and experiencing symptoms following gluten consumption, 2) gluten
consumers, representing the control group whom denied conscious attempts to avoid gluten. For pragmatic reasons, gluten avoiders will hereafter be referred to as GA, and gluten consumers as GC.

The current chapter will discuss the findings relating to the following measures:

7.4.1 – Qualitative themes

- Everyday Discrimination Scale – A scale that measures levels of perceived discrimination in a variety of everyday situations (EDS; 5.4.7).
- GP Satisfaction – A measure of GP satisfaction based on ratings for individual types of client-doctor rapport, including visit frequency (CARE; 5.4.5).
- Information consumption questionnaire – measuring usage rates and trustworthiness ratings of a variety of information sources (5.4.8).
- Food Choice Questionnaire – measuring the importance given to certain variables when engaging in food-choices (FCQ-R; 5.4.11).
- Food Neophobia Scale – measuring one’s aversion to new/novel foods (FNS; 5.4.12).

7.4.2 – Food perceptions and cognitive influences on choice

- Food perceptions questionnaire – measuring self-reported health and risk perceptions held by participants in regards to certain food types (5.4.5).
- Rational Experiential Inventory - measuring preferences for either experiential or rational thinking styles (REI-40, 5.4.10).
- Ambiguity Tolerance – measuring levels of discomfort associated with ambiguous situations/settings (MSTAT-1; 5.4.9).

7.4 Results

7.4.1 Qualitative themes

The qualitative study identified three themes that influenced food choice decisions for gluten avoiders: 1) psychosocial isolation, 2) food-consciousness and 3) self-sufficiency. A number of quantitative measures were included in the study survey in an attempt to capture these themes on a larger scale. These themes encompassed higher perceived discrimination from social networks, and dissatisfaction with GP interactions, as well as a high rate of online information consumption and a general preference for
natural/homemade food to alleviate fears of contamination. These qualitative findings were
explored quantitatively, and their findings are presented below.

7.4.1.1 Perceived levels of everyday discrimination

An independent samples t-test was conducted to compare perceived
discrimination levels amongst participants. There was a statistically significant difference in
perceptions of everyday discrimination for GA (M = 20.03, SD = 5.59) and GC (M = 18.43,
SD = 4.79), with GA reporting higher levels of perceived discrimination, t(1519) = -5.02, p <
.001, Cohen’s d = .31. Chi-square tests for independence were also used to examine
differences at the item level. A summary of these statistics can be viewed in Table 7-1.

Table 7-1
Chi-square tests for perceived everyday discrimination amongst participants

<table>
<thead>
<tr>
<th>Compared to other people you:</th>
<th>Sometimes/often</th>
<th></th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GC</td>
<td>GA</td>
<td></td>
</tr>
<tr>
<td>Are treated with less courtesy</td>
<td>41.0</td>
<td>50.7</td>
<td>12.11*</td>
</tr>
<tr>
<td>Are treated with less respect</td>
<td>40.2</td>
<td>44.5</td>
<td>4.16</td>
</tr>
<tr>
<td>Get poorer service at restaurants or stores</td>
<td>25.2</td>
<td>33.9</td>
<td>16.61*</td>
</tr>
<tr>
<td>People act as if they:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Think you are not smart</td>
<td>32.4</td>
<td>45.0</td>
<td>20.88**</td>
</tr>
<tr>
<td>Think you are dishonest</td>
<td>14.8</td>
<td>23.3</td>
<td>14.48*</td>
</tr>
<tr>
<td>Are afraid of you</td>
<td>19.8</td>
<td>34.3</td>
<td>31.92**</td>
</tr>
<tr>
<td>Are better than you</td>
<td>52.6</td>
<td>45.0</td>
<td>9.54*</td>
</tr>
<tr>
<td>You are called names or insulted</td>
<td>14.2</td>
<td>26.0</td>
<td>25.95**</td>
</tr>
<tr>
<td>You are threatened or harassed</td>
<td>11.0</td>
<td>22.7</td>
<td>36.00**</td>
</tr>
</tbody>
</table>

Note: * = p < .05, ** = p < .001, GC – Gluten consumers (n = 500), GA – Gluten avoiders (n = 740).

A higher proportion of GA reported experiencing harassment by others, being
insulted by others and felt that people thought they were not smart, or were afraid of them.
Although reaching statistical significance, these comparisons showed low effect sizes
throughout. Gluten avoiders also reported being more likely to receive poorer service in
restaurants and stores, as well as being treated with less courtesy and having people thinking
they were dishonest. Again, these effect sizes were small to very small, indicating that the
differences in these types of discrimination are minimal amongst participants. No significant
differences were found between the levels of respect shown to GA compared to GC. A Pearson’s correlation showed that although everyday discrimination scores were significantly correlated with gluten avoidance \( (r = .13, p < .001) \), the strength of this relationship was also very low. A correlation between everyday discrimination and the experience of gluten symptoms reflected a similar relationship \( (r = .15, p < .001) \).

7.4.1.2 Rapport with general practitioners

Chi-square tests for independence were used to observe differences in levels of GP rapport between participants (see Table 7-2). There was no significant difference found between the overall ratings participants gave their experiences with their doctors, \( X^2(6, N = 1240) = 10.58, p = .102 \). The majority of satisfaction ratings for the doctor-client relationship reflected this lack of differences amongst GC and GA. There were no significant differences found between participants in regards to doctors letting them tell their story, listening to them, showing care/compassion, explaining things clearly, and making plans of action with them. Only ratings of a doctor’s ability to make participants feel at ease and offer helpful advice reached significance, where GC rated their doctors’ abilities higher than GA. These findings, although small in effect size, indicate that GC typically rate their doctor experiences at least similarly to GA.

Table 7-2

<table>
<thead>
<tr>
<th>Rapport indicator</th>
<th>Rated positively (%)</th>
<th>( X^2 )</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td>Make you feel at ease</td>
<td>GC 59.8</td>
<td>GA 59.6</td>
<td>23.00*</td>
</tr>
<tr>
<td>Let you tell your story</td>
<td>GC 64.4</td>
<td>GA 61.3</td>
<td>7.15</td>
</tr>
<tr>
<td>Listen to you</td>
<td>GC 67.4</td>
<td>GA 64.0</td>
<td>2.44</td>
</tr>
<tr>
<td>Show care/compassion</td>
<td>GC 66.0</td>
<td>GA 63.0</td>
<td>6.30</td>
</tr>
<tr>
<td>Explain things clearly</td>
<td>GC 69.6</td>
<td>GA 61.9</td>
<td>10.78</td>
</tr>
<tr>
<td>Offer helpful advice</td>
<td>GC 70.4</td>
<td>GA 65.0</td>
<td>15.02*</td>
</tr>
<tr>
<td>Make a plan of action with you</td>
<td>GC 66.8</td>
<td>GA 62.5</td>
<td>4.24</td>
</tr>
<tr>
<td>Overall consultation experience</td>
<td>GC 70.6</td>
<td>GA 65.3</td>
<td>10.58</td>
</tr>
</tbody>
</table>

Note: * = \( p < .05 \), ** = \( p < .001 \), GC – Gluten consumers \( (n = 500) \), GA – Gluten avoiders \( (n = 740) \).

A Pearson’s correlation between gluten avoidance and overall GP ratings showed no significant relationship between the two variables \( (r = -.04, p = .15) \) suggesting that GP
satisfaction ratings are unlikely to be a major driver of gluten avoidance behaviours. Gluten avoiders reported visiting their doctors more frequently than GC, although Chi-square tests for independence revealed that this difference did not reach significance, $X^2(6, N = 1240) = 11.44, p = .08$.

A Pearson’s correlation revealed a statistically significant relationship between overall GP experience ratings given by participants and the frequency with which they visited them ($r = .31, p < .001$) which was moderate in size. Doctor visit frequencies were also significantly correlated with the avoidance of all foods except gluten, although the strength of these relationships was weak at best ($r = .06$ to .19). A correlation between visit frequency and food-symptoms showed statistically significant relationships for all foods. The strongest correlations observed were between visit frequency and eggs ($r = .20, p < .001$) or fats ($r = .18, p < .001$), suggesting that participants were more likely to report regular GP visits due to the experience of issues relating to eggs or fats than they were for issues relating to gluten. In the context of fats, this could simply be a reflection of concerns regarding weight management. Higher visit patterns related to egg symptoms are likely to be more thoroughly investigated on account of the unexpected nature in which these symptoms are experienced; in other words, there is no contention regarding the healthiness or natural quality of eggs, in contrast to gluten.

7.4.1.3 Information consumption patterns

Chi-square tests for independence were used to observe differences in the use of information sources between participants. These differences can be observed in Table 7-3. Gluten avoiders used significantly more newspaper/magazines, online articles, blogs, journal articles, and books to inform their food choice decisions than GC did. However, the effect sizes for these were only small. There was no significant difference found for the amount that participants used television, or the amount that they used government guidelines.

The most prominent difference between groups was found for the use of blogs, with more than half of all GA using blogs sometimes or more. A Pearson’s correlation revealed that gluten avoidance and blog only had a small positive correlation ($r = .19, p < .001$), despite being statistically significant. Usage of other information sources were also significantly correlated with gluten avoidance; however, these correlations were even smaller in size. Although a pattern of higher source use is apparent in GA, this does not appear to have a large effect on overall differences in behavior patterns between groups.
Chi-square tests for independence were also used to observe differences in the perceived trustworthiness of information sources between participants. These differences in source trust can be seen in Table 7-4. A higher proportion of GA typically rated each source as trustworthy, although these differences failed to reach significance for newspaper/magazines and government guidelines.

Table 7-4
*Chi-square tests for perceived trustworthiness of information sources as rated by participants*

<table>
<thead>
<tr>
<th>Information source</th>
<th>GC (%)</th>
<th>GA (%)</th>
<th>$X^2$</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newspaper/ Magazine</td>
<td>74.8</td>
<td>75.1</td>
<td>2.58</td>
<td>.046</td>
</tr>
<tr>
<td>Online Articles</td>
<td>69.6</td>
<td>76.1</td>
<td>18.84*</td>
<td>.123</td>
</tr>
<tr>
<td>Blogs</td>
<td>49.8</td>
<td>61.5</td>
<td>41.57**</td>
<td>.183</td>
</tr>
<tr>
<td>Journal Articles</td>
<td>75.0</td>
<td>82.7</td>
<td>18.93*</td>
<td>.124</td>
</tr>
<tr>
<td>Books</td>
<td>91.0</td>
<td>94.1</td>
<td>17.96*</td>
<td>.120</td>
</tr>
<tr>
<td>Television</td>
<td>78.8</td>
<td>77.2</td>
<td>9.61*</td>
<td>.088</td>
</tr>
<tr>
<td>Govt. Guidelines</td>
<td>83.8</td>
<td>83.9</td>
<td>4.10</td>
<td>.058</td>
</tr>
</tbody>
</table>

Note: * = $p < .05$, ** = $p < .001$, GC – Gluten consumers ($n = 500$), GA – Gluten avoiders ($n = 740$).
The effect sizes for these comparisons ranged from small to very small. A Pearson’s correlation between blog use and perceived trustworthiness confirmed that usage rates were strongly related to the amount that they were trusted ($r = .518$, $p < .001$). There was also a positive correlation found between trust in blogs and gluten avoidance ($r = .160$, $p < .001$); however, it was only small in size. Although higher levels of overall source trust are apparent in GA, this does not appear to have a large effect on overall behavior patterns between groups.

7.4.1.4 Food choice preferences

Food choice preferences were measured to assess the differences in priorities that determine food selection for participants. Independent samples t-tests were conducted to compare the scale scores amongst GA and GC on different variables of food choice preferences. There was a significant difference in total food choice scores for GC ($M = 116.35$, $SD = 20.71$) and GA ($M = 124.18$, $SD = 19.55$), with GA reporting higher levels of overall preoccupation with food choice preferences when making food-related decisions, $t(1238) = -6.76$, $p < .001$, Cohen’s $d = .39$. Overall, GA placed greater value on each food choice preference, indicating a higher rate of overall consideration when making everyday food choices. A statistically significant difference was found for the rank order of preferences for health, mood, natural content and weight control (see Table 7-5).

Table 7-5
Independent samples t-tests for food choice preferences amongst participants

<table>
<thead>
<tr>
<th>Food choice factor</th>
<th>Mean</th>
<th>$t$</th>
<th>Cohen’s $d$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health</td>
<td>20.76</td>
<td>22.60</td>
<td>-7.52**</td>
</tr>
<tr>
<td>Mood</td>
<td>18.33</td>
<td>19.81</td>
<td>-5.45**</td>
</tr>
<tr>
<td>Convenience</td>
<td>15.15</td>
<td>15.48</td>
<td>-1.64</td>
</tr>
<tr>
<td>Sensory Appeal</td>
<td>16.33</td>
<td>16.52</td>
<td>-1.16</td>
</tr>
<tr>
<td>Natural Content</td>
<td>14.07</td>
<td>16.46</td>
<td>-10.79**</td>
</tr>
<tr>
<td>Price</td>
<td>9.78</td>
<td>10.07</td>
<td>-1.92</td>
</tr>
<tr>
<td>Weight Control</td>
<td>13.66</td>
<td>14.88</td>
<td>-5.48**</td>
</tr>
<tr>
<td>Familiarity</td>
<td>8.27</td>
<td>8.35</td>
<td>-0.49</td>
</tr>
</tbody>
</table>

Note: ** = $p < .001$, GC – Gluten consumers ($n = 500$), GA – Gluten avoiders ($n = 740$).
The difference in preference for health, mood and weight control showed medium effect sizes, whilst the difference in preference for natural content showed a large effect size. Gluten avoiders were found to be less concerned with the convenience, sensory appeal, price, or the familiarity of foods. These findings suggest that GA preoccupied more specifically with the natural content of the foods they choose, and the way they impact health and weight. A Pearson’s correlation was used to observe the relationships between the major food preferences (natural content, health & weight control) and avoidance behaviours in participants, see Table 7-6. The food choice preferences reported by GA were all positively correlated with gluten avoidance, with natural content showing the strongest relationship with a moderate effect size. The strongest correlation between food choice preferences and non-gluten foods was found between natural content and preservatives avoidance, with a large effect size found. Health was also correlated more strongly to avoidance of preservatives than avoidance of gluten, with a moderate to large effect. Weight control was more strongly correlated with the avoidance of fats, with an effect size also approaching large.

Table 7-6

<table>
<thead>
<tr>
<th>Avoided food</th>
<th>Natural Content</th>
<th>Health</th>
<th>Weight Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gluten</td>
<td>.34</td>
<td>.27</td>
<td>.19</td>
</tr>
<tr>
<td>Dairy</td>
<td>.24</td>
<td>.14</td>
<td>.10</td>
</tr>
<tr>
<td>Eggs</td>
<td>.11</td>
<td>.02</td>
<td>.14</td>
</tr>
<tr>
<td>Carbohydrates</td>
<td>.24</td>
<td>.18</td>
<td>.32</td>
</tr>
<tr>
<td>Fats</td>
<td>.24</td>
<td>.25</td>
<td>.48</td>
</tr>
<tr>
<td>Preservatives</td>
<td>.58</td>
<td>.42</td>
<td>.25</td>
</tr>
</tbody>
</table>

Note: N = 1240. All correlations at or above $r = 0.10$ were statistically significant at the $p < .01$ level, and correlations above .13 were significant at the $p < .001$ level.

Chi-square tests for independence revealed there to be statistically significant difference between groups in their desire for food to contain no additives [$X^2(6, N = 1240) = 109.21, p > .001$, Cramer’s $V = .297$] and no artificial ingredients [$X^2(6, N = 1240) = 102.15, p > .001$, Cramer’s $V = .287$]. More than 25% of GA rated it as extremely important that their
food contained no additives, and more than 30% felt the same about their food containing no artificial ingredients. These rates were twice the amount found for GC. Thirty four percent of GA also considered it extremely important that their food contained natural ingredients, compared to only 18% of consumers.

7.4.1.5 Food neophobia

An independent samples t-test was used to assess the differences in aversion to new or novel foods amongst participants. There was a statistically significant difference in food neophobia score between GA ($M = 26.25, SD = 6.83$) and GC ($M = 25.08, SD = 7.80$), with GA reporting higher rates of neophobia, $t(1238) = -2.79$, $p < .01$, Cohen’s $d = .16$. However, the effect size found for this difference was small. Subsequent Chi-square tests for independence showed that these scores were influenced predominantly by responses to questions about foods with unknown content/ingredients. There were no significant differences found between groups for the questions that related to the consumption of ethnic foods specifically. The items that were endorsed by GA involved situations where a person with expected intolerances may become uncomfortable (If I don’t know what is in a food, I won’t try it) [$X^2(4, N = 1240) = 41.60, p > .001$, Cramer’s $V = .183$] or indicated dietary patterns that are to be expected of those with particular needs (I am very particular about the foods I will eat) [$X^2(4, N = 1240) = 56.16, p > .001$, Cramer’s $V = .213$]. These effect sizes were small, with the overall trends indicating that GA are not characterised by food neophobia per se, but simply express discomfort with situations in which the content of foods is unknown.

7.4.2 Food perceptions and cognitive influences on food choice

In addition to the qualitative study, further investigation of the literature has revealed a number of important cognitive influences that also remain uncharacterised within the GA space. Health and risk perceptions, thinking styles and tolerance to ambiguity are all thought to mediate consumption via cognitive processes that assist risk evaluations and food selection. This chapter aimed to characterise these cognitive influences on food-choice, the results of which are discussed below:

7.4.2.1 Health perceptions

A Chi-square test for independence was used to observe the difference in health perceptions held by participants about gluten. There was a statistically significant difference in the perceptions that were reported between groups, although the effect size for this
comparison was moderate in size; $X^2(4, N = 1240) = 127.39, p > .001$, Cramer’s $V = .289$. Gluten avoiders’ responses showed a positive skew towards the unhealthy end of the item-scale that was not mirrored by GC. A Pearson’s correlation revealed a negative relationship between perceived healthiness of gluten and gluten avoidance ($r = -.27, p < .001$) approaching a small effect size. This finding indicates that as participants’ health perceptions of gluten improved, the likelihood of them engaging in avoidance behaviors decreased.

Differences in participants’ health perceptions for non-gluten foods were also observed (see Table 7-7). In comparison to GC, GA consistently reported more negative health perceptions for each of the non-gluten foods. The most prominent difference between the health perceptions of the groups was found for dairy, with GA rating dairy as significantly less healthy than GC, with a small-medium effect size. The health perceptions that GA held about preservatives also reached a similar effect size, perceiving them to be significantly less healthy. The differences in health perceptions for eggs and fats were negligible, although still reaching statistical significance.

### Table 7-7
**Chi-square tests for health perceptions held by participants about non-gluten foods**

<table>
<thead>
<tr>
<th>Non-gluten food</th>
<th>Perceived as unhealthy$^\wedge$ (%)</th>
<th>$X^2$</th>
<th>Cramer’s $V$</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GC</td>
<td>GA</td>
<td></td>
</tr>
<tr>
<td>Dairy</td>
<td>4.4</td>
<td>14.8</td>
<td>50.63**</td>
</tr>
<tr>
<td>Eggs</td>
<td>3.4</td>
<td>6.9</td>
<td>16.67*</td>
</tr>
<tr>
<td>Carbohydrates</td>
<td>12.6</td>
<td>20.3</td>
<td>21.32**</td>
</tr>
<tr>
<td>Fats</td>
<td>35.2</td>
<td>34.1</td>
<td>10.68*</td>
</tr>
<tr>
<td>Preservatives</td>
<td>68.4</td>
<td>75.2</td>
<td>47.80**</td>
</tr>
</tbody>
</table>

Note: $^* = p < .05$, $^{**} = p < .001$, GC – Gluten consumers ($n = 500$), GA – Gluten avoiders ($n = 740$). $^\wedge$ - Percentage total based on responses to both ‘somewhat unhealthy’ and ‘not healthy at all’ options.

#### 7.4.2.2 Risk perceptions

A Chi-square test for independence was used to observe the difference in risk perceptions that were held by participants regarding gluten-consumption. There was a statistically significant difference in the perceptions that were reported between groups, with the majority of GA (74%) perceiving at least some risk associated with the consumption of
gluten; \(X^2(4, \, N = 1240) = 404.42, \, p > .001\), Cramer’s \(V = .571\). The same risk perceptions were only endorsed by 24% of gluten consumers. This difference between GA and GC was larger than the differences in health perceptions reported above. A Pearson’s correlation revealed a large and statistically significant relationship between perceived gluten risk and gluten avoidance (\(r = .61, \, p < .001\)), suggesting that it may be a significant factor in the decision to avoid gluten.

Further Chi-square analyses were completed to observe differences in the perceived risk that participants associated with the consumption of non-gluten foods. Gluten avoiders consistently reported more risk associated with the consumption of non-gluten foods than GC (see Table 7-8), with all comparisons reaching statistical significance to the \(p < .001\) level. The greatest difference between risk perceptions of GA and GC was reported for dairy products, where a medium to large effect size was found. There was also a medium effect size reported for the risk perceptions that participants held about carbohydrates. Gluten avoiders held risk perceptions about eggs and fats that were also significantly higher than GC, although these effect sizes were small to moderate.

Table 7-8

<table>
<thead>
<tr>
<th>Non-gluten food</th>
<th>Perceived as moderate/high risk (%)</th>
<th>(X^2)</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GC</td>
<td>GA</td>
<td></td>
</tr>
<tr>
<td>Dairy</td>
<td>3.8</td>
<td>18.5</td>
<td>229.82**</td>
</tr>
<tr>
<td>Eggs</td>
<td>2.6</td>
<td>13.6</td>
<td>83.90**</td>
</tr>
<tr>
<td>Carbohydrates</td>
<td>5.2</td>
<td>23.4</td>
<td>144.20**</td>
</tr>
<tr>
<td>Fats</td>
<td>26.6</td>
<td>35.4</td>
<td>32.15**</td>
</tr>
<tr>
<td>Preservatives</td>
<td>38.4</td>
<td>65.4</td>
<td>115.71**</td>
</tr>
</tbody>
</table>

Note: ** = \(p < .001\), GC – Gluten consumers (\(n = 500\)), GA – Gluten avoiders (\(n = 740\)).

Gluten avoiders reported significantly more risk associated with the consumption of preservatives than did GC. Although the effect reported for this difference was only medium in size, further inspection showed patterns of responding among GA that were more extreme than risk perceptions held for gluten. A total of 35% of GA rated the consumption of
preservatives as high risk, compared to only 9% of GA endorsing this option for gluten. Furthermore, GA endorsed this single risk rating more so than they did for the top two risk ratings for gluten combined (25%). Therefore, the risk perceptions that GA held about the consumption of preservatives were particularly clustered towards the extreme end, and should be considered as an additional characteristic feature of GA that has yet to be captured.

7.4.2.3 Correlations between perceptions, avoidance and symptomology

Pearson’s correlations were used to observe the relationships between the avoidance, symptoms, health perceptions and risk perceptions for all foods (see Table 7-9). By far the greatest relationship that was found for the avoidance of each food was the respective number of symptoms that were experienced following its own consumption. Gluten was the only food which also held numerous strong relationships with symptoms relating to other foods, indicating that it was determined by a varied combination of food related symptoms, not just those pertaining to the avoided trigger food. Gluten avoidance is therefore characterised by gluten symptoms, as well as those following the consumption of dairy, carbohydrates and preservatives.

There was a strong and significant positive relationship found between the perceived risk associated with a consumption of a food, and the extent to which it was avoided, with the exception of eggs, for which the correlation fell just below the threshold for a strong effect size. A persistent and significant positive relationship was therefore established between the perceived risks associated with a food’s consumption, and how much participants chose to avoid it. These risk perceptions also increased with increases in reported symptoms for that food type specifically for gluten, dairy, eggs and carbohydrates. Excluding gluten specific symptoms, risk perceptions for gluten were most strongly related to the number of symptoms reported following the consumption of carbohydrates and preservatives.

There were medium negative correlations found between health perceptions for all foods and subsequent avoidance behaviours towards said foods. Therefore, a persistent and significant negative relationship was also established between the perceived healthiness of a food, and how much it is avoided by participants – although these perceptions were not related to avoidance as strongly as the risk perceptions. Of note, the relationship
### Table 7-9

**Correlation matrix for frequency of food avoidance, symptoms, perceived healthiness and perceived risk associated with consumption of foods**

<table>
<thead>
<tr>
<th>Avoidance</th>
<th>Symptoms</th>
<th>Healthiness</th>
<th>Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>Gluten</td>
<td>- .52 .27 .44 .25 .42 .86 .51 .35 .53 .40 .55 - .27 - .13 .05 - .07 .09 - .08 .61 .40 .25 .36 .13 .32</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dairy</td>
<td>- .46 .38 .21 .33 .52 .77 .39 .42 .35 .43 - .09 - .31 - .09 .00 .11 .01 .39 .56 .29 .27 .09 .25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eggs</td>
<td>- .37 .28 .20 .29 .35 .70 .39 .36 .33 .08 - .08 - .20 .03 .00 .16 .25 .32 .47 .24 .19 .13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carbs</td>
<td>- .52 .40 .44 .31 .36 .66 .46 .47 - .08 - .02 .02 - .23 - .01 .00 .36 .27 .25 .51 .28 .26</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fats</td>
<td>- .44 .21 .15 .23 .35 .56 .30 .04 .09 .03 - .03 - .26 - .03 .17 .16 .19 .28 .51 .23</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pres</td>
<td>- .38 .31 .23 .39 .37 .61 - .10 - .04 .10 - .02 .06 - .28 .31 .23 .14 .24 .18 .52</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>Gluten</td>
<td>- .59 .38 .57 .42 .57 - .24 - .16 .03 - .08 .12 - .07 .62 .43 .25 .36 .12 .32</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dairy</td>
<td>- .44 .43 .38 .45 - .07 - .30 - .09 - .03 .08 .00 .39 .57 .31 .25 .08 .25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eggs</td>
<td>- .52 .44 .41 .08 - .09 - .22 - .02 .00 .17 .30 .34 .54 .30 .18 .13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carbs</td>
<td>- .63 .62 - .11 - .12 - .03 - .20 .01 .02 .45 .36 .34 .52 .25 .28</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fats</td>
<td>- .59 .00 - .03 - .06 - .08 - .18 .04 .31 .32 .33 .40 .43 .26</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pres</td>
<td>- .15 - .12 .00 - .10 .07 - .13 .47 .38 .28 .38 .19 .48</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
<td>1 2 3 4 5 6</td>
</tr>
<tr>
<td>Gluten</td>
<td>- .35 .13 .37 .18 .32 - .32 - .09 .05 - .14 .01 - .15</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dairy</td>
<td>- .58 .33 .12 .04 - .19 - .36 - .17 - .13 .01 - .03</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eggs</td>
<td>- .35 .28 - .13 .01 - .14 - .32 - .05 - .08 .14</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carbs</td>
<td>- .45 .20 - .10 - .04 - .03 - .35 - .14 - .06</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fats</td>
<td>- .22 .09 .10 - .02 - .10 - .43 .02</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pres</td>
<td>- .03 .11 .21 .05 - .03 .42</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: $N = 1240$, Correlation coefficients $r < .06$, $r < .08$, $r < .10$ are significant to the $p < .05$, $p < .01$ and $p < .001$ respectively. Carbs - carbohydrates, Pres – preservatives.
GLUTEN AVOIDANCE

between avoidance behaviours and all three additional variables (symptoms, health perceptions and risk perceptions) was found to be the strongest for gluten than for any other food type. Therefore, these variables are considered particularly important in the characterization of GA as a group.

7.4.2.4 **Cognitive thinking styles**

Independent samples t-tests were completed to assess the cognitive thinking styles of participants included in the study. There were trends observed whereby GA scored lower in measures of rational thinking styles, and higher in measures of experiential thinking styles than GC. However, none of these differences reached statistical significance.

Table 7-10
*Independent samples t-tests comparing scores on cognitive thinking subscales*

<table>
<thead>
<tr>
<th></th>
<th>GC</th>
<th>GA</th>
<th>t</th>
<th>Cohen’s d</th>
</tr>
</thead>
<tbody>
<tr>
<td>NFC</td>
<td>69.9</td>
<td>68.1</td>
<td>1.94</td>
<td>0.11</td>
</tr>
<tr>
<td>RA</td>
<td>35.8</td>
<td>35.1</td>
<td>1.97</td>
<td>0.11</td>
</tr>
<tr>
<td>RE</td>
<td>34.1</td>
<td>33.5</td>
<td>1.64</td>
<td>0.10</td>
</tr>
<tr>
<td>FI</td>
<td>66.7</td>
<td>67.8</td>
<td>-1.81</td>
<td>0.10</td>
</tr>
<tr>
<td>EA</td>
<td>34.1</td>
<td>34.7</td>
<td>-1.69</td>
<td>0.10</td>
</tr>
<tr>
<td>EE</td>
<td>32.6</td>
<td>33.1</td>
<td>-1.70</td>
<td>0.10</td>
</tr>
</tbody>
</table>

Note: *N = 1240, NFC Need for cognition, FI = Faith in intuition, RA = Rational ability, RE = Rational engagement, EA = Experiential ability, EE = Experiential engagement. GC – Gluten consumers (n = 500), GA – Gluten avoiders (n = 740).*

7.4.2.5 **Ambiguity tolerance**

An independent samples t-test was conducted to compare the levels of ambiguity tolerance between GA and GC. There was no statistically significant difference in the amount of ambiguity tolerance between GA and GC, demonstrating a lack of variability amongst groups. However, chi-square tests for independence revealed some small but significant item-level differences between GA and GC. Items that specifically related to ambiguity showed the greatest differences between groups. A higher proportion of GA reported that they didn’t tolerate ambiguous situations well \[X^2(6, 1238) = 37.22, p < .001, \text{Cramer’s } V = .173\] and try to avoid situations that are ambiguous \[X^2(6, 1238) = 20.83, p < .001, \text{Cramer’s } V = .130\], although these effect sizes were small. The possibility of these findings reflecting
discomfort/anxiety in GA due to the complications by gluten-related health risks was considered. A Pearson’s correlation between these items and avoidance revealed a small positive correlation for both ($r = .20$ and $r = .14$ respectively, $p < .001$).

Pearson’s correlations were also used to observe the relationship between the avoidance of foods measured and ambiguity tolerance. Only the avoidance of carbohydrates ($r = .06$, $p < .05$) and the avoidance of preservatives ($r = .09$, $p < .01$) reached significance. The other correlation coefficients were negligible in size. There were no significant associations between ambiguity tolerance and symptoms experienced after eating foods, or the perceived risk associated with foods. There was a significant positive correlation observed between ambiguity tolerance and the perceived healthiness of gluten ($r = .07$, $p < .01$), carbohydrates ($r = .09$, $p < .01$) and fats ($r = .11$, $p < .01$) although these were only very small. Therefore a person’s tolerance of ambiguous situations increased, so too did their health perceptions about gluten, carbohydrates and fats – all of which have been subject to significant scrutiny in the dietary literature. However, due to the sizes of these relationships, it can only be considered as supplementary motivation for gluten avoidance behaviours set amidst a complex set of food choice preferences and perceptions.

**7.5 Discussion**

The aim of this chapter was to develop an understanding of the cognitive characteristics that influence the decisions GA make relating to food choice, and the factors that influence these cognitive characteristics. There were a number of significant differences found in the cognitive characteristics that influence food choice for GA, including food choice preferences and food perceptions. There were also a number of significant differences found between GA and GC in the factors that may potentially influence these, including levels of perceived discrimination, and information consumption patterns. The food perceptions that were characteristic of GA were often similar amongst both gluten and non-gluten foods, indicating a lack of direct gluten-specific findings that support the previous discussion regarding non-specific symptomology and avoidance behaviours in Chapter 6. Paired together, these findings suggest that gluten avoidance may not be indicative of an isolated gluten experience – instead being mediated by a variety of poorly understood and complex interactions between both physiological and psychological variables.

Overall there was mixed support shown for the major qualitative themes identified in Chapter 3. The findings in this chapter suggest that the levels of everyday
discrimination reported by GA in the qualitative study appear to be reflected in the wider community of gluten avoiders. While the sources of this perceived discrimination can be determined, the data limits the ability to identify the context of these perceptions; in other words, do they experience this in the context of dietary choice specifically, or in regard to all social interactions. Although these measures are based on self-report items, findings indicate that GA believe other people hold negative opinions about them. Perceived harassment has been shown in other studies to have an adverse impact on wellbeing (Ambrey, Fleming, & Manning, 2014). We can therefore predict it is likely that the wellbeing of GA is being affected by these perceptions. The largest difference found between GA and GC was for perceived levels of threat/harassment by others. Some studies have shown that perceived threat levels can have a more adverse impact on life satisfaction than levels of actual threat in an environment (Ambrey et al., 2014). Fears relating to victimization have also been linked to overestimations of threat in neutral stimuli, and lead to higher expectations for future victimization (Jack & Egan, 2016). In the current chapter, discrimination levels showed small but significant relationships with both gluten avoidance and gluten symptoms, indicating that inflated levels of perceived discrimination are likely to be a characteristic of GA. This highlights the potential for GA to overestimate the threat of a neutral stimuli, interpreting certain acts as more threatening than controls.

When discrimination was considered within the context of doctor-patient experiences specifically, GA reported doctor-patient rapport levels that were equivalent to, if not greater than, those that were reported by GC. This finding is counter to the experiences discussed by GA in Chapter 3 and in previous papers, which identified the tendency for GA to discredit doctors in favour of self-diagnosis (Moore, 2014). Perceived discrimination may also lead to an attentional bias amongst GA that increases the amount that they monitor social cues relating to discrimination. There was no relationship found in a correlation between gluten avoidance and overall GP ratings, and GA were found to visit their GPs more often, as opposed to less. Surveys in the US have identified similar patterns of increased visitation to health practitioners in those categorized with stigmatized illnesses (Berger, Wagner, & Baker, 2005), which reflects the higher levels of unresolved physiological issues that they typically report. In addition, the definition of ‘doctor’ was not supplied to participants and could have been misconstrued to include alternative health professionals. The findings in Chapter 3 suggest that these professionals were more open and accommodating for symptoms of this
nature, and could cancel out any dissatisfaction trends that may have otherwise been captured within the results.

Information consumption patterns of GA were shown to be higher for almost all information sources, not just those that were based online. The largest difference between information source use amongst participants was found for blogs specifically, although this effect was small to moderate in size. Blog usage rates were also significantly correlated with both gluten avoidance and dairy-avoidance, indicating their likely role in the decision to follow diets that avoid these foods. These findings support previous studies that found GA consume large quantities of online information (Metchikoff, 2014). Gluten-avoiders were also characterized by higher levels of overall trust for most information sources, with the largest difference in trust reported for blogs. Although higher levels of overall source usage and trust are apparent in GA, they appear to be particularly characterized by how much they use blogs, and the faith they place in blogs as a type of information source.

Fears about food-related hazards have been connected with consumer trust levels, and the types of sources they collect health-risk information from (Liu, Pieniak, & Verbeke, 2014). The interaction between food and health information online has added to this phenomenon, driving increased confidence levels for self-diagnosis and management through dietary change (Meijboom, 2007). It is unknown whether the increased information consumption reported by GA is linked with higher interest levels, higher education levels, or is instead indicative of an unfulfilled desire to reconcile ambiguous food and health information. Since GA experience higher rates of emotional dysregulation (such as somatization – see Chapter 6), and emotionally vulnerable people have been shown to interpret ambiguous information as more threatening (Beck, 1979; Eubank et al., 2002; C. MacLeod & Cohen, 1993), it is likely that these increased consumption patterns serve to perpetuate heightened food concerns rather than abate them. As such, the tendency for GA to over-consume health data may complicate their ability to make clear assessments when the information they are accessing is particularly ambiguous – as is the case with gluten and its related effects. Gluten avoiders also reported more overall trust in sources than GC, which may serve to further increase their vulnerability to mixed gluten messages (Nash & Slutzky, 2014).

An analysis of food choice preferences indicated that GA prioritise all factors when they approach their food selection, with the largest differences between groups found
for preference of natural content, health and weight control. These findings support the theme of food consciousness reported in Chapter 3, with GA scoring higher in measures of overall preoccupation with factors relating to food choice. The most important factors reported by GA was that their food was free from additives and artificial ingredients. In the context of gluten avoidance, the prioritization of health and natural content consequently indicates that they devalue or would even look to avoid foods that are perceived as unnatural/unhealthy. Research indicates that consumers are much more accepting of natural as opposed to artificial food additives, and that this difference alone can influence the number of modern health worries associated with consuming certain foods (Devcich, Pedersen, & Petrie, 2007). These worries also correlate with the number of subjective health complaints that are reported, and how often people access health care services (Kaptein et al., 2005), which is similar to the behaviours observed in GA. These findings support the contention that conscious gluten avoidance is impacted by a complex set of interacting cognitive processes.

Gluten avoiders were found to perceive gluten as significantly more unhealthy, and associate its consumption with significantly more risk than GC. These two factors were also correlated with the frequency of gluten avoidance. Perceptions such as these have been recognized as key influences in consumer decision-making models and often contribute to the formation of product expectations (Grunert, 2005), adding to previous work linking the perceived health of food products and rates of consumption (Provencher et al., 2009). The food preferences discussed above also imply that these perceptions will hold greater weight for GA than they would for GC due to their particular focus on health and natural content. Previous studies have identified similar health perceptions in the consumers of organic foods (Zanoli & Naspetti, 2002), who are more inclined to manage illness through the regulation of their diets (Squires, Juric, & Bettina Cornwell, 2001). The risk that GA associated with gluten was even more pronounced than their health concerns, and was consistent with the fears that were captured in Chapter 3. The fact that more than 70% of GA are perceiving some risk associated with the consumption of gluten is likely fueling gluten-specific distress and perpetuating the attentional bias towards its effects (Crombez, Eccleston, Baeyens, & Eelen, 1998) which promotes future avoidance patterns. Although they are characterized by non-specific food avoidance patterns, this may explain why GA tend to focus on gluten as the main trigger when managing their perceived dietary needs.

Gluten avoiders also regarded specific non-gluten foods as significantly less healthy, and perceived significantly more risk associated with their consumption than did GC.
These non-gluten specific perceptions mirror the findings in Chapter 6, and indicate that GA possess a more generalized negative attitude across food products, which is correlated with their generalized patterns of avoidance. The levels of risk that GA associated with preservatives was particularly strong, even more so than their fears about gluten. This negative bias towards preservatives may demonstrate the workings of naive theory (Gelman, 2006), where unnatural ingredients are considered the most synthetic, and therefore most harmful by proxy. It may also indicate the presence of an underlying personality profile, which amplifies their food concerns on a more general level, as individual differences can influence the weight that is given to determinants of food choice such as natural content (Ronteltap, Sijtsema, Dagevos, & de Winter, 2012). It is also important to consider that, although it was not identified as a major theme in Chapter 3, gluten avoiders spoke about gluten as if it were an unnatural additive that is incorporated into trigger foods by large profit-focused corporations. The findings in this chapter mirror these sentiments, suggesting that GA hold inflated fears about its consumption.

In combination with higher somatosensory awareness, the above perceptions may amplify the anxiety associated with food choice, food consumption, and food symptoms. These effects have been captured within populations of similar contested illnesses, where the amplification of benign bodily sensations prolongs the experience of medically unexplained physical symptoms (Barsky, Ahern, Bailey, & Delamater, 1996; A. K. MacLeod, Haynes, & Sensky, 1998). Those who suffer from higher levels of gastrointestinal-specific anxiety (GSA) are predisposed to experience inflated fear perceptions following the experience of visceral sensations (Labus et al., 2007) like the symptoms which are reported by GA. These anxious thoughts are fuelled by fears of gastrointestinal sensations, and the context in which they believe those symptoms are likely to occur such as risk of illness. In patients with irritable bowel syndrome (IBS), GSA was found to be the strongest predictor of gastrointestinal symptom severity, and played a big role in the mental quality of life associated with the diagnosis (Jerndal et al., 2010). Considering the shared experiences reported by IBS and those with gluten sensitivity, it is possible that similar cognitive processes affect GA. If this is the case, ongoing psychological stress about the experience of symptoms after the consumption of gluten may be driving somatisation (Gwee et al., 1999) in an unending cycle which is only subdued by conscious avoidance efforts that mimic nocebo effects.

Although there were no statistically significant differences in the cognitive styles reported by GA and GC, trends were observed which indicated that in certain circumstances
they may prefer adopting an experiential approach to information processing. This cognitive style is far more prone to the use of heuristics when experiencing a higher cognitive load (Epstein et al., 1996), including times of increased stress or fear. Measures of experiential thinking have also been shown to significantly correlate with both positive and negative expressivity (Bjorklund, 2008) – traits that relate to one’s behavioural expression of emotions. This is supported by the somatisation levels reported by GA in Chapter 6, whereby the likelihood of interpreting emotional expressions as physiological ones complicated their ability to distinguish between gluten-specific and non-gluten symptomology. The opposing cognitive style, rationality, also holds a strong inverse relationship with neuroticism (Pacini & Epstein, 1999), supporting the likely role that emotions play in the maintenance of gluten avoidance behaviours. These food-related concerns are unlikely to be attributed to an aversion to new/novel foods, which was ruled out through the measurements of neophobia in both groups.

Individual item analyses revealed that GA would be experiencing more discomfort in situations in which they are unaware of, or cannot control, the content of their foods – an issue that was regularly discussed in earlier qualitative interviews. Gluten avoiders were also more likely to report being uncomfortable in ambiguous situations, although there were no significant differences observed in overall ambiguity tolerance scores between groups. People with high avoidance motivation have been shown to perceive food risks as scarier than those without this predisposition (Leikas et al., 2007), which is supported by these findings. Gluten avoiders’ risk perceptions may therefore be important factors to consider when determining motivations behind gluten-specific avoidance. Although the effect sizes reported for ambiguity tolerance were small, when paired with these considerations, they provide insight into possible mechanisms for the threat that gluten avoiders associate with gluten.

One of the factors that needs to be considered with the above findings is that the questionnaire used relies on the capacity of the participant to make an objective judgement regarding their discrimination levels in relation to those of other people. The answers provided therefore inadvertently capture any pre-existing perspective bias that may occur as a result of ongoing social issues relating to diet choice. The ability of people to accurately self-report their perceptions has always been a contentious issue (Chan, 2009). Therefore, the findings in the current study cannot be considered a complete and wholly accurate representation of sub-conscious thoughts and motivators for choice. What it does provide
however, is a clear picture of the conscious thoughts held by GA, and how these relate to their avoidance behaviours. Due to the quantitative nature of the design, some of the findings that were inconsistent with previous predictions could not be further clarified/understood by the researcher, as would be possible in a qualitative setting. Considering the scope of the current study, a compromise was made between practical application and quantification, on the basis of previous qualitative data collected. This was also worked into the structure of the chosen methodology, with the focus being on a sequential qualitative-quantitative design so that initial qualitative findings could inform the development of a broader quantitative study. The potential of utilizing interview methods in future studies remains a possibility for added depth of analysis.

7.6 Conclusion

The findings in this chapter clarify the important role that perceptions and beliefs play in the choice to avoid gluten. Gluten avoiders were found to report higher perceived levels of discrimination, use and trust information sources more readily, hold more negative perceptions towards both gluten and non-gluten foods alike, and prioritise foods that are healthy/natural. Therefore, their overall perceptive and cognitive characteristics were markedly different from those observed to be held by GC. Strong relationships between avoidance and risk perceptions suggest that these cognitive influences are likely to play a key role in the maintenance of avoidance behaviours. In the case of gluten specifically, ambiguous messages may exacerbate fears relating to its consumption, and would be most easily addressed by avoidance of the trigger. It is also likely that the consumption of gluten is thus linked to a stress response in GA, who prioritise health and food risk when making diet choices.

Considering GA have higher levels of somatisation, it is possible that physiological responses to gluten are higher than in others due to this added stress, as informed by negative gluten messages and perceptions. However, higher levels of non-gluten symptoms and perceptions indicate that the gluten avoidance may not be indicative of an isolated gluten experience – instead being mediated by a variety of poorly understood and complex interactions between both physiological and psychological variables. Further research is needed to clarify if this is supported through the additional measurement of individual differences such as stimulus amplification, arousability and personality features that may provide further clarity in the characterization of this particular behaviour.
Chapter 8: The role of individual differences: A consideration of sensitivity dysfunction

8.1 Introduction

Chapter 7 established that perceptions about health and risk play an important role in the decision to avoid gluten. The findings indicated that as a group, gluten avoiders have persistent negative perceptions about health and risk that are generalised across both gluten and non-gluten foods. These non-specific effects support the findings from Chapter 6, and further indicate the likely impact that physiology has on perceived symptoms, and the stress that follows as a result. Together, these results suggest that there is a significant difference between gluten avoiders and controls (gluten consumers), expressed through higher rates of symptomology, somatisation, and perceptions that perpetuate avoidance behaviours. Chapter 8 will explore the potential factors that contribute to this substantial difference between groups, observing the individual differences that characterise this phenomenon, including underlying sensitivity issues and a physiological predisposition for arousal.

8.2 Background

Individual differences in arousal levels was first conceptualised by (Eysenck, 1967) as an expression along the extraversion-introversion spectrum, where those higher in extraversion were hypothesised to have lower levels of arousability, justifying their desire to seek out more intense and frequent stimulation from the environment. This aspect of self-regulation linked in closely with measures of neuroticism, and was further defined in 1970 by Jeffrey Gray. Gray explained these arousability differences through measures of impulsivity and anxiety, postulating specific links between anxiety and sensitivity to punishment/negative affect (1970). Studies examining individual differences through the use of electroencephalograph have supported the conceptual links between psychological arousability (i.e. anxiety) and physiological arousability (Stenberg, 1992). Results indicate that trait anxiety is associated with emotionality, with anxious participants reacting more strongly in a negative emotional condition than non-anxious participants when the same stimulus is applied. A study in Germany revealed that the probability of experiencing an anxiety disorder was significantly greater in patients with CD (16.8%) and inflammatory bowel disease (14.0%) compared with the general population (5.7%, Häuser, Janke, Klump, Gregor, & Hinz, 2010). They found levels of anxiety in CD patients to be specifically predicted by gender, with
female coeliacs demonstrating the highest risk of an anxiety disorder. This study measured levels of anxiety and depression with the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), but found there to be no comparable difference in the prevalence of depressive disorders between patients. These findings indicate the likely connection between issues in the gut and symptoms that are linked with anxiety disorders.

An extension of Eysenck’s original conceptualisation, Gray’s model of personality considers sensitivity to reward and punishment as based on one’s levels of extraversion and neuroticism respectively. Extraversion is considered to be linked with one’s predisposition to positive affect, whilst neuroticism correlates strongly with sensitivity to negative affect (Larsen & Ketelaar, 1989). Therefore, if both personality dimensions provide insight into affect regulation - then both should be included in a holistic model that considers overall sensitivity. Instead of a clear segregation for arousal based on patterns within the central nervous system, this could suggest that those high on extraversion and neuroticism possess a unique trait profile allowing them to be more reactive to all moods. This notion was supported in a more recent fMRI study, indicating that even in healthy women, extraversion was correlated with the brain activity linked to positive stimuli, and neuroticism showed the same effects for negative stimuli (Canli et al., 2001). These findings were related to patterns of activity within the prefrontal cortex, anterior cingulate, insula and amygdala, which have all been associated with the processing of emotion. The study focused solely on women to eliminate the gender differences in reported intensity of emotional experiences. They also concluded that the relationship between extraversion and cingulate activation to positive stimuli might be an indication of attentional bias, a theory that has been posited in earlier studies.

The role that psychological factors play within inflammatory-type mechanisms continues to be explored within the literature today. A study of 75 patients with chronic bowel symptoms found that the likelihood of developing irritable bowel syndrome (IBS) following acute gastroenteritis significantly increases when patients reported high levels of anxiety, somatisation and neuroticism (Gwee et al., 1996). The comparison between those who developed IBS after their initial illnesses and those that did not assisted in the identification of psychological factors in the development of IBS. Ongoing psychological stress has also been linked with longer inflammatory responses in a similar study by (Gwee et al., 1999). Patients with higher levels of anxiety continued to show inflammation in a three month follow up despite having similar levels of biological triggers as those patients whose
responses reverted back to baseline. Patients who developed IBS also scored significantly higher on bodily preoccupation subscales of a hypochondriasis measure. Attention processes such as these have been linked to the amplification of sensory inputs. For example, it has been shown that attention paid to the stomach can significantly influence the perceptions of gastric distension (Accarino, Azpiroz, & Malagelada, 1997). Even when controlling for the influence of anxiety, somatosensory amplification scores were shown to positively correlate with modern health worries. Therefore, the capacity to accurately evaluate and regulate somatic responses is dependent on the interaction between these important physiological and psychological factors. Qualitative evidence collected from gluten avoiders in Chapter 3 showed high levels of symptom monitoring due to fears of contamination, which were supported in the generalised avoidance and somatisation levels that were captured in later chapters. Persistent negative attitudes towards food risk and health may further enhance these effects in gluten avoiders, leading to maximal amplification of somatosensory experiences.

An increased sensitivity to stimuli has already been identified in those with chronic pain, fibromyalgia, IBS and somatisation, and is hypothesised as a homogenous set of processes in the central nervous system that amplifies sensations in situations lacking clear triggers, such as pain (Phillips & Clauw, 2011). Research examining sensitivity in patients with rheumatic disorder revealed that even when specific causes for pain are identified and accounted for, the levels of pain and disability are still strongly correlated with somatisation (Wolfe & Rasker, 2006). Similar findings have been replicated in studies examining patients with fibromyalgia, where a predisposition for overall body tenderness was explained by a combination of psychological and/or neurobiological influences that interfere with sensory inputs (Granges & Littlejohn, 1993). These influences can cause decreased thresholds to a range of aversive stimuli such as high/low temperatures, and loud auditory tones, a finding that is found within a number of conditions that have cross-over symptoms (Phillips & Clauw, 2011). Research considers these conditions to share underlying non-specific sensory issues that are indicative of a more centralised issue with sensitivity – termed Central Sensitivity Syndromes by Yunus (2008). These syndromes align with contested illnesses, which all experience similar patterns of medically undiagnosed physiological symptoms (MUPS) as those reported by gluten avoiders. The concept of an underlying sensitivity syndrome is supported by the increased rates of sensitivity to varied types of stimuli. Some evidence suggests that the augmented processing of stimuli discussed above may be connected to differences in the neurochemicals linked with “volume control” within the body.
It is possible that similar sensory amplification is occurring within the population of gluten avoiders, due to the commonality between their reported experiences, and those people suffering other forms of contested illnesses. The generalised nature of the hypothesised sensory amplification would likely influence the experience of all symptoms that recruit an element of sensory perception, and not just those that are related to the gut specifically. Although gluten avoiders typically report issues with the gut on a qualitative level, the findings in Chapter 6 demonstrated that these sensations are much broader, including reactions to non-gluten foods, as well as symptoms unrelated to food consumption entirely.

Research on gluten avoiders is yet to define the role that arousal and amplification play in the perception and reporting of symptoms. These variables, paired with their relevant personality constructs, allows for the indirect observation of sensitivity levels within gluten avoiders without invasive or expensive procedures. Experiencing similar symptoms to the aforementioned sensitivity syndromes, it could indicate the need for both psychological and physiological treatments to be used when working with those who are consciously avoiding gluten without a medical diagnosis that requires them to so do. This chapter therefore aims to clarify the links between autonomic arousability, stimulus amplification and gluten avoidance through the observations of individual differences and related personality variables. Previous chapters have identified that gluten avoiders report increased levels of somatisation, food-avoidance and non-specific food symptoms, and are also influenced by a range of cognitive factors that are likely to inflate fears relating to the consumption of gluten. The following research questions were posed:

1) Do gluten avoiders score higher on self-report measures of autonomic arousability?
2) Do gluten avoiders score higher on measures of stimulus amplification?
3) Do gluten avoiders score higher on the measures of neuroticism?

8.3 Method

For a comprehensive overview of the method used to collect and analyse this data and the method used to categorise participants, see Chapter 5. A three-step process was used to categorise participants into two study groups; 1) gluten avoiders, representing those who report avoiding gluten, and experiencing symptoms following gluten consumption, 2) gluten consumers, representing the control group who denied conscious attempts to avoid gluten.
For pragmatic reasons, gluten avoiders will hereafter be referred to as GA, and gluten consumers as GC.

The current chapter will discuss the findings relating to the following measures:

- **Autonomic arousability**: This scale is used to measure self-reported rates of physiological arousability, and has been shown to be correlated with electrodermal activity, (APS, 5.4.15).
- **Stimulus amplification**: correlated with somatisation and hypochondriasis, this scale measures one’s tendency to amplify a range of symptoms (SASS, 5.4.12).
- **Personality scores**: measurements of the five major personality traits (extraversion, agreeableness, conscientiousness, neuroticism and openness) are provided as aggregate scale scores that reflect participant responses to self-report items (BIG5, 5.4.14).

### 8.4 Results

#### 8.4.1 Autonomic arousability

An independent samples t-test was conducted to compare the levels of autonomic arousability between participants. There was a statistically significant difference in levels of arousability for GA ($M = 35.66$, $SD = 7.23$) and GC ($M = 32.61$, $SD = 7.28$), with GA reporting higher levels overall; $t(1238) = 7.26$, $p < .001$, Cohen’s $d = .42$. The effect size for this test was moderate-large in size. Chi-square tests for independence were also used to observe differences between GA and GC on individual arousability items, and can be viewed below in Table 8-1. Gluten avoiders scored higher on every item, with self-reported ratings of calmness being the only item not reaching significance between groups. All the significant chi-square statistics had an effect that was small to moderate in size.

The most prominent difference between groups was found for responses endorsing a tendency to become emotional after sudden changes, and remaining excited/moved after seeing a good movie. These effect sizes were small. Similarly small sized effects were also found for differences in the ability to become easily excitable and easily startled. Despite consistently higher endorsement of each arousability symptom, GA reported being calm at similar rates to those of GC, which is the only item where no significant difference was found between groups. These findings highlight some
inconsistencies between the way GA report their experiences. It could also allude to the impact of social desirability bias, particularly affecting questions that have high face validity.

Table 8-1
*Chi-square tests for autonomic symptom frequency amongst participants*

<table>
<thead>
<tr>
<th>Symptom of autonomic arousal</th>
<th>Frequently/almost always (%)</th>
<th>( X^2 )</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GC</td>
<td>GA</td>
<td></td>
</tr>
<tr>
<td>Calm</td>
<td>5.6</td>
<td>5.9</td>
<td>5.50</td>
</tr>
<tr>
<td>Easily flustered</td>
<td>21.6</td>
<td>29.6</td>
<td>25.59**</td>
</tr>
<tr>
<td>Emotional after sudden changes</td>
<td>16.0</td>
<td>26.7</td>
<td>39.60**</td>
</tr>
<tr>
<td>Strong emotions post-trigger</td>
<td>23.6</td>
<td>34.0</td>
<td>21.44**</td>
</tr>
<tr>
<td>Restless/fidgety</td>
<td>15.8</td>
<td>21.4</td>
<td>20.04**</td>
</tr>
<tr>
<td>Mood influenced by new places</td>
<td>20.8</td>
<td>30.3</td>
<td>17.26*</td>
</tr>
<tr>
<td>Easily excitable</td>
<td>18.4</td>
<td>30.1</td>
<td>38.64**</td>
</tr>
<tr>
<td>Palpitations remain post-trigger</td>
<td>26.0</td>
<td>32.4</td>
<td>19.93*</td>
</tr>
<tr>
<td>Emotionally moved by simple things</td>
<td>24.8</td>
<td>36.9</td>
<td>35.99**</td>
</tr>
<tr>
<td>Easily startled</td>
<td>16.2</td>
<td>27.0</td>
<td>36.40**</td>
</tr>
<tr>
<td>Easily frustrated</td>
<td>18.8</td>
<td>30.9</td>
<td>31.30**</td>
</tr>
<tr>
<td>Remain excited/moved after good movie</td>
<td>17.0</td>
<td>27.2</td>
<td>39.53**</td>
</tr>
</tbody>
</table>

Note: * = *\( p < .01 \), ** = *\( p < .001 \), GC – Gluten consumers (\( n = 500 \)), GA – Gluten avoiders (\( n = 740 \)).

Pearson’s correlation coefficients were used to observe the relationships between mean arousability scale scores and other measures of interest discussed in previous chapters. Arousability was positively correlated with the aggregate scores\(^8\) for food-avoidance (\( r = .25, p < .001 \)), reported food-symptoms (\( r = .31, p < .001 \)), and perceived risk (\( r = .25, p < .001 \)), reaching significance on all occasions with small-moderate effect sizes. There was no relationship found between arousability and the health perceptions relating to foods. Arousability was also shown to have a statistically significant relationship with somatisation (\( r = .47, p < .001 \)), overall food pre-occupation (FCQ-Total, \( r = .38, p < .001 \)) and ambiguity tolerance (\( r = -.32, p < .001 \)).

\(^8\) Aggregate scores were calculated by adding participant responses for dairy, egg, carbohydrates, fats and preservatives, and dividing this total by five. This was considered a simple way to achieve an ‘overall’ non-gluten food measure for avoidance, symptoms and perceptions.
A gender comparison was completed across participants to establish whether the above differences found were related to the higher proportion of females occurring within the GA group. Gender has already been established as a factor impacting level of arousability in similar Australian samples (Saliba, Henderson, Deane, & Mahar, 1998). An independent samples t-test revealed that there was a significant difference found between males ($M = 33.5, SD = 7.7$) and females ($M = 35.0, SD = 7.2$) on arousability scores, with females demonstrating significantly higher means; $t(1238) = -3.49, p < .01$, Cohen’s $d = .20$. The female means were comparable with previously reported Australian APS means (see Saliba et al., 1998), although male means were found to be slightly higher. These differences were observed in the context of an interaction between gender and avoidance groups on arousability predisposition. A two-way ANOVA confirmed that there was a significant interaction between the effects of gender and avoidance on arousability scores; $F(1, 1240) = 8.59, p < .01$, with a partial eta squared of .007. However, a review of the means shows that the difference in arousability scores between male and female gluten avoiders was minimal (see Table 8-2) compared to gender differences observed in the control group.

<table>
<thead>
<tr>
<th>Arousability</th>
<th>GC</th>
<th>GA</th>
</tr>
</thead>
<tbody>
<tr>
<td>$M$</td>
<td>$SD$</td>
<td>$M$</td>
</tr>
<tr>
<td>Male</td>
<td>31.1</td>
<td>7.1</td>
</tr>
<tr>
<td>Female</td>
<td>33.8</td>
<td>7.3</td>
</tr>
</tbody>
</table>

Note: GC – Gluten consumers ($n = 500$), GA – Gluten avoiders ($n = 740$).

The main effects for gender on arousability [$F(1, 1240) = 10.4, p < .01$] were smaller than those observed between avoidance and arousability [$F(1, 1240) = 55.3, p < .001$]. Only 0.8% of variance in arousability was due to the independent effects of gender, whereas 4.3% of the variance in arousability scores was due to the effects of avoidance. Mean arousability scores for male GA closely replicated the mean arousability scores found for female GA. Therefore the disproportionate number of females in the gluten avoider group is unlikely to be a major confounding variable for the significant differences found between GA and GC on measures of arousability as reported above.
8.4.2 Stimulus amplification

Independent samples t-tests were conducted to compare levels of stimulus amplification reported by participants (see Table 8-3). There was a large and significant difference in amplification between GC and GA, with the latter group reporting higher levels of both internal and external symptom amplification, thus resulting in higher total stimulus amplification scores. The effect sizes for all of these tests were moderate-large in size. These findings indicate that GA have a greater tendency to amplify their symptoms, particularly those that are experienced internally. Pearson’s correlations between the internal stimulus amplification subscale and gluten-specific symptoms identified a moderate positive relationship for all symptoms ($r = .30 - .36, p < .001$). It was also associated more strongly with somatic symptoms ($r = .54, p < .001$) than the external stimulus amplification subscale was ($r = .41, p < .001$).

Table 8-3
Independent samples t-tests between arousability and avoidance behaviours for participants

<table>
<thead>
<tr>
<th></th>
<th>GC</th>
<th>GA</th>
<th>t</th>
<th>Cohen’s d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal SA</td>
<td>$15.84$</td>
<td>$17.72$</td>
<td>$8.14^{**}$</td>
<td>$0.47$</td>
</tr>
<tr>
<td>External SA</td>
<td>$21.13$</td>
<td>$24.46$</td>
<td>$9.62^{**}$</td>
<td>$0.56$</td>
</tr>
<tr>
<td>Total SA</td>
<td>$36.97$</td>
<td>$42.17$</td>
<td>$10.02^{**}$</td>
<td>$0.58$</td>
</tr>
</tbody>
</table>

Note: ** = $p < .001$, GC – Gluten consumers ($n = 500$), GA – Gluten avoiders ($n = 740$), SA – Stimulus amplification.

Pearson’s correlations were also used to explore the relationship between the stimulus amplification and measures of food avoidance/symptoms/perceptions (see Table 8-4). Stimulus amplification was related to the avoidance of non-gluten foods more strongly than it was gluten specifically. It was also more likely to be associated with symptoms following the consumption of non-gluten foods, showing a moderate-large effect size. On all occasions, symptoms and avoidance were more correlated with the internal rather than the external stimulus amplification subscale, indicating its likely role in the experience of food-symptoms, and the avoidance that is consciously used to manage these symptoms. Stimulus amplification was completed unrelated to health perceptions. Risk perceptions showed a moderate positive relationship in regards to both gluten and non-gluten foods.
Table 8-4
Correlations between stimulus amplification, avoidance, symptoms, and food perceptions for both gluten and non-gluten foods

<table>
<thead>
<tr>
<th></th>
<th>TSA</th>
<th>ISA</th>
<th>ESA</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gluten</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoidance</td>
<td>.30</td>
<td>.29</td>
<td>.24</td>
</tr>
<tr>
<td>Symptoms</td>
<td>.32</td>
<td>.32</td>
<td>.26</td>
</tr>
<tr>
<td>Healthiness</td>
<td>-.00</td>
<td>-.00</td>
<td>-.00</td>
</tr>
<tr>
<td>Risk</td>
<td>.32</td>
<td>.33</td>
<td>.24</td>
</tr>
<tr>
<td><strong>Non-gluten foods</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoidance</td>
<td>.34</td>
<td>.32</td>
<td>.30</td>
</tr>
<tr>
<td>Symptoms</td>
<td>.43</td>
<td>.41</td>
<td>.35</td>
</tr>
<tr>
<td>Healthiness</td>
<td>-.01</td>
<td>-.01</td>
<td>-.00</td>
</tr>
<tr>
<td>Risk</td>
<td>.33</td>
<td>.31</td>
<td>.28</td>
</tr>
</tbody>
</table>

Note: All correlation coefficients above are significant to the $p < .001$ level. $N = 1240$ for all correlations. TSA – Total stimulus amplification, ISA – Internal stimulus amplification, ESA – External stimulus amplification.

Chi-square tests for independence were used to observe differences between GA and GC on individual stimulus amplification items, and can be viewed below in Table 8-5. The largest difference found between groups was in responses to participants’ bruises being present for extended periods of time. This could reflect higher rates of body monitoring behaviours in GA, showing a small to medium effect size for the comparison. Similar sized effects were also found for participants’ sensitivity to loud noises and their tendency to attend to hunger contractions. Gluten avoiders reported lower pain thresholds than GC, although this comparison revealed a small effect size.

A Pearson’s correlation on amplification items showed that sensitivity to minor bites/splinters was the item that held the strongest association with food symptoms ($r = .34, p < .001$), well beyond any other item-association calculated. The degree to which that participants endorsed increased bodily awareness was most strongly associated with food avoidance ($r = .27, p < .001$). However, both of these correlations were moderate in size.
### Table 8-5
*Chi-square tests for amplification of certain stimuli amongst participants*

<table>
<thead>
<tr>
<th></th>
<th>Agreed to experiencing (%)</th>
<th>(X^2)</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contagious coughing</td>
<td>GC 8.8 GA 15.3</td>
<td>27.68**</td>
<td>.149</td>
</tr>
<tr>
<td>Intolerance to air pollutants</td>
<td>GC 65.8 GA 73.7</td>
<td>22.15*</td>
<td>.134</td>
</tr>
<tr>
<td>Increased body awareness</td>
<td>GC 54.8 GA 68.0</td>
<td>35.73**</td>
<td>.170</td>
</tr>
<tr>
<td>Bruises present for extended periods</td>
<td>GC 28.0 GA 45.5</td>
<td>69.22**</td>
<td>.236</td>
</tr>
<tr>
<td>Sensitivity to loud noises</td>
<td>GC 32.6 GA 48.6</td>
<td>59.13**</td>
<td>.218</td>
</tr>
<tr>
<td>Pulse/heartbeat throbbing in ear</td>
<td>GC 28.0 GA 39.3</td>
<td>32.48**</td>
<td>.162</td>
</tr>
<tr>
<td>Intolerance to high/low temperatures</td>
<td>GC 54.2 GA 66.4</td>
<td>26.72**</td>
<td>.147</td>
</tr>
<tr>
<td>Attend to hunger contractions</td>
<td>GC 30.8 GA 47.7</td>
<td>56.62**</td>
<td>.214</td>
</tr>
<tr>
<td>Sensitive to minor bites/splinters</td>
<td>GC 15.2 GA 28.9</td>
<td>50.75**</td>
<td>.202</td>
</tr>
<tr>
<td>Low tolerance for pain</td>
<td>GC 19.4 GA 24.5</td>
<td>15.10*</td>
<td>.110</td>
</tr>
</tbody>
</table>

Note: * = \(p < .05\), ** = \(p < .001\), GC – Gluten consumers \((n = 500)\), GA – Gluten avoiders \((n = 740)\).

Gender comparisons were again completed to ascertain if disproportionate rates of female participants were likely to skew the above results. An independent samples t-test revealed that there was a significant difference found between males \((M = 38.7, SD = 10.0)\) and females \((M = 40.9, SD = 8.8)\) on stimulus amplification scores, with females demonstrating significantly higher means; \(t(1238) = -3.96, p < .001\), Cohen’s \(d = .23\). These differences were observed in the context of an interaction between gender and avoidance groups on stimulus amplification. A two-way ANOVA confirmed that there was a significant interaction between the effects of gender and avoidance on stimulus amplification; \(F(1, 1240) = 10.5, p < .01\), with a partial eta squared of .008. However, as with arousability scores, a review of the means shows that the difference in stimulus amplification between male and female gluten avoiders was minimal (see Table 8-6) compared to gender differences observed in the control group.
Table 8-6

Descriptive statistics assessing effects of gender and avoidance on stimulus amplification scores

<table>
<thead>
<tr>
<th></th>
<th>Stimulus Amplification</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GC</td>
</tr>
<tr>
<td>Male</td>
<td>34.9</td>
</tr>
<tr>
<td>Female</td>
<td>38.5</td>
</tr>
</tbody>
</table>

Note: GC – Gluten consumers (n = 500), GA – Gluten avoiders (n = 740).

The main effects for gender on stimulus amplification \( F(1, 1240) = 12.5, p < .001 \) were smaller than those observed between avoidance and stimulus amplification \( F(1, 1240) = 103.7, p < .001 \). Only 1.0% of variance in stimulus amplification was due to the independent effects of gender, whereas 8% of the variance in stimulus amplification scores was due to the effects of avoidance. Mean stimulus amplification scores for male GA closely replicated the mean stimulus amplification scores found for female GA. Therefore the disproportionate number of females in the gluten avoider group is unlikely to be a major confounding variable for the significant differences found between GA and GC on measures of stimulus amplification as reported above.

8.4.3 Personality profile of gluten avoiders

Independent samples \( t \)-tests were conducted to compare personality scores amongst participants (see Table 8-7). There was a statistically significant difference in scores between GA and GC on the personality scales of extraversion, neuroticism, and openness. The strongest of these effects was found for the differences between participants in openness scores, with GA having significantly higher levels of openness than GC, to a small degree. There were also small-moderate effect sizes found for the differences in neuroticism and extraversion scores amongst participants.

Pearson’s correlations were used to observe the relationships between personality scores and food avoidance/symptoms/perceptions (see Table 8-8). Openness and neuroticism scores had small but significant positive relationships with the experience of negative symptoms following the consumption of both gluten and non-gluten foods. There was also a
Table 8-7
*Independent samples t-tests for BIG5 personality scores amongst participants*

<table>
<thead>
<tr>
<th></th>
<th>GC</th>
<th></th>
<th>GA</th>
<th></th>
<th>t</th>
<th>Cohen’s d</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extraversion+</td>
<td>23.20</td>
<td>6.33</td>
<td>24.27</td>
<td>5.62</td>
<td>-3.07*</td>
<td>0.18</td>
</tr>
<tr>
<td>Agreeableness</td>
<td>33.29</td>
<td>5.31</td>
<td>33.29</td>
<td>5.49</td>
<td>-0.01</td>
<td>0.00</td>
</tr>
<tr>
<td>Conscientiousness</td>
<td>33.92</td>
<td>5.95</td>
<td>33.33</td>
<td>5.73</td>
<td>1.75</td>
<td>0.10</td>
</tr>
<tr>
<td>Neuroticism+</td>
<td>22.40</td>
<td>6.46</td>
<td>23.66</td>
<td>5.92</td>
<td>-3.48*</td>
<td>0.20</td>
</tr>
<tr>
<td>Openness</td>
<td>33.15</td>
<td>5.41</td>
<td>34.64</td>
<td>5.43</td>
<td>-4.43**</td>
<td>0.26</td>
</tr>
</tbody>
</table>

Note: * = p < .01, ** = p < .001, GC – Gluten consumers (n = 500), GA – Gluten avoiders (n = 740), +assumption of equal variances has been violated in Levene’s Test.

small but significant positive correlation found for levels of neuroticism and perceived risk associated with the consumption of both gluten and non-gluten foods. These positive relationships suggest that the more neurotic and open a person is, the more likely they are to 1) avoid a food, 2) report negative symptoms following its consumption, and 3) perceive risks associated with its consumption. However, these findings are likely to be a reflection of the large sample size used, and should be considered in the context of the wider avoider profile.

Table 8-8
*Correlation matrix between personality scales, avoidance, symptoms, and perceptions for both gluten and non-gluten foods*

<table>
<thead>
<tr>
<th></th>
<th>E</th>
<th>A</th>
<th>C</th>
<th>N</th>
<th>O</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gluten</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoidance</td>
<td>.09</td>
<td>.02</td>
<td>-.02</td>
<td>.10</td>
<td>.13</td>
</tr>
<tr>
<td>Symptoms</td>
<td>.09</td>
<td>-.01</td>
<td>-.04</td>
<td>.11</td>
<td>.14</td>
</tr>
<tr>
<td>Healthiness</td>
<td>.03</td>
<td>-.03</td>
<td>-.03</td>
<td>-.06</td>
<td>.03</td>
</tr>
<tr>
<td>Risk</td>
<td>.06</td>
<td>-.02</td>
<td>-.06</td>
<td>.10</td>
<td>.09</td>
</tr>
<tr>
<td><strong>Non-gluten foods</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoidance</td>
<td>.13</td>
<td>.02</td>
<td>-.01</td>
<td>.06</td>
<td>.20</td>
</tr>
<tr>
<td>Symptoms</td>
<td>.12</td>
<td>-.08</td>
<td>-.11</td>
<td>.16</td>
<td>.19</td>
</tr>
<tr>
<td>Healthiness</td>
<td>.07</td>
<td>.05</td>
<td>.06</td>
<td>-.10</td>
<td>.08</td>
</tr>
<tr>
<td>Risk</td>
<td>.05</td>
<td>-.04</td>
<td>-.07</td>
<td>.12</td>
<td>.11</td>
</tr>
</tbody>
</table>

Note: N = 1240, E – Extraversion, A – Agreeableness, C – Conscientiousness, N – Neuroticism, O – Openness. All correlations equal to or greater than .06 have a per test significance level of p < .01, whilst those equal to or greater than .10 have a per test significance level of p < .001.
Correlations between the personality scales and other variables discussed in Chapter 8 were also completed, including somatisation, ambiguity tolerance, food preoccupation, and food nephobia (see Table 8-9). These additional analyses were completed in order to assess if any substantial relationships of interest existed between cross-chapter variables. Somatisation scores were more strongly related to neuroticism than to any other personality scale, with the latter showing a medium effect size ($r = .38$). Neuroticism was also highly correlated with autonomic arousability ($r = .67$).

Table 8-9  
*Correlations between personality scores and validated scales from Chapters 7 & 8*

<table>
<thead>
<tr>
<th></th>
<th>E</th>
<th>A</th>
<th>C</th>
<th>N</th>
<th>O</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHQ-15</td>
<td>-.03</td>
<td>-.15</td>
<td>-.18</td>
<td>.38</td>
<td>.11</td>
</tr>
<tr>
<td>MSTAT-I</td>
<td>.37</td>
<td>.18</td>
<td>.27</td>
<td>-.44</td>
<td>.41</td>
</tr>
<tr>
<td>FCQ-Total</td>
<td>.12</td>
<td>.21</td>
<td>.18</td>
<td>.01</td>
<td>.20</td>
</tr>
<tr>
<td>FNS</td>
<td>-.18</td>
<td>-.20</td>
<td>-.17</td>
<td>.17</td>
<td>-.23</td>
</tr>
<tr>
<td>APS</td>
<td>-.10</td>
<td>-.28</td>
<td>-.38</td>
<td>.67</td>
<td>.04</td>
</tr>
<tr>
<td>SSAS</td>
<td>-.02</td>
<td>-.12</td>
<td>-.16</td>
<td>.31</td>
<td>.14</td>
</tr>
</tbody>
</table>

Note: All correlations equal to or greater than .06 have a per test significance level of $p < .01$, whilst those equal to or greater than .10 have a per test significance level of $p < .001$. $N = 1240$. E – Extraversion, A – Agreeableness, C – Conscientiousness, N – Neuroticism, O – Openness. PHQ-15 – Patient Health Questionnaire, MSTAT-I – Ambiguity tolerance, FCQ-Total – Food Consciousness, FNS – Food Neophobia Scale, APS – Arousability Predisposition Scale, SSAS – Somatosensory Stimulus Amplification

8.5 Discussion

The aim of this chapter was to clarify the links between autonomic arousability, stimulus amplification and gluten avoidance through the observations of individual differences and personality characteristics. Gluten avoiders were found to have higher levels of autonomic arousability than controls, had a tendency to become emotional more quickly, and remain emotional for longer once a stimulus was removed. Gluten avoiders also reported higher levels of stimulus amplification, particularly for those stimuli that were experienced internally in the body. These individual differences were closely linked to the personality scales by which GA were characterised. Neuroticism was closely associated with the levels of arousability and amplification reported by GA. This observation adds weight to the biological
basis of sensory issues that perpetuate the experience of medically unexplained symptoms. They were also higher in openness, which is related to health-seeking behaviours and self-altering attentional patterns.

Participants who reported avoiding gluten were shown to have significantly higher levels of general autonomic arousability, and reported experiencing symptoms of arousal more frequently than controls. They were typically easier to startle and more easily excitable, indicating the key role that the autonomic nervous system plays in the experience and maintenance of symptoms reported by GA. The findings supported this with a significant positive relationship between levels of arousability and food symptoms being found. Women have been shown to exhibit higher levels of general arousability in similar Australian samples (Saliba et al., 1998) and this also needs to be taken into consideration with the overrepresentation of females within the GA group.

Autonomic arousability is driven by input from the limbic system, and is often characterised as the *fight-or-flight* response that assists quick mobilisation under threat. Studies have shown that emotional responses like these can be regulated on a neural basis through interpretation and labelling (Hariri, Bookheimer, & Mazziotta, 2000). Therefore, activation of the sympathetic nervous system can also be triggered by rumination and worrisome thoughts (Brosschot, Gerin, & Thayer, 2006), particularly when they are anticipatory in nature. In the current study a moderate positive relationship was observed between levels of arousability and the perceived risk that participants associated with the consumption of certain foods. This indicates that these risk perceptions may be assisting in the activation of an anticipatory threat response, leading to chronically higher levels of autonomic arousability. Bailer et al. (Bailer, Witthöft, & Rist, 2008) proposed a similar idea of cognitive causation, where modern health worries trigger an ongoing cycle of symptomology and focus on said symptoms, ultimately resulting in the misattribution of a causal relationship between the avoidance behaviours and symptom cessation. Considering the highly negative risk perceptions held by GA about all foods and their prioritisation of natural/healthy content (Chapter 7), it is possible that they hold fears that are disproportionate to actual risk. These fears would encourage a greater focus on health symptoms and health-related triggers. The resulting negative expectations from this cognitive process could result in somatisation, and thus an increase in physical symptoms which are only resolved via avoidance behaviours.
Participants who avoided gluten also reported significantly higher levels of stimulus amplification, demonstrating a clear difference in the way they attend and respond to non-pathological ailments, such as bruises and hunger contractions. These differences were particularly strong for the amplification of internal stimuli, suggesting that GA are especially sensitive to internal bodily sensations. These lower perceptive thresholds for internal cues are a trait that is also found among clinical patients with hypochondriasis and panic disorder (Martínez, Belloch, & Botella, 1999), as well as chronic fatigue syndrome and fibromyalgia. In these illnesses, pain stimuli are stimulated by both behavioural and cognitive factors (Meeus & Nijs, 2007). The brain structures that are involved in selective attention/threat perception are the same as those involved in the development and amplification of pain (Dubner & Ren, 1999), indicating that chronic issues of this nature are related to the attendance to health cues. The high rates of self-monitoring and autonomic arousability found in GA suggest that there are distinctive attention patterns that could similarly perpetuate the development and amplification of food-related symptoms.

A comparison of personality profiles between participants showed that GA had higher levels of openness to experience, neuroticism and extraversion, with the former showing the largest differences. Openness to experience is described by McCrae (1993) as a domain that indicates a preference for sensory, rather than intellectual experiences. Openness is considered to be a representation of internal experience seeking, and has some facets that load strongly on extraversion (Aluja, García, & García, 2003), which may further justify the small but significant differences found between extraversion levels of groups. Those high in openness have been shown to be significantly more vulnerable to anchoring cues, and the use of heuristics that are influenced by related external information (McElroy & Dowd, 2007). They are therefore more receptive to information, and are more likely to adjust their beliefs according to any external information that is relevant.

This processing style taps into other correlates of openness to experience, including absorption and private self-consciousness (McCrae, 1993). Absorption is considered an indicator of hypnotic susceptibility, and the capacity to become engaged in self-altering attention. A person high in absorption is able to experience sensations that seem present and real, even if the attentional object is constructed from memory. In the context of gluten avoidance, this could suggest that memories of previous food symptoms can be re-experienced in future situations where the trigger is no longer present due to their highly acute attentional capacity. Private self-consciousness adds to this notion, and is characteristic
of people who are skilled in self-directed attention and thought (Fenigstein, Scheier, & Buss, 1975). A major facet of private self-consciousness is self-reflection, which has been shown to positively correlate with both anxiety and stress due to ongoing patterns of inward examination and focus (Grant, Franklin, & Langford, 2002). The tendency for GA to score higher on openness to experience therefore indicates that they have an increased capacity to turn their focus inward, which can lead to heightened sensual experiences that can be easily influenced by external information.

When paired with health-related concerns specifically, openness levels have been shown to strongly predict health-related information seeking, facilitating the increased retrieval and use of information. This effect has a three-way interaction with levels of neuroticism, which increases one’s perceived levels of affliction, further fuelling health-related information seeking patterns (Bogg & Vo, 2014). In this chapter, neuroticism held the strongest relationship with the experience of negative symptoms, although this was only small in size. Therefore, neuroticism levels should be considered as a factor in the determination of symptom presentations amongst gluten avoiders. A study of the personality correlates for non-psychiatric IBS patients in Iran revealed similar findings (Farnam, Somi, Sarami, & Farhang, 2008), where bowel problems were associated with significantly higher levels of neuroticism and conscientiousness. They noted that neuroticism is often higher in patients with functional gastrointestinal disease, and this was a strong predictor of treatment outcomes. Neuroticism also increases the amount of attention that is paid to emotional influences, and tends to result in an overrepresentation of threat levels in relatively neutral stimuli (Ormell et al., 2013). The higher autonomic arousability identified earlier in GA only serves to accelerate this impairment in emotional-regulation and risk evaluation. One strategy that neurotics often employ to cope with chronic stress patterns is the use of escape or avoidance (Lee-Baggley, Preece, & DeLongis, 2005), which allows for an immediate alleviation of arousal caused by perceived threat. In the case of GA, it may be that the relief related to avoidance could lead to overestimates of the effectiveness of a GFD; therefore, gluten avoidance is directly leading to an improvement of overall wellbeing and symptomatology, but this is not due to the toxicity or dangers associated with gluten itself. Instead, the employment of a regimented dietary plan in those experiencing food-related symptoms can foster a sense of effective self-management, which biases any resulting improvements that are experienced as a consequence.
Another relevant factor that has been shown to positively correlate with both neuroticism and extroversion is emotional expressivity, or the behavioural experience of an emotion. Gross and John (1995) conceptualised this as a trait that could provide insight into both the strength of emotional response as well as the degree to which these are expressed. The total scale score for expressivity revealed positive correlations for extraversion, neuroticism, openness and agreeableness, with the first two dimensions showing the strongest relationships. The expressivity scale was also positively correlated with somatic complaints, in particular those experiences related to negative emotional impulses. It was also shown to have a strong negative correlation with measures of emotional control. Gross et al conclude that the specific correlations found between impulse strength, neuroticism and somatic complaints are theoretically consistent with Watson & Pennebaker’s symptom perception hypothesis (1989). This theory suggests that stronger emotional impulses places strain on one’s coping capacity, leading to an increase in somatic complaints that may reflect an additional and unique form of emotional expression in certain individuals. They noted that negative affectivity is related to increased reports of somatic complaints, but not to actual long-term measures of health status, including mortality rates, disability, and physician visits. This is thought to be an indication of an underlying dysfunction in emotional processing, as opposed to true indicators of a health disorder.

High levels of neuroticism and extraversion have been linked to brain structures that independently mediate emotional processing and somatosensory sensations. In an fMRI study by (Kehoe, Toomey, Balsters, & Bokde, 2012), neuroticism was observed to increase with reactivity to emotional arousal. They also identified relationships between high levels of extraversion and the activation of both the right insula lobe and somatosensory cortex – which are believed to moderate the interpretation of visceral sensations, and impact the conscious experience of an emotion based on these bodily changes (Straube & Miltner, 2011). The insula lobe is also known to activate during simulation of body ownership that involve stimulation to a fake rubber hand (Tsakiris, Hesse, Boy, Haggard, & Fink, 2006), supporting the notion that this brain structure is responsible for the development of an egocentric reference point for bodily self-consciousness. Due to the potential for emotions to increase attentional states, Kehoe et al. (2012) also posited that higher levels of extraversion could be related to an increased susceptibility to these effects, although this has yet to be confirmed through the use of brain imaging studies. The findings in this chapter revealed that GA report higher rates of body awareness, and tended to focus on and amplify symptoms that
were related to an internal experience. It may be the case that personality characteristics of GA can be used as indicators for such attentional preferences, leading to specific types of emotional processing that is associated with higher somatisation, amplification and autonomic arousability.

Due to the limitations posed by the length of the project, as well as the restraints on the study survey used, there is a selection of additional measures that could have provided additional clarity around the specifics for arousability/amplification that were not immediately considered to be relevant in the initial stages of study design. For example, the SASS provides a limited capacity to examine the differences between classes of internal symptoms; therefore, a distinction cannot be made between stimuli related to foodstuffs versus general gut-related anxiety presentations, etc. However, the findings do serve as a generalizable and wholly informative introduction into the likely sensitivity issues that are being reported by this population, and the links these share with the sympathetic nervous system. Future research can now use these differences to develop more sophisticated questionnaires for the population based on types of sensitivities and emotional affectivity to refine what is now known. Further exploration is also needed to clarify the characterisation between extraversion, neuroticism, arousability and the intricate experience of emotional bodily sensations.

8.6 Conclusion

The chapter aimed to clarify the links between autonomic arousability, stimulus amplification and gluten avoidance through the observation of individual differences and personality characteristics. Gluten avoiders were found to have unique personality profiles that indicate they are biologically predisposed to greater levels of autonomic arousability. They are also more likely to be internally focused, and have the capacity to engage in self-altering attention. This unique combination of attentional bias and autonomic sensitivity leads GA to experience higher levels of stimulus amplification, particularly those that occur within the body. Genuine health concerns thus encourage greater health-seeking behaviours, including both positive (higher receptivity to information) and negative (avoidance of proposed dietary triggers) behaviours aimed at reducing symptoms. Paired with negative risk perceptions, and complex patterns of somatisation, GA are likely to both perceive more and experience more in the context of food consumption, which fuels an ongoing sense of affliction. These experiences are reminiscent of other sensitivity syndromes that share similar patterns of discrimination within the community and lack of diagnostic clarity.
These findings help to clarify the pivotal role that individual differences play in the reporting and interpretation of negative food symptoms reported by GA, and provides some suggestions as to what underlying mechanisms may perpetuate them. The final chapter will discuss these findings within the context of the preceding chapters, in order to develop a preliminary theoretical basis that may help to increase an understanding of the drivers of gluten avoidance. Implications of the findings and significant contributions will also be discussed in regards to the thesis as a whole.
Chapter 9: Discussion and conclusion

9.1 Introduction

This thesis has presented five key findings, which help to form a preliminary understanding of gluten avoidance behaviours. Each of the findings has been independently discussed in the relevant chapter(s), with little or no integration with findings from other chapters. This chapter will discuss these findings, and any ancillary findings, in the context of all the discoveries made in this thesis. Implications for these findings will be discussed alongside the contributions they make, and the ways in which they satisfy the overall research aim to prevent unnecessary gluten restriction in the pursuit of symptom reduction. In doing so, this chapter will also provide recommendations for health practitioners working with this population, and for future researchers looking to extend upon these results. The limitations of the research are also presented, which further supplement the suggestions for future research.

9.2 A discussion of the key findings

9.2.1 The lack of perceived support options for gluten avoiders

The qualitative study in Chapter 3 reported that gluten avoiders felt unsupported by both their personal networks and by the health practitioners from which they sought advice. The physical and mental health consequences associated with low social support have been well documented within the literature (Kaplan, Patterson, Kerner, & Grant, 2013). Social support is shown to serve multiple mood moderating functions, including the level of stress and our resilience to future stressors (Kawachi & Berkman, 2001). Poor social support can even exacerbate the impact that pre-existing stressors were already having on physical health (Daoud et al., 2016) making them last longer and more difficult to treat. These effects have been shown to occur even when the beliefs are a product of a person’s perceived social treatment being experienced (Pascoe & Richman, 2009).

In Chapter 7, gluten avoiders reported significantly higher rates of perceived everyday discrimination compared to controls. This could have both short and long-term impacts on their health that could complicate the ability to discriminate between pre-existing and ongoing health problems. For example, in the context of racism, discrimination is often met with adaptation strategies aimed at improving one’s identity in the face of judgement and oppression. Sometimes this includes the internalisation of feelings which themselves manifest into chronic health problems and psychological distress (Williams et al., 1997). Perceived
discrimination can also increase one’s sense of susceptibility or vulnerability, which is another major factor driving health-related behaviours (Goldstein, 2004b). Therefore, it is important to consider the perpetuating role that levels of perceived discrimination have on the ability of gluten avoiders to respond to health-related stressors, and the physiological consequences of these.

Participants also reported struggling to establish legitimacy for their concerns with GPs, who were often unable to help them identify appropriate treatment strategies or referral pathways. Previous research has described similar experiences occurring in populations of gluten avoiders in other countries (Moore, 2014), and in wheat avoiders (Golley et al., 2017). Gluten avoiders in Chapter 3 explained that unmet health care expectations influenced their decision to transition to self-managed diets. In America, these experiences have been identified as a catalyst for self-diagnoses and an undermining of medical expertise (Moore, 2014). However, gluten avoiders may find that their capacity to do so is interrupted by the additional cognitive load added by the distress occurring as a result of psychosocial isolation discussed above.

The potential effects of this increased cognitive load were observed in Chapter 7, where gluten avoidance was found to be correlated to discrimination. This indicated that inflated levels of perceived discrimination are likely to be a characteristic of non-prescribed gluten avoiders. In Chapter 7, gluten avoiders reported adequate levels of GP satisfaction despite their qualitative concerns regarding gluten-specific interactions. The wider perceptions that consumers hold about their GPs may not be impacted by these experiences due to their specificity. In fact, their focus on food, health and wellbeing may drive them to interact with their GPs more, as they continue to grapple with their concerns regarding food-related symptoms. Therefore, GPs are presented with a unique opportunity to engage with this population, and assist them by engaging in shared decision-making about their health management.

A lack of symptom validation from health practitioners continues to be an issue for those experiencing medically unexplained conditions, and ailments that are yet to develop a standardised medical response. Studies have shown that the specific type of responses associated with contested illnesses directly impacted the mental health of sufferers (Malterud, 2000). Patients also play a crucial role in the social construction of their illnesses, particularly when their legitimacy is contested (Swoboda, 2006). The experiences reported by gluten
avoiders suggests that they were not comfortable engaging in decision-making processes with their GP due to previous judgement or lack of interest in their reported symptoms. Shared decision-making is recognised as the best practice in these treatment situations, where patients seek guidance for both their physiological and psychological mental health (Elwyn et al., 2012).

Without a strong therapeutic alliance between the GP and the patient, a consensus about appropriate treatment options is unlikely to be reached (Joosten et al., 2008). A recent paper by Golley et al. (2017) has proposed guidelines for Australian GPs who are working with people who avoid wheat, which emphasises validation of symptoms reported and integrated use of specialist referrals as part of a more holistic treatment approach. The findings in this thesis suggest that there may be utility in extending these guidelines for health practitioners beyond the initial target group to include gluten avoiders as well. This thesis highlighted that gluten avoiders feel they are victims of discrimination in both social and medical settings because of their chosen diets. These unique needs suggest that they may gain additional benefits from counselling services, an element that is yet to be considered in the context of best-practice model for gluten avoiders.

9.2.1.1 Implications

Previous research indicates that a lack of perceived social support, similar to that described by gluten avoiders, can have a negative impact on both mental and physical health. National policy and governing health bodies need to ensure that GPs are supported when engaging in shared decision-making practices for all patients, not just those presenting with medically explainable symptoms. As the primary care providers, it is also vital that GPs are given the training and resources necessary to assist individuals presenting with the unexplained symptoms that are typically associated with gluten. Care needs to be taken in addressing the legitimacy of the symptoms reported by gluten avoiders due to their pre-existing concerns about judgement and discrimination. This validation of the patient’s experience will ensure that gluten avoiders remain engaged with contemporary medical services long enough to access appropriate health care options rather than turn to self-management. It will also assist in discriminating between pre-existing gluten-related symptoms, and those that may be perpetuated by the stress associated with the treatment experience.
Symptoms connected with psychological factors are equally as valid as those that occur due to illness or disease, and are typically very difficult to treat. The findings in this thesis suggest that targeted training modules for GPs are needed to ensure optimal patient care and symptom validation when there is an absence of clear biological cause. Creed et al. (2010) suggest that even the term ‘medically unexplained symptoms’ itself creates a barrier for the development of a positive doctor-patient relationship due to the associated connotations. A multidisciplinary approach including a biopsychosocial model would be best suited for the management of these symptoms in the primary care environment. Although this is typically accepted as a standard for health care interventions, the model is rarely considered in the context of health care funding provisions and organisational outcomes (Wade & Halligan, 2017). This thesis suggests that such models are equally vital in policy discussions and the allocation of resources in response to non-prescribed gluten avoidance and the symptoms that perpetuate this behaviour.

9.2.2 Developing a demographic profile of the Australian gluten avoider

The second key finding is that there is a disproportionately high rate of gluten avoidance behaviours in Australia compared to estimated diagnostic rates for the gluten-related disorders that require such behaviours. This finding indicates that prescribed medical concerns are not the only reason for the decision to adopt a gluten free diet. In fact, there are higher rates of non-prescribed gluten avoidance than there is prescribed gluten avoidance. Almost 20% of Australians reported engaging in non-prescribed gluten avoidance to some degree, with the largest proportion of these people identifying themselves as occasionally avoiding gluten in their diet. These prevalence rates exceeded reports of medically prescribed gluten avoidance by more than 15%. Predicted rates of NCGS vary between countries and studies from 0.5% to 13% (Molina-Infante, Santolaria, Sanders, & Fernandez-Banares, 2015), with actual prevalence likely occurring somewhere between these two estimates. Large discrepancies between formal diagnoses and avoidance behaviours have also been reported in an Italian cohort in 2015, where self-perceived gluten symptoms were found to have little predictive value when assessing the presence of a gluten sensitivity (Capannolo et al., 2015). Therefore, it is likely that only a small proportion of the non-prescribed gluten avoiders identified in this thesis are eligible for a diagnosis of NCGS. Even after adopting the most extreme NCGS estimates (i.e. 13%) which is not likely to be an accurate representation of the prevalence for this disorder there remains a proportion of Australians (7%) that report avoiding gluten for reasons other than prescribed symptom management. This thesis was
designed to address these issues by including a large and representative pool of participants
that was specifically weighted against the true population. Designing the thesis in this way
ensures that the most accurate prevalence rates were captured and reported.

Both gender and age were found to have a significant association with gluten
avoidance behaviours. Females, and those in younger age groups have been identified to have
significantly higher prevalence rates of anxiety disorders (Baxter, Scott, Vos, & Whiteford,
2013). People in these categories also report higher rates of anxiety-related health
presentations such as non-specific chest pains (Remes, Brayne, Linde, & Lafortune, 2016).
Studies have hypothesised that anxiety and distress may contribute to the experience of non-
specific bodily issues more generally (Barsky et al., 2001), as well as in relation to specific
health conditions. The findings in this thesis did not support the age trends observed in people
with gluten sensitivity, where prevalence is found to be focused towards the age of 40 years
old (Volta & De Giorgio, 2012). This incongruence further distinguishes gluten avoiders as a
unique population, independent of people with gluten sensitivity. The incidence of gluten
avoidance in this study was found to be particularly high in those aged 25-34 years old. It is
unknown whether these results are reflective of an increasing rate of gluten sensitivity over
time, an increase in reporting rates, or additional factors that vary between cohorts.

The younger age groups tend to be the cohorts that are accessing tertiary
education during an age of technological advantage. These factors improve access to
information and online resources, and thus the amount of health information being consumed.
Health information consumption patterns have drastically changed over time, which is based
partially on the increasing accessibility that is provided by the internet (Hesse et al., 2005).
Whilst access to information is generally associated with good health literacy, this process
can be compromised when patients turn to the internet following a lack of support from
health care professionals (Tustin, 2010). If patients are not equipped to make educated
decisions about the varied information and sources available, it could lead to unnecessary or
inappropriate dietary restriction. Doctors have already been reporting that patients are far
more likely to present to clinics armed with pre-existing beliefs and knowledge about what
they believe is occurring – which can be considered both an advantage and a hindrance
(Powell, Darvell, & Gray, 2003).
9.2.2.1 Implications

The implications of the above findings are twofold. To date, estimates about gluten avoidance behaviours have been modelled from other countries such as America or England, or from data that observes characteristics of wheat avoiders as opposed to gluten avoiders specifically. This is the first large population survey to quantitatively confirm the prevalence rates of gluten avoidance within Australia. The confirmation of this phenomenon allows public health sectors to justify the allocation of resources to help further our understanding of the behaviour. Secondly, this thesis has established the likely scale of the phenomenon and the type of Australians most likely to participate in these behaviours. The high rates of non-prescribed gluten avoidance suggest that there is likely to be a substantial proportion of people engaging in unnecessarily restrictive diets, which can result in both nutritional and financial strain. A targeted public health response will help to ensure that the consequences of these behaviours (e.g. increased health care costs) are minimised through education strategies and policy development. These policies can be informed by the demographic profile that was reported in Chapter 4, which indicated they were likely to be younger aged and female. The scope of this issue suggests that significant strain may be placed on the health care system if intervention strategies are not appropriately targeted to their needs.

9.2.3 The non-specific nature of symptoms reported by gluten avoiders

Another major finding presented in this thesis includes the consistent pattern of adverse symptoms that were reported by gluten avoiders in response to other food groups in addition to gluten. The original sample was modified to exclude those persons who were avoiding gluten without any reported symptoms, so that the groups symptomology could be accurately explored. However, consistently reported symptomology following non-gluten food consumption was not expected. There was an explicit relationship observed between the quantity of symptoms being reported following the consumption of foods, and the frequency with which the foods avoided. This occurred regardless of whether the foods specifically contained gluten or not. These findings indicate that the phenomena driving non-prescribed gluten avoidance may not be appropriately captured by the examination of gluten-based triggers in isolation. In fact, only a very small proportion (1.9%) reported experiencing symptoms relating only to gluten, in the absence of symptoms to any other food measured.

This thesis suggests that the complications occurring in those who avoid gluten are similar to those that suffer from irritable bowel syndrome (IBS). Previous studies
observing trigger foods in IBS have recognised that a range of products produce a range of responses in people, complicating the investigation of the illnesses underlying mechanisms (De Giorgio et al., 2016). The presence of adverse symptoms following both gluten and non-gluten foods could significantly interfere with the ability to distinguish between symptoms relating to gluten specifically, and symptoms related to other food triggers. Wheat, milk and egg proteins have all been associated with a comorbid diagnosis of food hypersensitivity amongst IBS patients (Carroccio et al., 2010), and could provide a viable alternative explanation for the medically unexplained symptoms being reported by gluten avoiders. These findings add further weight to the symptom and diagnostic crossover that exists between gluten sensitivity, IBS and other food tolerances. The thesis suggests that gluten avoiders may be experiencing symptoms in response to a range of food triggers that they are misattributing to gluten.

9.2.3.1 Implications

These findings identify a more general food experience that is yet to be reported in the context of gluten avoidance. This helps to both establish the validity of the symptoms being reported by gluten avoiders whilst also suggesting alternative and potentially more accurate mechanisms for their experience. Gluten avoiders may be applying too narrow a definition to their symptoms based on interpretations that are confounded by an array of complex factors including somatisation. Laypersons are often not equipped to identify these effects and need the support of a health professionals in order to accurately make sense of their experience. The results presented in this thesis confirm that gluten avoiders are experiencing consistently higher rates of adverse symptoms from a variety of food sources requiring further investigation upon presentation to a primary health care provider. Models of best practice need to include investigative options that consider a full examination of the symptoms being experienced, as opposed to viewing physiological responses to gluten in isolation. These clinical presentations will likely require further testing and/or specialist referrals to rule out alternative diagnoses such as IBS or food hypersensitivity. By adopting a broader understanding of the symptoms being experienced by gluten avoiders, GPs can effectively respond to patients’ needs.

9.2.4 Cognitive differences between gluten avoiders and gluten consumers

There were a number of significant cognitive differences found between gluten avoiders and gluten consumers that were associated with their eating patterns. At times these differences were profound, representing a clear distinction in the way that gluten avoiders
think about both gluten, and about food in general. High levels of food consciousness (as discussed in Chapter 3) were echoed in the analysis that was completed on food choice preferences in Chapter 7. Gluten avoiders considered their food choices more carefully, prioritising the natural content and health of foods when making their decisions. These findings show similarities with the concept of involvement, which influences the amount of information that is sought about a product, and the related perceptions that are formed (Bell & Marshall, 2003). The most important factors reported by gluten avoiders influencing their food choice were that their food was free from both additives and artificial ingredients. Similar health-preferences have also been identified in people who tend to manage illness through regulation of their diets (Squires et al., 2001). The presence of these strong cognitive influences shows that the choice to avoid gluten is dependent on both psychological factors and physiological ones.

In this thesis, gluten avoiders reported perceiving all foods (gluten, dairy, eggs, carbohydrates, fats & preservatives) as more unhealthy, and associated a much higher risk with the consumption of each food type. Perceptions are recognised as a key influence in consumer decision-making models and often contribute to the formation of product expectations (Grunert, 2005). These expectations can impact the course of certain illnesses as well as the patients’ responses to treatment (Benedetti et al., 2007). Gluten avoiders in this thesis adopted a self-treatment approach by engaging in non-prescribed gluten avoidance behaviours, which led to a perceived improvement in their health. The fact that more than 70% of gluten avoiders perceived some risk associated with gluten is likely promoting negative expectations and perpetuating an attentional bias towards any symptoms that are felt because of its consumption (Crombez et al., 1998). Therefore, it is not unreasonable to suggest that a nocebo-like effect could be inflating the success that is gained by gluten avoiders when they employ these dietary strategies (Vernia et al., 2010).

Studies that have examined the impact that risk perceptions have on the willingness to consume foods have shown that these effects can be robustly moderated by the types of information to which consumers are exposed (Lusk & Coble, 2005). Research has also demonstrated that those with a chronic illness are more likely to turn to the internet as a source of information, and then use this information to adjust their behaviours for improved health (Ayers & Kronenfeld, 2007). This concept is supported by the findings in this thesis, where gluten avoiders used and trusted online information sources more so than other formats for their health information. Health information seeking behaviours are often associated with
distinct health motives, including those that are driven by illness specific concerns (Weaver et al., 2010). It is therefore unlikely that the decision to avoid gluten is motivated purely by exposure to negative gluten messages. Instead, the experience of medically unexplained symptoms could trigger initial health information searches, leading to exposure to messages that enflame existing risk perceptions and drive their desire to implement self-managed dietary strategies at home.

Theorists have also pointed out that the layperson definition of health and risk is often different to those defined by the biomedical paradigm of health (Goldstein, 2004b). In these cases, health belief systems and their resulting risk perceptions need to be accounted for holistically, rather than with a dichotomous view of patients either knowing or not knowing. Gluten avoiders engage with their risk perceptions via vernacular theory (see McLaughlin, 1996), where personal experience and language are used to understand their symptoms in the absence of clearly defined risks in the available literature. In order to manipulate these perceptions effectively, patient education needs to consider the pre-existing beliefs people have about gluten that are informed by personal experiences. This is not to say that the symptoms being experienced by non-prescribed gluten avoiders are not real or are invalid. In fact, these findings establish quite the opposite. This population is reporting higher rates of symptoms and are choosing to act in a way that they feel best manages these symptoms. Therefore, the avoidance of gluten, and other foods, also genuinely leads to a decrease in the experience of adverse symptoms. However, it is likely that the originating trigger of these symptoms is not the specific physiological reactions that one particular food produces within the gut.

9.2.4.1 Implications

By developing a better understanding of the food risk perceptions held by gluten avoiders, policy makers and industry professionals will be able to better predict the changes in consumer behaviour that occur based on the food safety information that is provided. Broad government-based education strategies are not likely to be effective in reducing the risk perceptions held by gluten avoiders. The strong relationship between perceptions and symptomatology requires a more individualised approach where health professionals assist patients in identifying the impact that their feelings and thoughts have on their physiological experience. This can be achieved in environments that simultaneously validate concerns whilst also considering the additional factors that may be influencing symptoms. A patient’s definition of risk also needs to be managed in the context of food consumption, so that the
sensations associated with natural digestion processes do not result in unnecessary inflation of perceived risk.

### 9.2.5 Individual differences and sensitivity dysfunction amongst gluten avoiders.

Another significant contribution made by this thesis is that gluten avoiders have unique personality profiles compared to controls, which is linked with greater levels of autonomic arousability and internal biases that amplify stimuli occurring within the body. These findings supplement the somatisation rates discussed earlier, acting as another indicator of biological differences that manipulate the attention to, and interpretation of symptoms in gluten avoiders. Higher levels of somatic complaints have also been identified in illnesses such as fibromyalgia and IBS (Creed et al., 2008). Researchers have theorised that these levels of somatisation indicate the symptoms typically associated with these diagnoses may actually be better accounted for by a central sensitivity disorder (Yunus, 2008). This is because patients with different functional somatic syndromes share the same disparity between stimulus and perception, as well as lower tolerance thresholds for stimuli (for a full review, see Bourke, Langford, & White, 2015). These sensitivity issues are considered in combination with the sufferer’s capacity to attend to, and emotionally cope with internal stimulation such as pain or digestion, or both.

This thesis confirmed that gluten avoiders are much more likely to experience the expression of emotions through physiological manifestations than those that do not avoid gluten. There was also a correlation found between levels of somatisation in gluten avoiders and the quantity of symptoms they experienced. Some suggest that the high rates of medically unexplained symptoms in patients reporting food-related issues are more characteristic of somatoform disorders (Steinbrecher et al., 2011) than they are of specific food intolerances. High levels of somatisation are reported in populations of IBS patients, which correlate with the severity of the symptoms they report (Creed et al., 2008). Therefore, additional consideration needs to be given to the role that emotional stressors play in the interpretation of symptoms being experienced in gluten avoiders. In Chapter 7, gluten avoiders were found to hold strong risk perceptions about gluten, increasing the chances of experiencing anxiety in relation to its consumption. Negative perceptions relating to a food tends to increase the attention paid to symptoms which occur immediately after eating (Crombez et al., 1998). This process helps to explain why gluten avoiders may perceive their symptoms to be triggered by gluten specifically, rather than based on a general response to foods overall. Exposure to these stressors is thus mediated by the avoidance of gluten (the
main emotional stressor), resulting in health improvements, which are then related back to gluten.

Small internal changes in gluten avoiders are likely to be met with disproportionate emotional responses, which can complicate the distinction between food-triggered symptoms and somatic responses. Correlations between bowel symptoms and levels of neuroticism have been identified as mechanisms of IBS patients in Iran (Farnam et al., 2008). Neuroticism has been identified as a key mediator of emotional processing and somatosensory sensations, and is also correlated with emotional expressivity, which can moderate the behavioural expression of emotions in the form of somatic symptoms (Gross & John, 1995). This has been demonstrated in studies examining patients with chronic uninvestigated dyspepsia, the incidence of which is strongly associated with somatic complaints (Heidari, Keshteli, Feizi, Afshar, & Adibi, 2017). Functional forms of dyspepsia are considered to be the most prevalent type of gastrointestinal disorders, and share a considerable amount of symptom overlap with IBS (Piacentino et al., 2011). These studies indicate that somatisation continues to be a key feature in the production of, and maintenance of, gastrointestinal symptoms.

Non-prescribed gluten avoiders were also found to have significantly higher levels of neuroticism. Paired with somatisation, these two factors are common in populations that suffer from negative emotion health coping (Deary, Scott, & Wilson, 1997), which can lead to mental health problems. Although the thesis did not include specific measures of anxiety, it is likely that gluten avoiders are experiencing more anxiety-like symptoms on a general basis. This is supported by a number of findings, least of which is their reported rates of anxiety-related symptoms (i.e. frequent heart palpitations). Further research should aim to include measures of anxiety when examining this population in detail. Gluten avoiders also reported significantly higher rates of autonomic arousal, which is linked to specific fight-or-flight mechanisms in the sympathetic nervous system. This type of arousal is typically experienced when a stimulus is interpreted as threatening (Crombez et al., 1998), resulting in a number of physiological changes in the body designed to assist someone in avoiding the threat. Anxiety disorders are known to be significantly more common in people who suffer from all types of eating disorders (Godart, Flament, Perdereau, & Jeammet, 2002). Receiving a diagnosis of a mood or anxiety disorder also doubles the chances of being diagnosed with a functional gastrointestinal disorder (e.g. IBS, dyspepsia, constipation) in the years following (Jones et al., 2017).
9.2.5.1 Implications

It is important to consider the role that anxiety plays within the process of food-avoidance. This thesis has hypothesised a biological basis for the experience of adverse symptoms following the consumption of gluten in the absence of a CD diagnosis. None of the available results indicate that a specific intolerance to gluten is driving this phenomenon. Instead, a clear sensitivity dysfunction has been identified that is not found amongst populations of gluten consumers. As such, gluten avoiders may benefit from additional treatment options that also provide training in the areas of emotional regulation, and the recognition of somatic symptoms as connected to these emotions. General practitioners should consider referrals to mental health professionals to assist this population in distinguishing between somatic symptoms and indicators of illness. Cognitive-based therapies allow participants to explore their thoughts, and how these thoughts impact their physical and emotional health. A treatment approach that improves cognitive skills will help to reduce anxiety, and thus the types and frequency of anxiety-related symptoms that are experienced. In order to ensure that patient symptoms are properly validated, these referrals should be paired with testing for sensitivity issues.

If this approach was successfully implemented, it would likely lead to a reduction in those presenting to their health practitioners and engaging in restrictive diets based on fears relating to certain food types. This would reduce the strain on primary care givers, as they work towards finding a definable solution for sufferers of medically unexplained symptoms. Such treatment could provide supplementary outcomes in relation to the mood-related symptoms that are typically exacerbated by the convoluted diagnostic process. Furthering our understanding of cognitive processes in these individuals may also assist in the creation of screening tools that can help with the identification of people who are vulnerable to developing food-related symptoms due to this sensitivity dysfunction.

9.3 Significant contributions of the research

The contributions in this thesis provide the most benefit to people who chose to engage in non-prescribed gluten avoidance, the primary health care providers that they seek subsequent advice from, and the health care policy makers that regulate the provision of these services. Together, these contributions demonstrate that gluten avoiders are a unique group of individuals, who report a range of complex issues that require specialised treatment and care. These contributions are broken down below:
9.3.1  **Developing an understanding of pre-existing knowledge about gluten avoidance.**

1. The literature review presented in Chapter 2 established that there is yet to be an accurate characterisation of gluten avoiders, or the mechanisms that drive their behaviours in the literature. This review contributes to a better understanding of the complications associated with obtaining an accurate gluten-related diagnosis and the variety of factors that may jeopardise this process. This known ambiguity has very real consequences for gluten avoiders looking to achieve some diagnostic clarity from medical professionals in relation to their reported symptoms.

9.3.2  **Characterising the subjective experience of gluten avoiders**

1. Gluten avoiders reported significantly higher levels of perceived discrimination from their support circles and from their doctors during the qualitative interviews discussed in Chapter 3. The associated distress is likely to interfere with the success of subsequent treatments that are adopted. This contribution fosters a better understanding of the psychological impacts that are associated with the decision to become gluten-free without a diagnosis and their connection to health problems.

2. Unmet healthcare expectations led to the decision to begin self-managing diets in an effort to alleviate the symptoms being experienced. A lack of symptom validation and poor referral pathways continued to limit the success that gluten avoiders had when attempting to understand their issues. This establishes the need to develop best-practice principles that doctors can utilise when working with this population to ensure they remain engaged with professionals that can guide them through their treatment.

3. Doctors were less likely to adopt shared decision-making practices for the medically unexplained symptoms reported by gluten avoiders, leading to a sense of epistemic injustice. This contribution identifies a service gap perpetuated by the lack of diagnostic clarity currently available for gluten-related disorders that need to be addressed through targeted policies and education initiatives.
9.3.3 Identifying the demographic characteristics of gluten avoiders

1. The results from the demographic survey reported in Chapter 4 established highly accurate prevalence rates for both prescribed (2%) and non-prescribed (20%) gluten avoidance in Australia. The use of a demographically weighted sample ensures that these calculations accurately reflect the scope of this issue across the country, allowing for appropriate allocation of resources.

2. A complete demographic profile was defined and compared against both those participating in prescribed gluten avoidance and those that freely consume gluten. Non-prescribed gluten avoiders in Australia were more likely to be female, and aged between 18-35 years. This contribution allows policies and healthcare services to be better targeted towards this group's specific needs.

3. The rate of non-prescribed gluten avoidance being reported by participants exceeded the amount of people following prescribed gluten-free diets beyond rates that could be accounted for by undiagnosed gluten sensitivity. This contributes to the understanding of non-prescribed gluten avoidance as its own specific phenomenon.

9.3.4 Identifying the unique psychological characteristics of gluten avoiders.

1. The findings discussed in Chapter 6 demonstrate that gluten avoiders report consistently higher rates of all types of adverse symptoms following the consumption of gluten. This contributes to the legitimisation of issues being reported in primary care settings by this group. A profile of specific symptom types has been developed to assist medical professionals in understanding this experience further.

2. Gluten avoiders also reported significantly greater rates of adverse symptoms following consumption of non-gluten foods, suggesting that they may be inaccurately categorised by their gluten-specific concerns. This research is the first to establish clear and distinct symptomology relating to non-gluten foods, indicating that this population is more accurately characterised by their response to all foods, not just gluten alone.

3. There was a strong positive relationship identified between avoidance patterns and symptoms experienced for all food types, indicating that physiological symptomology is a significant driver of food avoidance for this population.
This contribution allows for clarification around the existence of physiological symptoms that may not be able to be medically detected in gluten avoiders.

4. Gluten avoiders reported significantly higher somatisation scores, demonstrating a greater tendency to express their emotional distress through physiological symptoms. They reported these somatic symptoms despite their attempts to moderate consumption of the suspected trigger (gluten) indicating that they may be misattributing most of their symptoms to gluten in error. This contribution allows for a holistic understanding of the symptomology associated with gluten avoidance as one that relates to both physical and emotional health.

5. The findings in Chapter 7 confirm that there are also significant cognitive differences between gluten avoiders and gluten consumers. Gluten avoiders held more negative perceptions of foods, and considered their food choices more carefully than controls. They prioritised foods that were healthy/natural and avoided foods that they associated with risk. These risk perceptions held the strongest relationship with avoidance ($r = .61$), second only to the experience of direct physiological symptoms ($r = .86$). These findings identify a sophisticated set of cognitive processes that determine the need for conscious gluten avoidance in the pursuit of health.

6. The findings in Chapter 8 provided clear evidence that gluten avoiders have distinctly different levels of arousability and stimulus amplification to controls. They become emotional more quickly and remain emotional for longer once a stimulus is removed. They also pay greater attention to stimuli that are experienced internally in the body, and amplify these sensations significantly more than controls. This research is the first to link the experience of gluten avoiders with the likely presence of a sensitivity dysfunction that mirrors the concerns of other contested illnesses.

7. Gluten avoiders reported significantly different personality profiles to those that consume gluten, being higher in openness and neuroticism. These findings suggest that gluten avoiders may be having heightened sensual experiences that can be easily influenced by external information. These responses could be an indication of an underlying dysfunction in emotional processing, as opposed to true indicators of a specific food intolerance.
9.4 Limitations of the research

Limitations that pertain specifically to each study are independently discussed within their corresponding chapters. This section considers the thesis as a total research project and presents the major limitations that are considered important when interpreting the overall findings.

An important consideration for this research is that it was not pragmatic to include direct medical or physiological measures within the studies. The inclusion of these would assist in identifying discrepancies between self-reported and actual symptoms being experienced. However, it is important to note that this thesis was not designed with an aim to confirm nor deny the actual presence of physiological symptoms. Instead, it is assumed that self-reported symptoms are of equal importance when assessing the impacts that they have on behaviours, as this process is in itself a factor that can influence health and wellbeing. The limited medical accuracy of self-report measures prevents this research from being utilised as a substitute method for the identification and diagnosis of gluten sensitivity. It is acknowledged that the presence of non-prescribed gluten avoidance does not necessarily indicate the presence of a definable gluten disorder; although, it is likely that some people with undiagnosed gluten sensitivity would be captured within the samples that were collected. Since the study was limited by these factors, it should be considered as a preliminary exploration of the reasons that people engage in non-prescribed gluten avoidance.

The thesis was restricted by the time limits that are typically imposed on a project of this size. Each phase of the research was designed based on a limited understanding of the phenomenon due to the lack of pre-existing literature. A number of unexpected findings meant that some important variables were not included within the original study design; for example, state and trait anxiety. Anxiety may have been a contributing factor; however, it was not reported specifically by participants in Chapter 3. In this sense, the sequential mixed methods design limited the research focus, where the chosen variables of interest were restricted to those explicitly discussed by gluten avoiders themselves in a qualitative setting. This approach was also necessary to restrict the size of the survey so that it was manageable for participants to complete.

Due to the unexpectedly broad nature of the results, there were also no in-depth measures of symptom types for non-gluten foods included in the research design. Initially this inclusion was utilised as a management tool to reduce any social desirability effects that may
have restricted responses about gluten. This prevented any comparison between the specific responses for gluten and non-gluten foods measured via self-report. This comparison would clarify if gastrointestinal specific symptoms (e.g. bloating) were experienced following the consumption of all foods. Findings such as these would allow further distinction between gluten-specific responses (as determined by self-report) and those that are believed to be triggered by non-gluten related digestive processes.

The limitations presented in Chapter 5 are also considered relevant to the thesis as a whole. This section noted that the use of predominantly self-report measures has both advantages and disadvantages in the pursuit of further insights. The majority of the measures used in this thesis have been widely used, have well-established psychometric properties and have been validated in similar samples. Whilst these types of measures allow a researcher access to internal thought processes and perceptions, they are also limited to the participants’ ability to reflect and report on these concepts. Whilst these limitations need to be considered in considerations of validity, they are also accepted as additional factors of interest for the overall research questions. The perceptions and capacity of these participants would likewise be impacting their actual experience of food-related symptoms, and the way that they respond to them. Therefore, even if their direct responses are limited, their overall response patterns are considered as an additional indicator of their overall cognitive style.

Although the findings indicate that gluten avoiders are experiencing more general symptoms for a range of foods, it does not exclude the possibility that they are experiencing gluten sensitivity amongst a range of additional co-morbid food sensitivities within a central sensitivity syndrome. Such clarifications will not be able to be made until there is a significant improvement in the ease and accessibility of accurate diagnostic processes. However, it is important to note that such a presentation would be more indicative of food hypersensitivity as defined by the experience of adverse physiological reactions to multiple food triggers. This thesis, along with other research, provides evidence that symptom monitoring, attentional biases, and a generally higher baseline of autonomic arousability may confound such hypersensitive presentations. Consequently, it is unlikely that such a presentation can be triggered by physiological reactions alone without the additional impact of psychological factors. Health related symptoms are intimately connected with psychological wellbeing, and future research needs to consider this when targeting populations reporting the existence of medically unexplained physiological symptoms.
Despite the range of practical and theoretical limitations in this thesis, the research remains applicable and generalisable across the population of non-prescribed gluten avoiders within Australia. The studies were designed to achieve maximum representativeness within the confines of the thesis parameters. Sophisticated sampling techniques were adopted by a professional research company and reflected the most accurate national population data available. The findings that were gleamed from these studies are also likely to be appropriate for comparison in other Western cultures that have similar demographic profiles and are equally as established. Although preliminary in nature, these results provide some substantial insights into the mechanisms that drive these behaviours, and have established some clear pathways for future research in this field.

9.5 Suggestions for future research

This thesis acts as a preliminary exploration of factors that influence the adoption of non-prescribed gluten avoidance. However, there is a range of issues that are yet to be addressed, and further research is necessary to clarify the assumptions made here on a more confident basis.

There is great difficulty in establishing causality between physiological issues and their relation to psychological factors, such as perception and emotions. This process is further complicated when considering the impact of food, nutrition and gastrointestinal diseases. A natural progression of the current thesis would be to include simple food trials and direct physiological measures to assess likely responses in the gut. This would also assist researchers in discriminating between gluten-specific effects versus those that are recognised more generally during digestion. There is also utility in investigating measures of non-gut related physiological responses (e.g., pain, temperature sensitivity, sound perception) in order to confirm the likelihood of gluten avoiders suffering from broad sensitivity issues as opposed to gut-related ones. More broadly, research is needed to determine whether the positive impact that avoiders report following their diets relates to foods at all, or whether the monitoring and organisation associated with such a diet allows them to remain focused and engaged with a quasi self-care strategy. Similar cognitive strategies are known to improve one’s mindfulness skills, and thus the ability to detect and cope with distress in multiple settings. Considering the likely role that modern health worries and anxiety play in the perpetuation of food-based symptoms, this method may indirectly improve emotional awareness and somatic expression. Longitudinal studies could be utilised in this regard to monitor the impacts of cognitive therapies over time, to assess whether there is a reduction in
self-reported symptoms. Longitudinal studies would also reveal whether changes in attitudes over time relate to the frequency with which gluten avoiders choose to avoid gluten. This would be of interest in both clinically treated populations, and untreated NPGAs which have maintained the diet throughout the lifespan. It is noted that there are innate difficulties with longitudinal studies relating to dietary behaviours, as there is no practical way to measure the accuracy with which participants are reporting their eating behaviours over time. Therefore, a study of this nature would need to implement contingencies to mitigate these issues.

The experience of anxiety-like symptoms reported by gluten avoiders needs to be further examined in the context of generalised anxiety. Incorporating measures such as State-Trait Anxiety Inventory (STAI) will help to clarify existing diagnoses of anxiety, as well as provide added potential to measure changes in stress that occur over time. The STAI has previously been shown to be sensitive to distress levels that vary due to changes in support systems and health (Elliott, Shewchuk, & Richards, 2001), which makes it uniquely applicable to research looking to gauge the effectiveness of new treatments and policy changes. Measures like the Visceral Sensitivity Index (Labus et al., 2004) would help to assess the role that gastrointestinal symptom-specific anxiety plays in non-prescribed gluten avoidance. The fact that such measures were not included impacts the assumptions that can be drawn from findings in relation to ruminative thoughts and modern health worries. It also prevents the creation of a full and complete model of gluten avoidance. Future research should address these limitations by observing a range of food avoiders in relation to their psychological state, including measures of typical disorders such as anxiety and depression. This research could also add weight to the findings presented in Phase A that indicates non-prescribed gluten avoiders are impacted on an emotional level by their experiences and the way they are treated by others. To develop a full clinical picture of gluten avoiders, additional studies will be needed to capture existing mental health conditions or risk factors that may further increase their risk to said conditions.

Non-prescribed gluten avoiders were shown to be a homogenous group of people that are predisposed to have specific physiological responses in the context of food intolerances. This group was easily distinguished from gluten consumers on the basis of their persistent characteristics, leading to the suggestion that they be defined more simply as general avoiders of foods. The homogenous nature of this groups suggests that they may be able to be identified through simple screening questions relating to food preferences, sensitivity and personality. Developing such a scale or questionnaire is beyond the scope of
this research, however it is possible that such a tool may be easily fashioned from some of the measures used in Phase C, or those that measure similar variables. Further work is required to establish the predictive value in such a scale, which could then be used in clinical settings to avoid lengthy and possible misdirected medical investigations.

Future work should also consider a full independent analysis of those eliminated from the current study as a possible ‘fad diet’ group. This group included those that avoided gluten but reported a total lack of adverse symptoms following its consumption. In the current study this population was fairly small, so future studies should look to collect a much larger group of this population to properly assess the motivations for their behaviours. This group would be of particular interest regarding the common assumption that they are prone to the adoption of ‘fad diets’. Items of relevance within such a design would include information pertaining to previous dietary behaviours, as well as links to other persons suffering from a diagnosed gluten-related disorder. These factors could be compared against personality profiles to assess whether 1) there is a true “fad” group, and 2) if so, how these people are generally characterised.

To effectively design these additional studies, there are some things that future researchers must consider when targeting this specific population. Although health and behaviour research relies primarily on self-report measures, it often does not explore the way that personality traits impact these response patterns. Several studies have already demonstrated the significant effects that can occur when certain personality types are not otherwise accounted for within the data. The findings presented in this thesis suggest that non-prescribed gluten avoiders typically belong to a group with predictable personality profiles that are high in openness to experience and neuroticism. In combination, these traits are likely to skew the responses of this population and this needs to be accounted for in any analysis that follows. One way that these influences can be managed is to ensure a range of measures are utilised, including those that are based on self-report, those that have less face validity, and those which are entirely objective in nature. A three-way comparison of these measures should allow for a more sophisticated observation of the interactions that occur between personality, perception and behaviours.

9.6 Conclusion

This study was the first to adopt a mixed-methods approach to assess the role that a variety of factors play in the decision to follow a non-prescribed GFD. This research
identified many shared experiences described by non-prescribed gluten avoiders that mirrored concerns by patients in other contested illnesses. Gluten avoiders also reported experiencing higher rates of somatisation alongside frequent adverse symptoms experienced after the consumption of gluten, dairy, eggs, carbohydrates, fats and preservatives. Strong negative food perceptions were shown to interact with these symptoms and behaviours, indicating the likely role that psychological factors play in making this decision. This notion was extended upon with the observations of individual differences which revealed gluten avoiders had higher levels of autonomic arousability, were much more likely to amplify internal stimuli and were substantially higher in personality traits such as openness and neuroticism.

Together, these findings indicated that this population is a homogenous group which is attending to more, sensing more, feeling more and responding more strongly to a range of foods and their effects. Overall, the research established large differences in psychological features between gluten avoiders and controls, which indicate that their behaviours cannot be fully understood without consideration of the role that these also play. These findings can assist health practitioners to better respond to people who present with medically unexplained symptoms that they believe are associated with gluten. Product developers can utilise these insights to ensure that they account for the possible shift in demand for gluten-free foods once the mechanisms behind gluten sensitivity are refined. Finally, researchers can also utilise these results when building on the insights developed here, to ensure that their data does not become significantly skewed by the factors that shape the perceptions and reporting of this population.

The findings in this thesis provide a new understanding of the mechanisms that drive gluten avoidance behaviours. This research utilised insights from the population to build surveys that could quantitatively examine which variables best characterise this population. The findings provide unequivocal support for the definition of non-prescribed gluten avoiders as a unique group that needs to be examined within the context of their wider behaviours, as opposed to their physiological response to gluten alone. Perhaps the group would be better defined more simply as general avoiders, whose behaviours could transfer to different food types based on their emotional state, cognitive focus and exposure to risk messages. Whilst the trigger of self-reported symptoms is difficult to establish, this thesis has provided deeper insight into the relationship between the physiological and psychological variables that influence the experience of food digestion, and the interpretation of the symptoms that follow.
Not only does this thesis provide a unique opportunity to begin addressing unnecessary gluten avoidance, but it also allows for the targeting of other food-avoidance patterns that may occur because of similar mechanisms. These insights will inform non-prescribed gluten avoiders and their health care professionals about key factors that need to be addressed in order to improve the symptoms being experienced. The findings can also be used to inform health policy, best-practice standards, and education packages that ensure that the specific needs of this unique group are met.
References


GLUTEN AVOIDANCE

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Metchikoff, E. D. (2014). *Examining knowledge of the gluten-free diet among non-celiacs following the diet*. California State University, Long Beach.


Moore, L. R. (2014). “But we're not hypochondriacs”: The changing shape of gluten-free dieting and the contested illness experience. *Social Sciences and Medicine, 105*, 76-83. doi:10.1016/j.socscimed.2014.01.009


Appendix A – Ethics approval for qualitative study

27 November 2015

Kyah Hester
48 Springfield Way
DUBBO NSW 2830

Dear Kyah,

The Arts Faculty Human Ethics Committee has approved the variation to your proposal ‘Non-Coeliac gluten avoidance: Trust and the perception of risk’ for an additional twelve month period from 27 November 2015.

The protocol number issued with respect to this project is 100/2015/134. Please be sure to quote this number when responding to any request made by the Committee.

Please note the following conditions of approval:

- all Consent Forms and Information Sheets are to be printed on CSU letterhead. Students should liaise with their Supervisor to arrange to have these documents printed;
- you must notify the Committee immediately in writing should your research differ in any way from that proposed. Forms are available at www.csu.edu.au/research/forms/ehrc_anrep.doc;
- you must notify the Committee immediately if any serious and or unexpected adverse events or outcomes occur associated with your research, that might affect the participants and therefore ethical acceptability of the project;
- amendments to the research design must be reviewed and approved by the Faculty Human Ethics Committee or if no longer minimal risk research referred to the University Human Research Ethics Committee before commencement. Forms are available at the website above;
- if an extension of the approval period is required, a request must be submitted to the Faculty Human Ethics Committee or if no longer minimal risk research referred to the University Human Research Ethics Committee. Forms are available at the website above;
- you are required to complete a Progress Report form, which can be downloaded as above, by 27 November 2016 if your research has not been completed by that date;
- you are required to submit a final report, the form is available from the website above.

You are reminded that an approval letter from the FHEC constitutes ethical approval only.

If your research involves the use of radiation, biological materials or chemicals separate approval is required from the appropriate University Committee.

Please don’t hesitate to contact the Executive Officer by telephone (02) 6933 4799 or email artsfhec@csu.edu.au if you have any enquiries about this matter.
Yours sincerely,

Pseud

Dr Andrew McGreth
Chairperson
Arts Faculty Human Ethics Committee
Telephone 633 84591
Email artshec@csu.edu.au

NOTE: Variation to original ethics approval was required due to lack of participant interest. Variation included the addition of a $25 Myer gift card as incentive to encourage participants to apply.
Appendix B – Advertisement for qualitative study

Looking for participants:
Are you following a gluten-free diet without a diagnosis of Coeliac Disease??
By understanding the experiences of this population, we can create targeted resources and evidence based food information sources to promote health and wellbeing.

I’m looking for non-coeliac gluten avoiders to participate in my PhD project. You must be over 18, in Australia and never have received a diagnosis of Coeliac Disease or Non-Coeliac Gluten Sensitivity from a medical professional.

This study will require you to participate in an online interview via Skype. You will be asked questions about your experience by a trained professional, including your attitudes towards gluten, and motivations that encourage you to continue following the gluten-free diet.

If you, or anyone you know fit this target group, I would appreciate you taking the time to consider reading my information sheet and getting in touch. I’d love to hear from you and arrange a time to chat.

Regards,
Kyah Hester

This study is investigating the attitudes and determinants which lead non-coeliacs to choose a gluten-free lifestyle. This research is being conducted by Kyah Hester as part of Doctorate thesis in psychology at Charles Sturt University. Kyah is working under the supervision of Professor Anthony Saltba, who can be contacted on 02 6933 2306 or by email at asaltba@csu.edu.au. The project has been funded by the Australian Research Council (ARC – ITTC Scholarship) under a transformational project that aims to examine issues impacting grains consumption.

There is evidence to suggest the sale and consumption of gluten free products is growing more popular for people whom have not been diagnosed with Coeliac Disease. While gluten avoidance is the only treatment option for Coeliac Disease, there are those without an formal medical diagnosis that also choose to follow this dietary restriction. Gluten-free diets are often linked to a big lifestyle change, and as such choices of this nature are not made lightly. This study is dedicated to learning about the individual experience of making this choice.

Your experience will be captured via a semi-structured interview via the free online teleconferencing software Skype. Skype provides encrypted protection of your communications, see their privacy policy here. The video-call interview will be approximately one hour long, and will be centred around your experience choosing to follow a gluten-free diet.

If you do not wish to use your personal Skype account, or do not have one, an anonymous Skype account and password can be made for you by the researcher. You will be interviewed directly by the researcher at a time that is convenient for both parties, as agreed via email. You will require access to a computer with internet and a webcam for participation to be successful.

The Skype interview will be captured via audio recording for transcription purposes. This is necessary for the conversations to be analysed in the future. If you would not like your conversation recorded, you are welcome to stop reading and withdraw your participation from the research now without any consequences. The video component of the conversation is necessary to maintain rapport and allow the assessor to respond to cues during the conversation.

PhD Information Sheet.doc

DRIVE.GOOGLE.COM
Appendix C – Information sheet for qualitative study

This research is being conducted by Kyah Hester as part of a doctoral thesis in psychology at Charles Sturt University. Kyah is working under the supervision of Professor Anthony Saliba, who can be contacted on 02 6933 2306 or by email at asaliba@csu.edu.au. The project has been funded by the Australian Research Council (ARC – ITTC Scholarship) under a transformational project that aims to examine issues impacting grains consumption. This study is investigating the attitudes and determinants which lead non-coeliacs to choose a gluten-free lifestyle.

Participants will be awarded a $20 Myer e-gift card to compensate them for the time they devote to the study.

There is evidence to suggest that the sale and consumption of gluten free products is growing more popular for people who have not been diagnosed with Coeliac Disease. While gluten avoidance is the only treatment option for Coeliac Disease, there are those without a formal medical diagnosis who also choose to follow this diet. Gluten-free diets are often linked to big lifestyle changes. This study is dedicated to learning about the individual experience of making this choice.

Your experience will be captured via an online Skype interview. Skype provides encrypted protection of your communications, see their privacy policy [here](#). The video-call interview will be approximately one hour long, and will be centred around your experience choosing to follow a gluten-free diet. If you do not wish to use your personal Skype account, or do not have one, an anonymous Skype account and password can be made for you. You will be interviewed directly by the researcher at a time that is convenient for both parties, as agreed via email. You will require access to a computer with internet and a webcam for participation to be successful.

The Skype interview will be captured via audio recording for transcription purposes. This is necessary for future data analysis. The video portion of the interview will not be recorded. Please advise the researcher if you are strongly against participating in the video portion of the interview.

If you would like to participate, please contact me, Kyah Hester, via email at khester@csu.edu.au, and you will be contacted to arrange a suitable interview time. Your agreement to participate in an online interview will be taken as evidence of consent.

Thank you for your consideration,

Kyah Hester

NOTE: The Faculty of Arts Ethics Committee has approved this project. If you have any complaints or reservations about the ethical conduct of this project, you should forward your response to the Acting Executive Officer, Arts Faculty Human Ethics Committee, by email to aethec@csu.edu.au.

Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.
Appendix D – Interview schedule for qualitative study

GFD AND EFFECTS

1. Can you tell me a bit about the very first time you tried going gluten free? When was that? Why did you try it?
2. How long did it take for you to decide to go gluten free permanently? What information did you base your decision on? Was there a transition period? How did you make the change?
3. Can you give me a run down on the rules of a gluten free diet as you understand them? Are you very strict when adhering to this diet? Have you ever accidentally consumed gluten? Are there any other diets you also follow or have tried?
4. What changes if any have you noticed since being on the diet? What has stayed the same? Has anything gotten worse?
5. How has becoming gluten free changed your life at all? In what ways? How extreme were these changes?
6. Can you tell me about the most important factors you look for when you come to buying your groceries? How would you order the importance of each of these issues? Do these preferences ever change?

ADVICE AND SUPPORT

7. Have you explained your choice to your family/friends at all? What were their reactions? Would you ever encourage them to try the GFD? Why?
8. Do you know anyone else who has tried a gluten free diet? How did it work for them?
9. Have you had any experience interacting with support groups or forums online? How important do you think it is to share your stories with other people? Why? What impact did this have on you?
10. Have you sought advice in the past from a doctor about your diet? What was their advice? Have you ever received conflicting information from professionals? How did you discriminate between opinions?
11. Do you have any other health professionals regularly involved in your eating plan? Why/Why not?

KNOWLEDGE PREFERENCES

1. How would you describe gluten to someone who hasn’t heard of it before? Have you done any research into what gluten is or what it’s made up of?
2. Why do you think that they continue to make and sell gluten-containing products?
3. Where do you prefer to get your information about food and health from? Are there sources that you don’t trust to give you the right information? What makes them untrustworthy?
4. If you had a close friend looking to get into a GFD, which information sources would you direct them to? What factors lead you to trust this source specifically?
5. At the end of the day, do you think everybody would benefit from going gluten free? How do you know if someone is a good candidate for GFD? Is there anyone that the GFD is not appropriate for?
6. Thank you for all that valuable information, is there anything else you’d like to add as a take home message before we come to a close?

**Reasonable judgement will be used to probe further into responses given by participants. These probes will be in the direct context of the main questions**
Appendix E – Ethics approval for quantitative study

1st June, 2016

Miss Kyah Hester
48 Springfield Way
DUBBO NSW 2830

Dear Kyah,

The Arts Faculty Human Ethics Committee has approved your proposal "Non-Coeliac Gluten Avoidance: Trust and the perception of risk" for a twelve month period from 1st June, 2016.

The protocol number issued with respect to this project is 100/2016/174. Please be sure to quote this number when responding to any request made by the Committee.

Please note the following conditions of approval:

- all Consent Forms and Information Sheets are to be printed on CSU letterhead. Students should liaise with their Supervisor to arrange to have these documents printed;
- you must notify the Committee immediately in writing should your research differ in any way from that proposed. Forms are available at http://www.csu.edu.au/research/ethics_safety/human/hrec_forms;
- you must notify the Committee immediately if any serious and or unexpected adverse events or outcomes occur associated with your research, that might affect the participants and therefore ethical acceptability of the project;
- amendments to the research design must be reviewed and approved by the Faculty Human Ethics Committee or if no longer minimal risk research referred to the University Human Research Ethics Committee before commencement. Forms are available at the website above;
- if an extension of the approval period is required, a request must be submitted to the Faculty Human Ethics Committee or if no longer minimal risk research referred to the University Human Research Ethics Committee. Forms are available at the website above;
- you are required to complete a Progress Report form, which can be downloaded as above, by 1st June, 2017 if your research has not been completed by that date;
- you are required to submit a final report, the form is available from the website above.

You are reminded that an approval letter from the FHEC constitutes ethical approval only.

If your research involves the use of radiation, biological materials or chemicals separate approval is required from the appropriate University Committee.

Please don’t hesitate to contact Dr Andrew McGrath, telephone 633 84591 or email artshec@csu.edu.au, if you have any enquiries about this matter.

Yours sincerely,

Dr Andrew McGrath
Chairperson
Telephone 63384591
Email artshec@csu.edu.au
Faculty of Arts Human Ethics Committee

www.csu.edu.au

CRICOS Provider Numbers for Charles Sturt University are 00005F (NSW), 01647G (VIC) and 03600B (ACT). ABN: 13 067 708 561
Appendix F – Information sheet for quantitative study

You are invited to participate in a food choice questionnaire. This research is being conducted by Kyah Hester as part of her doctoral thesis in psychology at Charles Sturt University. If you would like to contact her, you can do so via email at khester@csu.edu.au. Kyah is working under the supervision of Professor Anthony Saliba, who can be contacted on 02 6933 2306 or by email at asaliba@csu.edu.au. The project has been funded by the Australian Research Council (ARC – ITTC Scholarship) under a transformational project that aims to examine a range of issues impacting the Australian food industry.

You will be provided with an online questionnaire which can take up to 20 minutes to complete. Questions will range from demographic questions (age, gender), right through to questions asking about your own personal attitudes and behaviours. All your answers will be linked to an anonymous identification number in order to protect your personal privacy, and will not be able to be linked back to you. You are encouraged not to spend too much time on any one question, and to answer each question to the best of your ability. It is important to answer all the questions, so please don’t skip any. If you wish to exit the survey, you may do so at any time. However, incomplete questionnaires will not be able to be used in the study for accuracy reasons.

Your agreement to participate in the online survey will be taken as evidence of consent.

Please click next to proceed.

NOTE: The Faculty of Arts Ethos Committee has approved this project. If you have any complaints or reservations about the ethical conduct of this project, you should forward your response to the Acting Executive Officer, Arts Faculty Human Ethics Committee, by email to arts@csu.edu.au. Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.
## Appendix G – Survey questions for quantitative study

<table>
<thead>
<tr>
<th>#</th>
<th>Scale</th>
<th>Subscale</th>
<th>Question/item</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>FOOD AVOIDANCE</td>
<td>How much do you avoid eating the following:</td>
</tr>
<tr>
<td>1</td>
<td>Cover Qs</td>
<td>Avoidance</td>
<td>Gluten</td>
</tr>
<tr>
<td>2</td>
<td>Cover Qs</td>
<td>Avoidance</td>
<td>Dairy</td>
</tr>
<tr>
<td>3</td>
<td>Cover Qs</td>
<td>Avoidance</td>
<td>Eggs</td>
</tr>
<tr>
<td>4</td>
<td>Cover Qs</td>
<td>Avoidance</td>
<td>Carbohydrates</td>
</tr>
<tr>
<td>5</td>
<td>Cover Qs</td>
<td>Avoidance</td>
<td>Fats</td>
</tr>
<tr>
<td>6</td>
<td>Cover Qs</td>
<td>Avoidance</td>
<td>Preservatives</td>
</tr>
<tr>
<td></td>
<td></td>
<td>FOOD SYMPTOMS</td>
<td>How often have you experienced negative symptoms after eating the following:</td>
</tr>
<tr>
<td>7</td>
<td>Cover Qs</td>
<td>Symptoms</td>
<td>Gluten</td>
</tr>
<tr>
<td>8</td>
<td>Cover Qs</td>
<td>Symptoms</td>
<td>Dairy</td>
</tr>
<tr>
<td>9</td>
<td>Cover Qs</td>
<td>Symptoms</td>
<td>Eggs</td>
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<td>Symptoms</td>
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<td>Cover Qs</td>
<td>Symptoms</td>
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<td>12</td>
<td>Cover Qs</td>
<td>Symptoms</td>
<td>Preservatives</td>
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<tr>
<td></td>
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<td>RISK PERCEPTIONS</td>
<td>How much risk do you believe is associated with eating the following:</td>
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<td>13</td>
<td>Cover Qs</td>
<td>Risk</td>
<td>Gluten</td>
</tr>
<tr>
<td>14</td>
<td>Cover Qs</td>
<td>Risk</td>
<td>Dairy</td>
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<td>15</td>
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<td>Risk</td>
<td>Eggs</td>
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<tr>
<td>16</td>
<td>Cover Qs</td>
<td>Risk</td>
<td>Carbohydrates</td>
</tr>
<tr>
<td>17</td>
<td>Cover Qs</td>
<td>Risk</td>
<td>Fats</td>
</tr>
<tr>
<td>18</td>
<td>Cover Qs</td>
<td>Risk</td>
<td>Preservatives</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HEALTH PERCEPTIONS</td>
<td>How healthy do you believe the following are:</td>
</tr>
<tr>
<td>19</td>
<td>Cover Qs</td>
<td>Health</td>
<td>Gluten</td>
</tr>
<tr>
<td>20</td>
<td>Cover Qs</td>
<td>Health</td>
<td>Dairy</td>
</tr>
<tr>
<td>21</td>
<td>Cover Qs</td>
<td>Health</td>
<td>Eggs</td>
</tr>
<tr>
<td>22</td>
<td>Cover Qs</td>
<td>Health</td>
<td>Carbohydrates</td>
</tr>
<tr>
<td>23</td>
<td>Cover Qs</td>
<td>Health</td>
<td>Fats</td>
</tr>
<tr>
<td>24</td>
<td>Cover Qs</td>
<td>Health</td>
<td>Preservatives</td>
</tr>
<tr>
<td></td>
<td></td>
<td>PHQ15</td>
<td>During the past 4 weeks how much have you been bothered by any of the following problems</td>
</tr>
<tr>
<td>1</td>
<td>PHQ15</td>
<td>DIG</td>
<td>Stomach pain</td>
</tr>
<tr>
<td>2</td>
<td>PHQ15</td>
<td>PHQ12</td>
<td>Back pain</td>
</tr>
<tr>
<td>3</td>
<td>PHQ15</td>
<td>PHQ12</td>
<td>Pain in your arms or legs or other joints</td>
</tr>
<tr>
<td>4</td>
<td>PHQ15</td>
<td>PHQ12</td>
<td>Menstrual cramps or other problems with your periods (women only)</td>
</tr>
<tr>
<td>5</td>
<td>PHQ15</td>
<td>PHQ12</td>
<td>Headaches</td>
</tr>
<tr>
<td>6</td>
<td>PHQ15</td>
<td>PHQ12</td>
<td>Chest Pain</td>
</tr>
<tr>
<td>7</td>
<td>PHQ15</td>
<td>PHQ12</td>
<td>Dizziness</td>
</tr>
<tr>
<td>8</td>
<td>PHQ15</td>
<td>PHQ12</td>
<td>Fainting spells</td>
</tr>
<tr>
<td>9</td>
<td>PHQ15</td>
<td>PHQ12</td>
<td>Feeling your heart pound or race</td>
</tr>
<tr>
<td>10</td>
<td>PHQ15</td>
<td>PHQ12</td>
<td>Shortness of breath</td>
</tr>
<tr>
<td>11</td>
<td>PHQ15</td>
<td>PHQ12</td>
<td>Pain or problems during sexual intercourse</td>
</tr>
<tr>
<td>12</td>
<td>PHQ15</td>
<td>DIG</td>
<td>Constipation, loose bowels, or diarrhea</td>
</tr>
<tr>
<td></td>
<td>PHQ15</td>
<td>FCQ-R</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>13</td>
<td>PHQ15</td>
<td>DIQ</td>
<td>Nausea, gas, or indigestion</td>
</tr>
<tr>
<td>SPECIFIC GLUTEN SYMPTOMS</td>
<td>After eating products containing gluten, how much have you been bothered by the following:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Gluten effects</td>
<td>Symptom frequency</td>
<td>Fatigue</td>
</tr>
<tr>
<td>2</td>
<td>Gluten effects</td>
<td>Symptom frequency</td>
<td>Headaches</td>
</tr>
<tr>
<td>3</td>
<td>Gluten effects</td>
<td>Symptom frequency</td>
<td>Stomach cramps</td>
</tr>
<tr>
<td>4</td>
<td>Gluten effects</td>
<td>Symptom frequency</td>
<td>Bloating</td>
</tr>
<tr>
<td>5</td>
<td>Gluten effects</td>
<td>Symptom frequency</td>
<td>Weight gain</td>
</tr>
<tr>
<td>6</td>
<td>Gluten effects</td>
<td>Symptom frequency</td>
<td>Skin rash/sores</td>
</tr>
<tr>
<td>7</td>
<td>Gluten effects</td>
<td>Symptom frequency</td>
<td>Mood changes</td>
</tr>
<tr>
<td>8</td>
<td>Gluten effects</td>
<td>Symptom frequency</td>
<td>Diarrhea</td>
</tr>
<tr>
<td>9</td>
<td>Gluten effects</td>
<td>Symptom frequency</td>
<td>Brain fog</td>
</tr>
<tr>
<td>10</td>
<td>Gluten effects</td>
<td>Symptom frequency</td>
<td>Dizziness</td>
</tr>
<tr>
<td>11</td>
<td>Gluten effects</td>
<td>Symptom frequency</td>
<td>Hormone issues</td>
</tr>
<tr>
<td>12</td>
<td>Gluten effects</td>
<td>Symptom frequency</td>
<td>Inflammation</td>
</tr>
<tr>
<td>SASS</td>
<td>Please rate how much you agree with each of the following statements:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>SSAS</td>
<td>External</td>
<td>When someone else coughs, it makes me cough too.</td>
</tr>
<tr>
<td>2</td>
<td>SSAS</td>
<td>External</td>
<td>I can't stand smoke, smog, or pollutants in the air.</td>
</tr>
<tr>
<td>3</td>
<td>SSAS</td>
<td>Internal</td>
<td>I am often aware of various things happening within my body.</td>
</tr>
<tr>
<td>4</td>
<td>SSAS</td>
<td>Internal</td>
<td>When I bruise myself, it stays noticeable for a long time.</td>
</tr>
<tr>
<td>5</td>
<td>SSAS</td>
<td>External</td>
<td>I hate to be too hot or too cold.</td>
</tr>
<tr>
<td>6</td>
<td>SSAS</td>
<td>Internal</td>
<td>I can sometimes hear my pulse or my heartbeat throbbing in my ear.</td>
</tr>
<tr>
<td>8</td>
<td>SSAS</td>
<td>Internal</td>
<td>I am quick to sense the hunger contractions in my stomach.</td>
</tr>
<tr>
<td>9</td>
<td>SSAS</td>
<td>Internal</td>
<td>Even something minor, like an insect bite or a splinter, really bothers me.</td>
</tr>
<tr>
<td>10</td>
<td>SSAS</td>
<td>Internal</td>
<td>I have a low tolerance for pain.</td>
</tr>
<tr>
<td>FCQ-R</td>
<td>It is important to me that the food I eat on a typical day:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>FCQ - R</td>
<td>Health</td>
<td>Is high in fibre and roughage</td>
</tr>
<tr>
<td>2</td>
<td>FCQ - R</td>
<td>Mood</td>
<td>Cheers me up</td>
</tr>
<tr>
<td>3</td>
<td>FCQ - R</td>
<td>Convenience</td>
<td>Is easy to prepare</td>
</tr>
<tr>
<td>4</td>
<td>FCQ - R</td>
<td>Sensory appeal</td>
<td>Tastes good</td>
</tr>
<tr>
<td>5</td>
<td>FCQ - R</td>
<td>Natural content</td>
<td>Contains no additives</td>
</tr>
<tr>
<td>6</td>
<td>FCQ - R</td>
<td>Price</td>
<td>Is not expensive</td>
</tr>
<tr>
<td>7</td>
<td>FCQ - R</td>
<td>Weight control</td>
<td>Is low in calories</td>
</tr>
<tr>
<td>8</td>
<td>FCQ - R</td>
<td>Familiarity</td>
<td>Is familiar</td>
</tr>
<tr>
<td>9</td>
<td>FCQ - R</td>
<td>Health</td>
<td>Is nutritious</td>
</tr>
<tr>
<td>10</td>
<td>FCQ - R</td>
<td>Mood</td>
<td>Helps me cope with stress</td>
</tr>
<tr>
<td>11</td>
<td>FCQ - R</td>
<td>Convenience</td>
<td>Can be cooked very simply</td>
</tr>
<tr>
<td>12</td>
<td>FCQ - R</td>
<td>Sensory appeal</td>
<td>Smells nice</td>
</tr>
<tr>
<td>13</td>
<td>FCQ - R</td>
<td>Natural content</td>
<td>Contains natural ingredients</td>
</tr>
<tr>
<td>14</td>
<td>FCQ - R</td>
<td>Price</td>
<td>Is cheap</td>
</tr>
<tr>
<td>15</td>
<td>FCQ - R</td>
<td>Weight control</td>
<td>Is low in fat</td>
</tr>
<tr>
<td>16</td>
<td>FCQ - R</td>
<td>Familiarity</td>
<td>Is like the food I ate when I was a child</td>
</tr>
<tr>
<td>17</td>
<td>FCQ - R</td>
<td>Health</td>
<td>Contains a lot of vitamins and minerals</td>
</tr>
<tr>
<td>18</td>
<td>FCQ - R</td>
<td>Mood</td>
<td>Helps me relax</td>
</tr>
<tr>
<td>19</td>
<td>FCQ - R</td>
<td>Convenience</td>
<td>Takes no time to prepare</td>
</tr>
<tr>
<td>20</td>
<td>FCQ - R</td>
<td>Sensory appeal</td>
<td>Has a pleasant texture</td>
</tr>
<tr>
<td>21</td>
<td>FCQ - R</td>
<td>Natural content</td>
<td>Contains no artificial ingredients</td>
</tr>
<tr>
<td>22</td>
<td>FCQ - R</td>
<td>Weight control</td>
<td>Helps me control my weight</td>
</tr>
<tr>
<td>23</td>
<td>FCQ - R</td>
<td>Health</td>
<td>Keeps me healthy</td>
</tr>
<tr>
<td>24</td>
<td>FCQ - R</td>
<td>Mood</td>
<td>Makes me feel good</td>
</tr>
</tbody>
</table>

**FNS**  
*Please rate how much each statement reminds you of yourself:*

1. FNS  Neophobia  I am constantly sampling new and different foods.
2. FNS  Neophobia  I don’t trust new foods.
3. FNS  Neophobia  If I don’t know what is in a food, I won’t try it.
4. FNS  Neophobia  I like foods from different countries.
5. FNS  Neophobia  Ethnic food looks too weird to eat.
6. FNS  Neophobia  At dinner parties, I will try a new food.
7. FNS  Neophobia  I am afraid to eat things I have never had before.
8. FNS  Neophobia  I am very particular about the foods I will eat.
9. FNS  Neophobia  I will eat almost anything.
10. FNS  Neophobia  I like to try new ethnic restaurants,

**MSTAT-1**  
*Please rate how much you agree with each of the following statements:*

1. MSTAT - I  Tolerance  I don’t tolerate ambiguous situations well.
2. MSTAT - I  Tolerance  I find it difficult to respond when faced with an unexpected event.
3. MSTAT - I  Tolerance  I’m drawn to situations which can be interpreted in more than one way.
4. MSTAT - I  Tolerance  I would rather avoid solving a problem that must be viewed from several different perspectives.
5. MSTAT - I  Tolerance  I try to avoid situations which are ambiguous.
6. MSTAT - I  Tolerance  I am good at managing unpredictable situations.
7. MSTAT - I  Tolerance  I prefer familiar situations to new ones.
8. MSTAT - I  Tolerance  Problems which cannot be considered from just one point of view are a little threatening.
9. MSTAT - I  Tolerance  I avoid situations which are too complicated for me to easily understand.
10. MSTAT - I  Tolerance  I am tolerant of ambiguous situations.
11. MSTAT - I  Tolerance  I enjoy tackling problems which are complex enough to be ambiguous.
12. MSTAT - I  Tolerance  I try to avoid problems which don’t seem to have only one “best” solution.
13. MSTAT - I  Tolerance  I often find myself looking for something new, rather than trying to hold things constant in my life.
14. MSTAT - I  Tolerance  I generally prefer novelty over familiarity.
15. MSTAT - I  Tolerance  I dislike ambiguous situations.
16. MSTAT - I  Tolerance  Some problems are so complex that just trying to understand them is fun.
| 18 | MSTAT - I | Tolerance | I have little trouble coping with unexpected events. |
| 19 | MSTAT - I | Tolerance | I pursue problem situations which are so complex some people call them “mind boggling”. |
| 20 | MSTAT - I | Tolerance | I find it hard to make a choice when the outcome is uncertain. |
| 21 | MSTAT - I | Tolerance | I enjoy an occasional surprise. |
| 22 | MSTAT - I | Tolerance | I prefer a situation in which there is some ambiguity. |

**GP EXPERIENCE**

Please rate your overall experience with doctors at:

| 1 | CARE | Experience | Making you feel at ease |
| 2 | CARE | Experience | Letting you tell your story |
| 3 | CARE | Experience | Listening to you |
| 4 | CARE | Experience | Showing care and compassion |
| 5 | CARE | Experience | Explaining things clearly |
| 6 | CARE | Experience | Offering helpful advice |
| 7 | CARE | Experience | Making a plan of action with you |
| 8 | CARE | Experience | Overall how would you rate your consultation with doctors |
| 9 | CARE | Experience | How often do you visit the doctor typically |

**REI-40**

Please rate how much you agree with each of the following statements:

<p>| 1 | REI | RE | I try to avoid situations that require thinking in depth about something |
| 2 | REI | RA | I’m not that good at figuring out complicated problems |
| 3 | REI | RE | I enjoy intellectual challenges |
| 4 | REI | RA | I am not very good at solving problems that require careful logical analysis |
| 5 | REI | RE | I don’t like to have to do a lot of thinking. |
| 6 | REI | RE | I enjoy solving problems that require hard thinking |
| 7 | REI | RE | Thinking is not my idea of an enjoyable activity |
| 8 | REI | RA | I am not a very analytical thinker |
| 9 | REI | RA | Reasoning things out carefully is not one of my strong points. |
| 10 | REI | RE | I prefer complex to simple problems. |
| 11 | REI | RE | Thinking hard and for a long time about something gives me little satisfaction. |
| 12 | REI | RA | I don’t reason well under pressure. |
| 13 | REI | RA | I am much better at figuring things out logically than most people. |
| 14 | REI | RA | I have a logical mind. |
| 15 | REI | RE | I enjoy thinking in abstract terms. |
| 16 | REI | RA | I have no problem thinking things through carefully. |
| 17 | REI | RA | Using logic usually works well for me in figuring out problems in my life. |
| 18 | REI | RE | Knowing the answer without having to understand the reasoning behind it is good enough for me |
| 19 | REI | RA | I usually have clear, explainable reasons for my decisions. |
| 20 | REI | RE | Learning new ways to think would be very appealing to me. |
| 21 | REI | EE | I like to rely on my intuitive impressions. |
| 22 | REI | EA | I don’t have a very good sense of intuition. |
| 23 | REI | EA | Using my gut feelings usually works well for me in figuring out my problems in life. |
| 24 | REI | EA | I believe in trusting my hunches. |
| 25 | REI | EE | Intuition can be a very useful way to solve problems. |
| 26 | REI | EE | I often go by my instincts when deciding on a course of action. |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>27</td>
<td>REI</td>
<td>EA</td>
<td>I trust my initial feelings about people.</td>
</tr>
<tr>
<td>28</td>
<td>REI</td>
<td>EA</td>
<td>When it comes to trusting people, I can usually rely on my 'gut feelings'.</td>
</tr>
<tr>
<td>29</td>
<td>REI</td>
<td>EA</td>
<td>If I were to rely on my gut feelings, I would often make mistakes.</td>
</tr>
<tr>
<td>30</td>
<td>REI</td>
<td>EE</td>
<td>I don’t like situations in which I have to rely on intuition.</td>
</tr>
<tr>
<td>31</td>
<td>REI</td>
<td>EE</td>
<td>I think there are times when one should rely on one’s intuition for important decisions.</td>
</tr>
<tr>
<td>32</td>
<td>REI</td>
<td>EE</td>
<td>I think it is foolish to make important decisions based on feelings.</td>
</tr>
<tr>
<td>33</td>
<td>REI</td>
<td>EE</td>
<td>I don’t think it is a good idea to rely on one’s intuition for important decisions.</td>
</tr>
<tr>
<td>34</td>
<td>REI</td>
<td>EE</td>
<td>I generally don’t depend on my feelings to help me make decisions.</td>
</tr>
<tr>
<td>35</td>
<td>REI</td>
<td>EA</td>
<td>I hardly ever go wrong when I listen to my deepest gut feelings to find an answer.</td>
</tr>
<tr>
<td>36</td>
<td>REI</td>
<td>EE</td>
<td>I would not want to depend on anyone who described him/herself as intuitive.</td>
</tr>
<tr>
<td>37</td>
<td>REI</td>
<td>EA</td>
<td>My snap judgements are probably not as good as most people’s.</td>
</tr>
<tr>
<td>38</td>
<td>REI</td>
<td>EE</td>
<td>I tend to use my heart as a guide for my actions.</td>
</tr>
<tr>
<td>39</td>
<td>REI</td>
<td>EA</td>
<td>I can usually feel when a person is right or wrong even if I can’t explain how I know.</td>
</tr>
<tr>
<td>40</td>
<td>REI</td>
<td>EA</td>
<td>I suspect my hunches are inaccurate as often as they are accurate.</td>
</tr>
</tbody>
</table>

**INFORMATION SOURCE USE**

<p>| | | | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1</td>
<td>Source Use</td>
<td>Use</td>
<td>Print (Newspaper/Magazine) articles</td>
</tr>
<tr>
<td>2</td>
<td>Source Use</td>
<td>Use</td>
<td>Online articles</td>
</tr>
<tr>
<td>3</td>
<td>Source Use</td>
<td>Use</td>
<td>Written Blogs</td>
</tr>
<tr>
<td>4</td>
<td>Source Use</td>
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<td>Journal articles</td>
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<td>Use</td>
<td>Books</td>
</tr>
<tr>
<td>6</td>
<td>Source Use</td>
<td>Use</td>
<td>Television programs</td>
</tr>
<tr>
<td>7</td>
<td>Source Use</td>
<td>Use</td>
<td>Government Guidelines</td>
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**INFORMATION SOURCE TRUST**

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</tr>
<tr>
<td>2</td>
<td>Source trust</td>
<td>Trust</td>
<td>Online articles</td>
</tr>
<tr>
<td>3</td>
<td>Source trust</td>
<td>Trust</td>
<td>Written Blogs</td>
</tr>
<tr>
<td>4</td>
<td>Source trust</td>
<td>Trust</td>
<td>Journal articles</td>
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</tr>
<tr>
<td>6</td>
<td>Source trust</td>
<td>Trust</td>
<td>Television programs</td>
</tr>
<tr>
<td>7</td>
<td>Source trust</td>
<td>Trust</td>
<td>Government Guidelines</td>
</tr>
</tbody>
</table>

**APS**

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>APS</td>
<td>Arousability</td>
<td>I am a calm person.</td>
</tr>
<tr>
<td>2</td>
<td>APS</td>
<td>Arousability</td>
<td>I get flustered if I have several things to do at once.</td>
</tr>
<tr>
<td>3</td>
<td>APS</td>
<td>Arousability</td>
<td>Sudden changes of any kind produce an immediate emotional effect on me.</td>
</tr>
<tr>
<td>4</td>
<td>APS</td>
<td>Arousability</td>
<td>Strong emotions carry over for one or two hours after I leave the situation which caused them.</td>
</tr>
<tr>
<td>5</td>
<td>APS</td>
<td>Arousability</td>
<td>I am restless and fidgety.</td>
</tr>
<tr>
<td>6</td>
<td>APS</td>
<td>Arousability</td>
<td>My mood is quickly influenced by entering new places.</td>
</tr>
<tr>
<td>7</td>
<td>APS</td>
<td>Arousability</td>
<td>I am excited easily.</td>
</tr>
<tr>
<td>8</td>
<td>APS</td>
<td>Arousability</td>
<td>I find that my heart keeps beating fast for a while after I have been &quot;stirred up&quot;.</td>
</tr>
<tr>
<td>9</td>
<td>APS</td>
<td>Arousability</td>
<td>I can be emotionally moved by what other people consider to be simple things.</td>
</tr>
<tr>
<td>10</td>
<td>APS</td>
<td>Arousability</td>
<td>I startle easily.</td>
</tr>
</tbody>
</table>
### APS Arousability

11. I am easily frustrated.

12. I tend to remain excited or moved for a long period of time after seeing a good movie.

### EDS Discrimination

<table>
<thead>
<tr>
<th></th>
<th>EDS Discrimination</th>
<th>APS Arousability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>You are treated with less courtesy than other people.</td>
<td>I am easily frustrated.</td>
</tr>
<tr>
<td>2</td>
<td>You are treated with less respect than other people.</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>You receive poorer service than other people at restaurants or stores.</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>People act as if they think you are not smart.</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>People act as if they are afraid of you.</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>People act as if they think you are dishonest.</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>People act as if they are better than you are.</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>You or your family members are called names or insulted.</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>You are threatened or harassed.</td>
<td></td>
</tr>
</tbody>
</table>

### BIG5 Extraversion

1. I think of myself as someone who:

2. Is talkative.

3. Tends to find fault with others.

4. Does a thorough job.

5. Is depressed, blue.

6. Is original, comes up with new ideas.

7. Is helpful and unselfish with others

8. Can be somewhat careless.


10. Is curious about many different things.

11. Is full of energy.

12. Starts quarrels with others.

13. Is a reliable worker.

14. Can be tense.

15. Is ingenious, a deep thinker.

16. Generates a lot of enthusiasm.

17. Has a forgiving nature.

18. Tends to be disorganised.

19. Worries a lot.

20. Has an active imagination.

21. Tends to be quiet.

22. Is generally trusting.

23. Tends to be lazy.

24. Is emotionally stable, not easily upset.

25. Is inventive.

26. Has an assertive personality.

27. Can be cold and aloof.

28. Perseveres until the task is finished.

29. Can be moody.

30. Values artistic, aesthetic experiences.

31. Is sometimes shy, inhibited.
<table>
<thead>
<tr>
<th></th>
<th>BIG5</th>
<th>Personality Trait</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>32</td>
<td>BIG5</td>
<td>Agreeableness</td>
<td>Is considerate and kind to almost everyone.</td>
</tr>
<tr>
<td>33</td>
<td>BIG5</td>
<td>Conscientiousness</td>
<td>Does things efficiently.</td>
</tr>
<tr>
<td>34</td>
<td>BIG5</td>
<td>Neuroticism</td>
<td>Remains calm in tense situations.</td>
</tr>
<tr>
<td>35</td>
<td>BIG5</td>
<td>Openness</td>
<td>Prefers work that is routine.</td>
</tr>
<tr>
<td>36</td>
<td>BIG5</td>
<td>Extraversion</td>
<td>Is outgoing, sociable.</td>
</tr>
<tr>
<td>37</td>
<td>BIG5</td>
<td>Agreeableness</td>
<td>Is sometimes rude to others.</td>
</tr>
<tr>
<td>38</td>
<td>BIG5</td>
<td>Conscientiousness</td>
<td>Makes plans and follows through with them.</td>
</tr>
<tr>
<td>39</td>
<td>BIG5</td>
<td>Neuroticism</td>
<td>Gets nervous easily.</td>
</tr>
<tr>
<td>40</td>
<td>BIG5</td>
<td>Openness</td>
<td>Likes to reflect, play with ideas.</td>
</tr>
<tr>
<td>41</td>
<td>BIG5</td>
<td>Openness</td>
<td>Has few artistic interests.</td>
</tr>
<tr>
<td>42</td>
<td>BIG5</td>
<td>Agreeableness</td>
<td>Likes to cooperate with others.</td>
</tr>
<tr>
<td>43</td>
<td>BIG5</td>
<td>Conscientiousness</td>
<td>Is easily distracted.</td>
</tr>
<tr>
<td>44</td>
<td>BIG5</td>
<td>Openness</td>
<td>Is sophisticated in art, music or literature.</td>
</tr>
</tbody>
</table>

END SURVEY