The impact of food allergy on household level

Jantine Voordouw

Thesis committee

Thesis supervisors
Prof. dr. L.J. Frewer
Professor of Food Safety and Consumer Behaviour
Wageningen University

Prof. dr. G. Antonides
Professor of Economics of Consumers and Households
Wageningen University

Thesis co-supervisor
Dr. ir. J.R. Cornelisse-Vermaat
Post-doc researcher
Wageningen University

Other members
Dr. A. Dunn Galvin, University College Cork, Ireland
Prof. dr. H. Maassen van den Brink, University of Amsterdam
Prof. dr. W.F. van Raaij, Tilburg University
Prof. dr. C.M.J. van Woerkum, Wageningen University

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Jantine Voordouw

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To my grandfather Bram Neuteboom the angel of my life time

Contents

Chapter 1

General introduction

1.1 Introduction

Adverse reactions to food can be caused by food allergy or food intolerance. The classification of adverse reactions to food is shown in Figure 1 (Patriarca et al., 2009). Patients suffering from food allergy have inappropriate reactions of their autoimmune system to potentially harmless food components. Food allergy is immune mediated and can be IgE-mediated (e.g., food allergies) or non-IgE-mediated (e.g., celiac disease). In the case of food intolerance the immune system is not involved (e.g., lactose deficiency). The same food products may cause reactions in food allergic patients and patients with food intolerances. The majority of the food allergic reactions are caused by the following foods; milk, egg, peanuts, tree nuts, fish, soya, wheat and shellfish (Rona et al., 2007). Food allergic reactions can be classified into four categories of severity using the Mueller grading scale (Mehl, Wahn, & Niggemann, 2005; Mueller, 1966). The symptoms caused by a food allergic reaction involve skin rashes (grade I); gastrointestinal problems, such as diarrhoea or angio-oedema (grade II); respiratory tract, such as tightening of the throat (grade III); cardiovascular system, such as anaphylactic shock (IV).

The prevalence of food allergy is estimated at around 5–8% for children and 1–2% for adults (Buttriss, 2002; Mills et al., submitted; Sicherer, Noone, & Munoz-Furlong, 2001). The prevalence of self-reported food allergy is even as high as 25% (Buttriss, 2002; Knibb et al., 2000). Many studies have been conducted on the medical treatment of food allergy. Unfortunately to date no general treatment is available, although research aimed at curing the disease is promising (Clark et al., 2009).

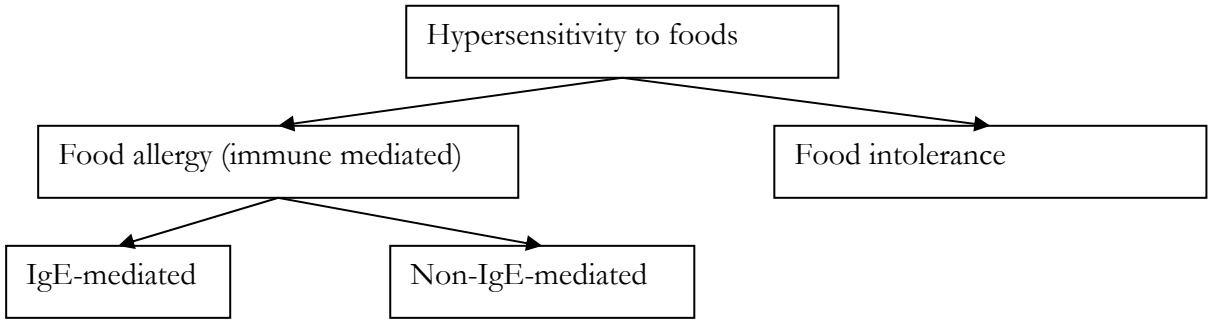

Figure 1. Classification of adverse reactions to food (adapted from Patriarca et al., 2009)

As described above food hypersensitivity includes both food allergy and food intolerance. This thesis will focus on people with food allergy. Food allergic people were chosen because food intolerance causes mild allergic reactions while food allergy can cause mild to severe allergic reactions, therefore the consequences of food intolerance might have less impact on the quality of life and economic functioning of these people and their family compared to food allergy.

1.2 Management of food allergy

Patients with food allergy must avoid food allergens in their diet completely in order to avoid the symptoms that might occur. For these people, it is of vital importance that those who provide food, either through food purchase or food preparation, are aware of the risks and consequences of food allergy. Every day, food allergic patients and their caregivers are burdened with a variety of tasks, including careful label reading of manufactured food products, obtaining information about cross-contamination of foods with food allergens, avoiding accidental exposure that may occur and limiting common social activities associated with eating (Cornelisse-Vermaat, Voordouw, Yiakoumaki, Theodoridis, & Frewer, 2008; Flokstra-De Blok et al., 2010; Gowland, 2002; Joshi, Mofidi, & Sicherer, 2002). Patients with food allergy, for example, have to tell the host beforehand about what they can or cannot eat when eating out. Moreover, they cannot easily stay for a meal with someone spontaneously. They need to explain repeatedly to people that they have a food allergy and what the risks are. Patients with food allergy also face emotional impact, such as fear of accidental exposure, concerns that food allergy cannot be treated, and disappointment when people do not take food allergy into account when preparing a meal. In conclusion, the management of food allergy consists of constant vigilance of allergen avoidance, the risks of accidental exposure, and emotional impact. Dietary restrictions can have a

negative effect on the quality of life and economic functioning of both the food allergic patient and their family members (DunnGalvin & Hourihane, 2008; Flokstra-De Blok et al., 2010).

1.3 Costs related to food allergy

The economic impact of food allergy on both the household level and the individual level can be estimated in different ways. As well as affecting the food allergic patient, the economic impact may also extend to other household members. Costs may be incurred as part of the provision of social and medical care. Besides these costs, also costs for special food for food allergic individuals may be incurred, especially in households with children suffering from food allergies.

There are three types of economic impact for households or individuals with food allergies: (1) direct costs, (2) indirect costs, and (3) intangible costs, including loss of welfare and well-being (Miles, Fordham, Mills, Valovirta, & Mugford, 2005).

1. *Direct costs* can be defined as financial costs, due to medical treatment, medicines and extra costs associated with specific dietary choices, special foods or avoidance of potentially problematic foods (Flabbee, Petit, Jay, Guenard et al., 2008; Miles, Fordham, Mills, Valovirta, & Mugford, 2005). Medical treatment may be obtained during visits to health care professionals, visits by medical professionals to the patient's home or during hospital admissions, which may also be associated with costs. Direct costs also include costs of travelling to health care centres, and information costs. Other household members and people outside the household, who provide care to a food allergic patient, may also face direct costs, for example, travel costs while accompanying a patient to the health care centre or buying special food products when providing food to an allergic patient.

2. *Indirect costs* can be defined as time costs, like opportunity costs, i.e., the costs of forgoing other benefits (for example lost working days or holidays), and loss of education, or other human capital or promotion opportunities (Posnett & Jan, 1996; Reed, Lee, & McCrory, 2004). Indirect costs can also be measured in terms of the time spent in obtaining medical care, searching for the right type of food, and looking for information about the management of the food allergy. Time costs may also be incurred by other household members while providing care. Indirect costs may be estimated by comparing the behaviour of households with food allergic individuals to that of households without such patients.

3. *Intangible costs* are generally considered as being equitable to reduced quality of life, including health related quality of life, financial security, standard of living, family and friends, and spiritual contentment (Antonides & Van Raaij, 1998; Miles, Fordham,

Mills, Valovirta, & Mugford, 2005). The health related costs caused by having food allergy can cause a reduced subjective welfare and reduced subjective well-being. Furthermore, the subjective health status may be affected by having a food allergy as a result of the physical and mental suffering related to the disease.

1.4 The development of the "household cost of food allergy" questionnaire

After a systematic review of literature no valid instrument to measure the costs of food allergy to the individual and the household were found. Therefore, the first step was to develop an instrument to estimate these costs. An elaborate description of the development of the instrument can be found elsewhere (Fox et al., 2009). The questionnaire designed to measure the costs of illness for patients with inflammatory polyarthritis provided a basis for the economic costs questionnaire for patients with food allergy (Cooper, Mugford, Symmons, Barrett, & Scott, 2003). Disease specific questions on inflammatory polyarthritis were removed and questions related to food allergy were added. Several focus groups were conducted in the UK and the Netherlands to assess whether all cost items were included in the questionnaire, which cost items were missing, and how frequently these costs occurred. In the UK three focus groups were conducted with in total 10 participants with clinician diagnosed food allergy. In the Netherlands, 18 participants with self-reported food allergy took part in two focus groups. An expert panel of researchers and clinicians developed a topic guide for the discussion (including sociologists, health economists, consumer psychologists, nutritionists, and food allergologists). According to the results of the focus groups and the expert panel the pilot "household cost of food allergy" questionnaire was developed. The pilot questionnaire included questions on medical costs, travel costs to obtain health care, costs of informal care, cost of living (e.g., groceries expenses, lunch expenses, holiday costs), and intangible costs (e.g., inability to perform the job one would like, fear of passing on the disease to children). Thereafter, an exploratory study was performed with the aim to assess whether the questions were easy to answer, to identify which questions were most appropriate and meaningful to respondents, and to reduce the length of the questionnaire by identifying redundant questions (Voordouw et al., in press). Taking the results into account, the questionnaire was simplified by creating closed questions with tick boxes, removing unnecessary questions and including simple filter instructions to skip non-applicable questions. The study confirmed that the "household cost of food allergy" questionnaire produced plausible results and provided appropriate data to estimate costs of households both with and without food allergic family members. The

"household cost of food allergy" questionnaire was used to measure the direct, indirect and intangible costs associated with food allergy.

1.5 Welfare and well-being associated with food allergy

Research shows that individuals with food allergy experience reduced quality of life (Baiardini, Braido, Brandi, & Canonica, 2006; De Blok et al., submitted; Gowland, 2002; Knibb et al., 2000; Semper & Knibb, 2005; Sicherer, Noone, & Munoz-Furlong, 2001). Quality of life concerns various factors in a person's life, such as financial security, freedom, spiritual contentment, quality of environment, health, and interactions between these factors. The World Health Organisation (WHO) has provided the following definition of quality of life: "the individual's perception of their position of life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards, and concerns" (Kuyken et al., 1995). This thesis will study welfare and well-being as part of the overall quality of life and make comparisons between individuals suffering from food allergy and individuals asymptomatic to any food and their family members.

Households with food allergic family members may experience reduced welfare and well-being due to the impact of the food allergy compared to individuals asymptomatic to foods and their households. Therefore, one objective of this thesis will be to investigate the self-perceived subjective welfare and well-being of individuals suffering from food allergy to food and their households compared to individuals asymptomatic to foods and their households. Welfare can be described as inversely related to the discrepancy between the individual needs and the resources available to meet these personal needs. Many health professionals have indicated that food allergic individuals and their households may have higher costs for primary needs in the Maslow pyramid (food, water, shelter, clothing and medical care) than households without food allergic individuals (Anaphylaxis Campaign (UK), 1 April 2010; Australasian Society of Clinical Immunology and Allergy, 1 April 2010; Consortium of Food Allergy Research (coFAR), 1 April 2010; European Federation of Asthma and Allergy Associations, 1 April 2010; Food Allergy and Anaphylaxis Network (FAAN) (USA) 1 April 2010; Global Allergy and Asthma European Network (GA_LEN), 1 April 2010; International Union of Immunological Societies (IUIS), 1 April 2010; World Allergy Organisation, 1 April 2010). Therefore, the resources for secondary needs (e.g. social activities) will be reduced. Moreover, this can lead to the perception of decreased welfare in households with individuals suffering from food allergy. To estimate the welfare in households with food allergic individuals the 'income evaluation question' will be used (Van Praag & Ferrer-i-Carbonell, 2004).

Well-being of individuals suffering from food allergy can be described as the psychological impact on food allergic individuals and their households. This psychological impact may include, for example, limitations caused by the health status, being unable to effectively engage in paid employment or other work activities, or having a restricted social life (Kahneman, Diener, & Schwarz, 1999; Van Praag, Frijters, & Ferrer-i-Carbonell, 2003). Well-being can be assessed using a 'ladder-of-life' scale, on which respondents can indicate how they perceive their position relative to the 'best possible life' and the 'worst possible life' that they can imagine (Cantril, 1965). Since global well-being captures one's happiness with life as a whole, the cost-equivalent should capture the subjective aspects of direct, indirect and intangible (psychological) costs (Miles, Fordham, Mills, Valovirta, & Mugford, 2005).

1.6 Food allergy information search strategies

Members of households with individuals suffering from food allergy have to make judgments concerning the safety of food products. They have to rely on the labelling of food products and product information available from other sources (e.g., the Internet) (Mills et al., 2004). Therefore, an objective of this thesis is to investigate the information needs of food allergic consumers and how these needs are met with the current product labelling. Improving the information delivery strategy will positively influence the welfare and well-being of food allergic individuals and their families. Adequate food allergy information will also have a positive effect on the costs associated with food allergy. For example, the indirect cost can be reduced by preventing accidental food allergic reactions in food allergic individuals therefore lowering the medical costs (e.g., hospitalisation, medicines).

The discrepancy between the lack of information with current labelling practices and the information requirements of the food allergic consumer needs to be resolved. This discrepancy could be solved by implementing new information delivery strategies, including both traditional package labelling techniques, information booklets, and modern electronic equipment.

1.7 Aims and outline of this thesis

The current lack of understanding of food allergy on the processes involved in these diseases, the lack of good quality information on the prevalence of food allergy, and the lack of information about its economic costs and quality of life is hampering efforts to manage food allergy problems effectively. Regulators responsible for consumer protection need objective information about food allergy to be able to develop adequate guidelines. Without this knowledge regulation could over protect

food allergic consumers leading to unnecessary dietary restrictions or under protect them leading to accidental exposure to food allergens. Consequently, there is a need for this information and tools for policy makers, regulators and the food industry to effectively manage food allergies across Europe. Effective management of food allergy can deliver an improved quality of life to food allergic consumers. The research presented in this thesis contributes to solving the discrepancy between the available and the required information and tools. This thesis aims at better understanding the impact of food allergy on households with individuals suffering from food allergy with respect to their costs (time and money), welfare, well-being, and information search strategies. The outline of the thesis is built around a conceptual model developed for this research, shown in Figure 2, the elements of which will be considered next.

Several issues influence the impact of food allergy on individuals and their households. This thesis focuses on the financial costs, intangible costs (welfare and well-being) and the time costs associated with searching for information to be able to develop a personal management strategy to identify safe foods.

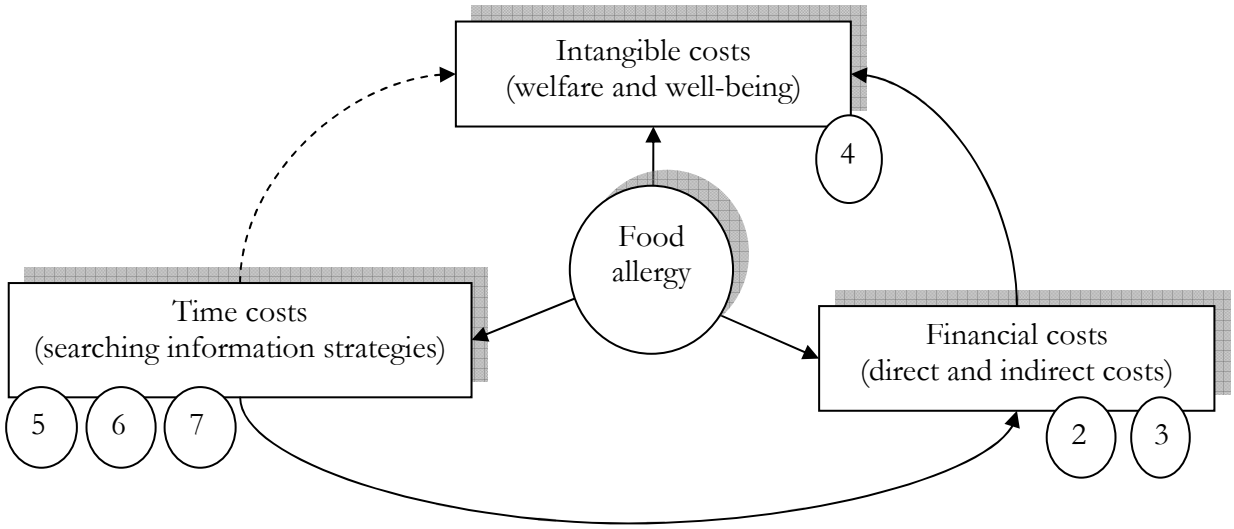

Figure 2. Conceptual research model (numbers correspond to chapters)

Chapter 2 describes the exploratory study (n= 190) of the pilot economic cost questionnaire. The aim of this study was to investigate whether the developed questionnaire produced plausible results and provided appropriate data to estimate the costs associated with food hypersensitivity. Furthermore, the study aimed at improving the questionnaire by reducing its length and eliminating redundant questions.

Chapter 3 describes the results of the main study (n= 1575) in the Netherlands, Poland, Spain and the UK using the cost questionnaire developed in Chapter 2. A comparison was made between direct and indirect costs of individuals

and households including food allergic and food intolerant patients to households of which all family members were asymptomatic to any food. **Chapter 4** describes the results of the subjective welfare and the subjective well-being experienced by the food allergic patient and their family members in the same sample.

The time forgone due to finding information about safe food is captured in the indirect costs described in Chapter 3. Improving the information supply to food allergic patients might improve the quality of life and ultimately the well-being of those individuals. The first step in this process was to establish the information preferences of food allergic individuals and assessing whether the current labelling was sufficient to satisfy their needs. **Chapter 5** describes the results of a study performed in the Netherlands and Greece in which 40 self-reported food allergic consumers were observed and interviewed while they were shopping for groceries in a supermarket. The results provided insight into the information preferences of food sensitive consumers and the discrepancy between their needs and the current labelling of food products.

Currently, labelling of food products is the main information source for food sensitive consumers to establish whether a food product is safe to consume. The study in **Chapter 6** aimed to identify the preferences of food allergic consumers regarding different information provision scenarios. Self-reported food allergic consumers (n=272) filled out a web-based questionnaire, using a conjoint design, on their preferences regarding a food label, an in-store information booklet, and an ICT-solution, like a hand-held scanner or information terminal in the store. According to the results of Chapters 5 and 6 real prototype food labels, an information booklet and a hand-held scanner were developed. **Chapter 7** describes the results of food allergic consumers (n=62) rating these three prototype information delivery tools on convenience, usefulness and confidence. The aim of this study was to investigate whether these prototype information delivery tools met the needs of the participants and were able to help in making an informed product choice.

Chapter 8 concludes this thesis and provides a general discussion on the results and conclusions from the previous chapter and suggestions for future research.

1.8 EuroPrevall

The thesis presented here was part of an EC-funded multidisciplinary integrated project named EuroPrevall (FOOD-CT-2005-514000). The project involved 17 European member states, Switzerland, Iceland and Ghana. The main objective of this project was to assess the epidemiology of food related diseases and allergies. Specifically, to examine the complex interactions between food intake and

metabolism, immune system, genetic background and socioeconomic factors to identify key risk factors and develop common European databases. The results from this project were ultimately aimed at an improved quality of life of food allergic sufferers by delivering the information and tools necessary for policy makers, regulators and the food industry to effectively manage food allergies across Europe.

Chapter 2

Household and health care costs associated with food allergy: An exploratory study

This chapter is based on the following publication: Voordouw, J., Cornelisse-Vermaat, J.R., Fox, M., Antonides, G., Mugford, M., and Frewer, L.J. (in press). Household and health care costs associated with food allergy: An exploratory study. *British Food Journal.*

Abstract

Purpose

Food allergy has potential to affect direct, indirect and intangible economic costs experienced by food allergic individuals and their families, resulting in negative impacts on welfare and well-being. The purpose was to develop an instrument to assess these economic costs of food allergy at household level and to conduct an exploratory analysis of potential economic impact.

Method

A case-controlled postal pilot survey was conducted, using a self-completion instrument. Cases had either clinically or self-diagnosed food allergy. Controls were obtained from households in which none of the members had food allergies.

Findings

The instrument appeared sensitive to the economic cost differences between households with and without food allergic members. Direct costs of health care were significantly higher for cases than for controls. Similar differences were identified for indirect cost of lost earnings, and costs due to inability to perform domestic tasks because of ill health. Intangible costs (self-reported health status and well-being), indicated significantly lower subjective well-being for cases.

Research limitations and implications

Larger sample sizes will be needed to reliably assess the size of impact, cross-cultural variation in costs, and whether costs vary according to severity of food allergy or between diagnosed *versus* self-reported food allergy. The costs effectiveness of diagnostic methods or interventions may also be assessed using this instrument. If economic costs of food allergy are significant in the population further consideration from a public health policy perspective will be required.

Originality

To date, economic impact of food allergy on individuals and households has not been quantified.

2.1 Introduction

The severity of food allergy symptoms can vary from uncomfortable (e.g., itching, rashes) to potentially fatal (e.g., anaphylactic shock) (Buttriss, 2002; Rona et al., 2007). Food allergy may also have an impact on the quality of life and economic functioning of individuals and their households (Baiardini, Braido, Brandi, & Canonica, 2006; De Blok, DunnGalvin et al., 2007; De Blok, Vlieg-Boerstra et al., 2007; Flokstra-De Blok et al., 2008; Primeau et al., 2000; Sicherer, Noone, & Munoz-Furlong, 2001). The latter may extend from increased time utilised by food allergic individuals and their households for shopping (Voordouw et al., 2009), or time spent away from normal occupations, to increased societal costs, including healthcare costs and work-related absences. Given that behavioural changes may occur independent of clinical diagnosis (see, for example, Cornelisse-Vermaat, Voordouw, Yiakoumaki, Theodoridis, & Frewer, 2008), it is important to assess the individual and societal costs of both self-diagnosed and clinically diagnosed food allergy in order to establish effective policy responses (for example, in terms of food labelling or investment in formal diagnosis within the health system).

The main objective of the research reported here was to develop an instrument which can be used to assess the economic costs of food allergy at both the individual and household level in different countries and population groups, and to conduct an exploratory analysis of the potential economic impact of food allergy. Although estimated costs for several non-food related allergies have been provided (UCB, 1997), similar data is not available for food allergy. In a review of what is known about the costs of food allergy, Miles et al. (2005) suggested that the cost of food allergy can be divided into three categories, namely *direct*, *indirect* and *intangible* costs (Miles, Fordham, Mills, Valovirta, & Mugford, 2005). The direct and indirect costs are potentially measurable by monetary expenses or monetary value of resources used (defined here as "direct costs"), or the monetary value of time spent as a result of having the allergy (defined as "indirect costs"). Intangible costs are defined as loss of value or utility, which are difficult to measure in monetary terms but can be indicated by loss of self-reported health status, loss of well-being and loss of economic welfare experienced as a consequence of food allergy.

An annotated cost questionnaire, designed to assess the patients' health related costs associated with chronic illness in general (Wordsworth, Thompson, & on behalf of the UK Working Party on Patient Costs, 2001) was validated in a study of early inflammatory polyarthritis patients as a measure of the cost of illness (Cooper, Mugford, Symmons, Barrett, & Scott, 2003). This questionnaire, together with the framework for measuring societal costs of IgE-mediated food allergy (Miles, Fordham,

Mills, Valovirta, & Mugford, 2005), formed the basis of the instrument designed to measure the cost of food allergy. The costs associated with health care use and food-related behaviour of participants were also assessed, together with self-reported health, welfare and well-being. The purpose of the instrument was to be able to identify differences in costs for individuals, and their families, with either self-diagnosed or clinically-diagnosed food allergy, compared to the economic costs for non-food allergic people. A detailed description of the development process is provided elsewhere (Fox et al., 2009).

This paper presents the results of an exploratory study to determine whether economic costs were associated with food allergy. The research instrument was designed to be a self-administered postal questionnaire, completed by either food allergic adults, parents of food allergic children or non-food allergic (control) individuals. The objectives of this study were to test whether costs could be estimated using the instrument, whether responses were consistent, internally and between different settings, and whether, within the limits of the sample size, there was any indication of cost differences between allergic and non-allergic groups.

2.2 Method

2.2.1 Cost categories included in the economic instrument

Costs arise from the use of resources (human time and materials) to produce outputs that are needed and valued. These costs can arise in any part of the economy. This paper distinguishes between those borne by the household and by the health sector, as two important areas of provision of care for people with food allergy. Costs related to food allergy also arise in the food industry (Miles, Fordham, Mills, Valovirta, & Mugford, 2005), but these were not the focus of this paper. Costs may also be subdivided as follows.

2.2.1.1 Direct costs

Direct costs can be defined as the financial costs individuals or their family incur as a result of experiencing particular diseases. Travel costs for medical treatment represents a direct cost for both the food allergic individual and any accompanying person. Cost of living contributes to the direct costs, and includes (for example) expenditure on food, holiday expenses, additional equipment required to prepare safe meals, and domestic help. The direct cost measures in the questionnaire included items concerning travel costs to obtain medical treatment, costs of (alternative) medication, cost of help with domestic duties, additional costs for food, and specific costs incurred

during leisure activities. It was hypothesised that cases incur greater living and health care costs compared to controls.

2.2.1.2 Indirect costs

Indirect costs can be defined as time lost, lost productivity and opportunity costs (lost working days or holidays, loss of education or working opportunities, lost earnings and lost human capital) (Posnett & Jan, 1996). Time spent obtaining health care, shopping for safe foods, lost leisure time and time spent on searching for more information about food allergy also represent indirect costs potentially incurred by both food allergic individuals and their caregivers in the family (Posnett & Jan, 1996). Indirect health care costs are defined as the time cost of obtaining medical treatment (e.g., time spent on visits to or by health care professionals, travel time, consultation time, and days lost due to hospital admissions). The indirect costs of food allergy can be estimated by comparing these variables between households with and without food allergic members. It is hypothesised that "cases" (i.e., households with food allergic members) incur greater loss of time, opportunity costs and lost productivity compared to controls (i.e., households without food allergic members). This may apply to both perceived and clinically-diagnosed food allergy.

2.2.1.3 Intangible costs

Intangible costs were measured as self-reported health status, loss of welfare and loss of well-being experienced as a consequence of having a food allergy. Health status was measured by the EQ-5D scale and the self-perceived health scale. The EQ-5D is a validated questionnaire used to assess health status and health-related quality of life across five non-disease specific dimensions (Johnson, 1998). The EQ-5D was included in the questionnaire to enable comparison of the overall health status and disease-related quality of life of food allergic individuals and controls. The five-point self-perceived health (SPH) scale was included to enable assessment of subjective health status. Individuals rated their own current health status on a five-point scale ('poor health', 'fair health', 'very good health', 'good health', 'excellent health') (Benyamini & Idler, 1999).

Welfare can be defined as the relationship between perceived needs experienced by an individual, and their means to satisfy these. Welfare is considered low / high if the individual perceives that insufficient / sufficient resources, such as income and time, are available to satisfy needs. It is hypothesised that food allergic individuals will have higher costs for primary needs, such as food and medical care, and have less money available to expend on secondary needs, such as leisure and social

activities, compared to non-food allergic individuals. In addition, food allergic individuals are expected to experience higher indirect cost than controls. As a consequence, the former may perceive a relatively low level of welfare, resulting in proportionally lower evaluation of their income. An income evaluation scale will enable comparison between cases and controls to provide a subjective indication of intangible costs (Van Praag & Ferrer-i-Carbonell, 2004).

The well-being of a food allergic individual can be described as the psychological impact of food allergy on the individual and the household. This may include, for example, various limitations caused by health status, such as being unable to perform a job, or restrictions on social life (Kahneman, Diener, & Schwarz, 1999; Van Praag, Frijters, & Ferrer-i-Carbonell, 2003). Well-being was assessed by using the 'ladder-of-life' scale, in which respondents can indicate how they perceive their position relative to the 'best possible life' and the 'worst possible life' (Cantril, 1965). As this well-being measure captures people's happiness in all life domains, not just economic, the impact of food allergy on life as a whole can be assessed. It is hypothesised that food allergic individuals have reduced health status, welfare and well-being compared to controls.

2.2.2 Recruitment of the sample

A case-control pilot survey was conducted in the Netherlands and the UK to establish whether the instrument was sensitive to potential cost differences between households with and without food allergic members. Cases were recruited through advertisements in newspapers and patient organisation websites. The case sample consisted of households with adults or children who reported that they had a member suffering from food allergies further classification was made according to their reported symptoms. The control sample consisted of households with no food allergic individuals. In the Netherlands these were recruited through personal contacts of the cases. In the UK a random sample was selected from the Norfolk population. In the Netherlands, monetary incentives were provided: 10 euro to cases, 15 euro was given to cases if they supplied a control respondent and 15 euro to controls. In the UK respondents were entered into a prize draw for 50 pounds. The recruitment of the participants in the pilot study differed between UK and NL; however, it is not expected that the method of recruitment had a significant effect on the results. The cases were either clinician or self-diagnosed patients with food allergy (all avoided inclusion of allergens in their diets). The participants were informed about the study before they gave their consent to be included. For this study, ethical approval was obtained in the Netherlands and UK.

To measure the severity of symptoms, the Mueller scale was used, which asks food allergic individuals about the symptoms experienced after ingesting problematic foods, focusing on their most negative allergic response post-ingestion. These symptoms are categorised into four levels ranging from mild to severe reactions (Mueller, 1990); see, for example, Ewan and Clark (2005). The control sample did not differ significantly from the case sample with respect to work status, income level, and educational level.

2.2.3 Analysis

The *adult version* of the questionnaire was designed to estimate the household costs experienced by adults with or without (perceived) food allergies. The *parental version* was designed to provide the same estimates in households including children with or without food allergy. The difference in costs items for direct, indirect and health care sector between cases and controls were statistically tested with ANOVA using SPSS 15.0 for windows. The difference in costs items for the intangible cost, EQ5D and well-being, were statistically tested with ANOVA, the self-perceived health scale (SPH) was statistically tested with a non-parametric Mann-Whitney U ranking test, and the welfare (income evaluation) scale was statistically tested with a Chi-square test.

2.3.Results

In the Netherlands, the case sample consisted of 66 food allergic respondents and the control sample consisted of 33 non-food allergic respondents. In the UK, the cases sample consisted of 60 food allergic respondents and the control sample consisted of 31 non-food allergic respondents. The response rate for the case sample was 70% in the UK and 71% in the Netherlands. The response rate for the control sample was 10% in the UK and 36% in the Netherlands. This can be explained by the difference in recruitment strategy. The distribution of the severity in the case sample, measured by the Mueller scale ranging from level I to level IV, was respectively, 5.6, 15.2, 42.4, and 32.8 percent.

Analysis of the data was performed on the total data set without splitting the data set into countries or versions. The sample size in each country was too small to produce interpretable results if analysed separately. The distributions of cases and controls, as well as the distribution of parental and adult versions of the instrument were similar in the UK and the Netherlands, and both countries were equally represented in the total data set. All cost estimate analyses were performed at the household level.

The total direct cost for households with food allergic members was not significantly different from households without food allergic members. The breakdown figures of the total direct costs are provided in Table 1. Household costs for health care for cases were higher than for controls (p<.05). The direct cost of medication was also significantly higher for cases than for controls (p<.01). The cost of health insurance shows a trend to be higher for cases than for controls.

Table 1. Direct costs in Euros per annum of food allergic cases compared with non-food allergic controls on the household level (standard errors of the means between parentheses)

	Cases (SE)	**Controls (SE)**	**Cost of food allergy**		**N**
Total costs of living of the household, including the costs of food, holiday expenses, additional equipment to prepare safe meals, and the costs of domestic help	8104 (468)	7460 (657)	644	*n.s*	190
Total costs health care	880 (77)	436 (108)	444	**	190
Total travel costs of visiting household member in hospital	*41 (18)*	*1 (26)*	*40*	*n.s.*	*182*
Total travel costs of visiting health care professionals for the household	*10 (2)*	*3 (3)*	*7*	*n.s.*	*190*
Total costs of (alternative) medicines	*290 (20)*	*91 (28)*	*199*	**	*181*
Total costs of (health) insurance	*586 (77)*	*358 (109)*	*228*	†	*181*
Total direct costs for households (euro)	8984 (472)	7896 (662)	1088	*n.s*	190

Note. † p<.10, ** p<.05, *** p<.01, n.s.= not significant
The total could be lower than the sum of the breakdowns due to excluding missing cases.
The sum of the breakdowns is higher than the total because the mean is calculated over unequal groups.

Statistically significant differences in direct costs appeared to be primarily related to those associated with obtaining health care. The total direct costs were

significantly higher for cases than for controls, in particular in association with medication and health insurance.

Table 2. Indirect costs in Euros per annum of food allergic cases compared with non-food allergic controls on the household level (standard errors of the means between parentheses)

	Cases (SE)	**Controls (SE)**	**Cost of food allergy**		**N**
Total costs value of lost time being unable to perform domestic tasks due to sick household member	2672 (483)	473 (678)	2199	**	*190*
Total costs value of lost time being unable to perform domestic tasks due to sick adult (adult version)	*2159 (406)*	*426 (569)*	*1733*	*	*190*
Total costs value of lost time being unable to perform domestic tasks due to sick child (parental version)	*513 (132)*	*46 (185)*	*467*	*	*190*
Total costs value seeking info on food allergy	149 (10)	27 (14)	122	**	*190*
Total costs value of time spent on food shopping and preparing food	5788 (626)	6059 (875)	-271	*n.s*	*190*
Total costs value of spent time of visiting household members in the hospital	24 (2)	21 (3)	3	*n.s*	*184*
Total costs value of spent time with all health professionals for household (travel and consult) of respondent and partner	201 (43)	96 (61)	105	*n.s*	*190*
Total lost earnings	481 (140)	23 (196)	458	†	*190*
Total indirect costs value of lost time for households (euro)	*9269 (835)*	*6698 (1172)*	*2758*	†	*190*
Lost days school/work in household due to illness (days)	25 (5)	4 (7)	21	*	*190*

Note. † p<.10, * p<.05, **p<.01, n.s. = not significant
The total could be lower than the sum of the breakdowns due to excluding missing cases.
The sum of the breakdowns is higher than the total because the mean is calculated over unequal groups.

The indirect costs were measured in reported time loss due to different activities. The estimated total indirect costs *per annum* were significantly different between cases and controls (p<.01). The breakdowns of the indirect cost are provided in Table 2.

In addition, lost time was expressed as a monetary value by using the wage rate of working respondents and minimum wage rate for those without paid work. Compared to households without food allergic members, households with food allergic members had significantly higher costs associated with time spent performing domestic tasks (i.e., childcare, home cleaning, gardening, grocery shopping) due to illness of family member (p<.01). The total costs of time spent seeking information about food allergy were significantly higher for cases than for controls (p<.01), which was in line with expectations. However, food allergic families did not spend significantly more time on shopping for, and preparing, food, compared to non-food allergic families. A trend was observed suggesting that cases incurred higher lost earnings due to time taken off from work for ill health or hospitalisation compared to controls, although this only reached marginal significance (p<.10). The number of days spent away from work or school was significantly higher for food allergic sufferers and non-food allergic people (p<.01), (Table 3).

The estimated total cost including both direct and indirect costs expressed in monetary values for households with food allergic members compared to households without food allergic members was significantly higher for cases than for controls (Table 3).

Table 3. The total cost of food allergy combining direct and indirect costs and the cost for the health sector per annum comparing cases with controls (standard errors of the means between parentheses)

	Cases (SE)	**Controls (SE)**	**Cost of food allergy**		**N**
Total direct and indirect costs for households	18253 (978)	14594 (1373)	3659	*	*190*
Total cost of healthcare, drugs and hospital episodes to the public sector	379 (56)	170 (78)	*209*	*	*190*

Note. * p<.05

The societal costs incurred by the health care sector include the costs for consultation by general practitioner, dietician and physiotherapist, the cost of medication, and the costs of hospitalisation. These costs for the health care sector were significantly higher for the cases than for the controls (p<.05) (see Table 4).

Intangible costs were assessed using four measures: the EQ-5D, Self Perceived Health scale, income evaluation question, and well-being scale (Table 4).

Table 4. Intangible costs per annum of food allergic cases compared with non-food allergic controls on the household level (standard errors of the means between parentheses)

	Cases (n=125)	**Controls (n=62)**		**N**
EQ-5D (mean, SE)	0.803 (.022)	0.887 (.031)	*	190
Self Perceived Health (mean ranking, SD)[a]	106 (1.0)	71 (.75)	**	187
Welfare[b]				
Own income below sufficient level (no. of cases, percentage)	24 (31)	54 (69)	*n.s*	119
Own income above sufficient level (no. of cases, percentage)	8 (20)	33 (81)		
Well-being (mean, SE)				
Adult version				
Respondent	6.7 (.19)	7.5 (.27)	*	129
Partner	7.6 (.20)	7.6 (.27)	*n.s*	
Child	6.8 (.36)	7.6 (.58)	*n.s*	
Parental version				
Respondent	6.8 (.29)	7.6 (.37)	†	58
Partner	7.1 (.25)	7.1 (.38)	*n.s*	
Child	7.0 (.28)	8.5 (.46)	**	

Note. † p<.10, * p<.05, ** p<.01, n.s. not significant

[a] Mann-Whitney U test

[b] Chi-square test

The EQ-5D score was significantly lower for cases than for controls (p<.05), indicating lower overall health status experienced by cases. Similarly, the self-perceived health scale (where higher ranking scores reflect lower self-perceived health status) indicated that cases perceived their health status to be lower than controls (p<.01).

The welfare measured as the percentage of respondents who considered their own income as below or above the level considered as sufficient did not significantly differ between the two groups. Higher well-being scores indicated better self-

perceived life status. The adults with food allergy in the case sample reported significantly lower personal scores than the controls ($p<.05$). The parents of children with food allergies also reported (marginally) lower scores for cases compared to controls ($p<.10$). Furthermore, the child's well-being was reported to be significantly lower for cases than the controls ($p<.01$). To summarize, the well-being results indicated that food allergy experienced by children had a negative impact on the child's life as well as that of the parent primarily responsible for the child's care; in the case of food allergic adults, their condition only affected their own well-being.

2.4 Discussion and conclusion

Currently, no instrument is available to measure the economic impact of food allergy. The development of this instrument is therefore innovative. In this exploratory study, either clinician-diagnosed or self-diagnosed food allergic consumers were included in the sample. This could potentially lead to a dilution of the results, assuming that self-diagnosed consumers will have lower costs for health service usage compared to clinician-diagnosed consumers. Further research could be performed to determine the costs difference between self-diagnosed and clinician-diagnosed. Despite these limitations, the survey instrument captured some differences in economic functioning between food allergic individuals and controls. These differences related primarily, although not exclusively, to indirect costs and intangible costs. Further research is required in larger and more homogeneous samples to confirm these effects, to test hypotheses about costs experienced within different populations and through application of different definitions of illness, and to extend the findings to a broader cross-national context. If food allergy is demonstrated to have a substantial impact on the economic functioning of afflicted individuals and their households, there are clear policy implications regarding (for example) health service provision and research directed towards innovation in prevention and treatment strategies in the future. The impact of health interventions in terms of household and health sector economic functioning can also be assessed. Further research into the economic costs of food allergy is therefore warranted. At the present time the instrument is being used to collect data in various European countries (in their national language[1]) and preliminary analyses will be expected mid-2009. These results will provide more insight into the magnitude of the economic costs of food allergy. European cost estimates of food

[1] The authors will supply a copy of the instrument in the required language upon request. The instrument is available in the following languages; Bulgarian, Czech, Dutch, English, France, German, Greek, Icelandic, Italian, Lithuanian, Polish and Spanish, where back translation has been applied to ensure the accuracy of the translation process.

allergy can be used to develop policies which can improve the welfare, well-being and quality of life of households with food allergic members.

In conclusion, the results of this exploratory study suggest that economic costs (at the level of the individual, household and society) are associated with having a food allergy. Further research is therefore warranted to establish the extent of such costs, whether they vary according to national or regional differences (for example, local health services provision or food labelling practices) and severity of the response. It is also relevant to note that the psychological impact of experiencing a food allergy may also result in behavioural changes with subsequent impacts on quality of life and economic functioning, implying the need to more extensive availability of formal diagnosis within health service provisioning.

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Chapter 3

The direct and indirect costs associated with food hypersensitivity in households: A study in the Netherlands, Poland, Spain and United Kingdom

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Abstract

Introduction

Recent studies show that food hypersensitivity, like food allergy or food intolerance, has potential to affect direct, indirect and intangible economic costs experienced by individuals and their families. This research assesses the direct and indirect economic costs of food hypersensitivity at the household level in the Netherlands, Poland, Spain and UK.

Method

A self-administered postal survey was conducted (n=1592). Respondents with food hypersensitivity were clinically diagnosed patients recruited through clinical centres in Poland and Spain. In the Netherlands and UK food hypersensitivity patients were recruited through hospitals, patient organisations and advertisements. The respondents asymptomatic for foods formed the baseline sample and were obtained from households in which none of the members had food hypersensitivity. The monetary value of indirect costs, forgone time, was calculated using the opportunity cost method. The indirect and direct costs were expressed in purchasing power parity. Analysis of co-variance on the cost items was used to test the within-country differences between respondents with food hypersensitivity and respondents without food hypersensitivity, as well as across the four countries.

Results

The average total direct and indirect costs across all countries for families with food hypersensitive family members are lower than for households without food hypersensitive members. The additional costs of households with food hypersensitive family members, for example, higher travel costs and payments for health care, are compensated by lower cost of living and less time spent on household tasks.

Discussion and conclusion

These results do not support the commonly held belief of lobbyists that all food allergies incur high costs to the individual.

3.1 Introduction

Food allergy is a chronic disease for which, at the present time, no general treatment is available, although research aimed at curing the disease is promising (Clark et al., 2009). The only treatment currently available is managing the disease through avoidance of problematic allergens in the diet of food allergy sufferers (Asero et al., 2007; Dutau & Rance, 2006). Despite application of precautionary measures, accidental exposure to allergenic proteins may result in allergic responses. The socio-economic burden of food allergy is experienced not only by food allergy sufferers themselves, but also other family members and caregivers (Cornelisse-Vermaat, Voordouw, Yiakoumaki, Theodoridis, & Frewer, 2008; Flabbee, Petit, Jay, Guénard et al., 2008; Flokstra-de Blok, 2009; UCB, 1997; Voordouw et al., in press).

A meta-analysis of existing epidemiology surveys suggests that the prevalence of self-reported food allergy also varies across the population, with self-reported allergy rates reaching 35% (Clark et al., 2009; Pereira et al., 2005; Rona et al., 2007; Venter et al., 2006; Woods et al., 2002). Estimates of prevalence derived from oral food challenges, such as double blind placebo controlled food challenges (DBPCFC), tend to be more conservative, but nevertheless suggest that food allergy affects a substantial percentage of the population (Rona et al., 2007). There is some evidence to suggest that the prevalence of food allergy is increasing. Studies focusing on peanut indicate that prevalence rates in children have increased, exceeding 1% in school-aged children. A 2008 Centres for Disease Control and Prevention report indicated an 18% increase in childhood food allergy from 1997 to 2007, with an estimated 3.9% of children currently affected (Branum & Lukacs, 2008; Decker et al., 2008; Ross et al., 2008; Sicherer & Sampson, 2007).

The increase in prevalence of food allergies affects the economic burden of food–allergy management. Although various studies have provided estimates of the economic costs of respiratory allergies (Gupta, Sheikh, Strachan, & Anderson, 2004; Reed, Lee, & McCrory, 2004), very little research has been conducted which focuses on the economic costs of food allergy to households and individuals. A French study estimated the costs per patient for the health care sector for severe anaphylaxis resulting from food allergy to vary from 1895 to 5610 euro in nonfatal cases, and three working or school days per year lost due to ill health (Flabbee, Petit, Jay, Guenard et al., 2008). There is more information about the aggregate costs of major allergic diseases, which were estimated at 10 billion ECU (European currency unit) for direct costs and 19 billion ECU for indirect costs in Europe (UCB, 1997). However, a recent study has reported that food allergic individuals self-report spending more time on food shopping, lose more time because of inability to perform everyday (household)

tasks, and face higher societal costs, including health care costs and work-related absences, compared to non-allergic individuals (Cornelisse-Vermaat, Voordouw, Yiakoumaki, Theodoridis, & Frewer, 2008).

Miles et al. (2005) developed a framework which could be applied to measure the costs of food allergy. This study suggested that the costs can be divided into three categories, namely, direct costs, indirect costs and intangible costs (Miles, Fordham, Mills, Valovirta, & Mugford, 2005). The *direct costs* can be defined as the financial (out-of-pocket) costs food allergic individuals and their family incur as a result of the disease. The *indirect costs* can be defined as time loss, lost productivity and opportunity costs due to illness (Posnett & Jan, 1996). *Intangible costs* are defined as loss of value or utility, which are difficult to measure in monetary terms but can be indicated by self-reported health status, well-being and economic welfare experienced as a consequence of food allergy. This suggests that food allergy may potentially have a negative effect on the quality of life and economic functioning of food allergic individuals and their households.

The burden on health care services associated with chronic diseases leads to an increased interest in their economic impact. In making decisions about optimal allocation of health care resources, it is important to consider the economic effects of chronic diseases, such as food allergy. Evidence is needed regarding the relative importance of food hypersensitivity, including food allergy and food intolerances, compared to other chronic diseases to justify the economic cost for development of new legislation or policies (for example, in terms of food and ingredient labelling, food production or investment in formal diagnosis within the health care system (Pfaff et al., submitted).

The purpose of this study is to assess the direct and the indirect cost of food hypersensitivity at the household level. The hypothesis to be tested is that families with food hypersensitive family members incur higher direct and indirect cost on all items compared to households without food hypersensitive members. The results could be used to prioritise resources for development of new food allergy management strategies and could help to inform legislation in this area.

3.2 Method

3.2.1 Study population

This study was part of the large EU-funded project EuroPrevall. The respondents from Poland and Spain were collected as part of the epidemiological study performed within EuroPrevall. The protocol on the sampling strategy is described elsewhere

(Kummeling et al., 2009; Mills et al., 2007). This epidemiological study was designed as a clinical case-control study to establish the prevalence of food allergy and food hypersensitivity. In the Netherlands and UK, the protocol from the epidemiologic study was used to select the patients with food hypersensitivity and food allergy. The recruitment was conducted through hospitals and patient organisations. Respondents were included if they indicated having one or more food allergies to the 14 food allergens listed in the EC Directive 2006/142/EC, reported experiencing symptoms following accident ingestion of food allergens, and reported that they had been diagnosed as having food allergy by a health professional. A pre-analysis was performed to test if the patients from each sampling method were comparable. No significant differences between the recruitment methods were identified. The target group of respondents with food allergy or food hypersensitivity and their family were compared to a baseline sample which consisted of a group of respondents reporting that they and their families were asymptomatic to any type of food allergy. This baseline group in Spain and Poland were recruited controls as part of the epidemiological study. In the Netherlands and UK the baseline sample was selected to be comparable on the demographic characteristics of the target patient sample. Pre-analysis showed that the sampling method in the baseline group was not significantly different between countries. The patients recruited through the epidemiological study were tested through double blind placebo controlled food challenges (DBPLCFC), resulting in the majority of the cases being classified as *food hypersensitive* and the minority *food allergic*. Therefore, in this study we will use the broader term food hypersensitivity indicating all patients with food allergy and food intolerances.

The survey was conducted in the Netherlands, Poland, Spain and the UK to estimate potential cost differences between households with and without food hypersensitive members, enabling comparison of the target food hypersensitive group to the asymptomatic baseline sample. The participants received written information about the study together with the questionnaire inquiring about the costs on the household level. Their participation was voluntary and had no consequences for their treatment. Participants did not receive any incentive for their contribution. The questionnaires were assigned unique codes to provide a data set with anonymous records. Only the researcher could match the unique codes with the personal data of the participants. Ethical approval from the medical ethical commission in the participating hospitals, clinical centres and universities was obtained.

Table 1. Distribution of adult and parental versions of the questionnaire

		Adult version	Parental version	Total
Netherlands	Case	65	67	132
	Control	52	92	144
Poland	Case	97	149	246
	Control	224	163	387
Spain	Case	97	96	193
	Control	190	231	421
United Kingdom	Case	30	12	42
	Control	20	7	27
	Total	775	817	1592

In total, 1592 respondents were included in this study (Table 1). The target sample comprised both food hypersensitive adults, and food hypersensitive children. In the case of the latter, the parent of the child completed the questionnaire. The food hypersensitive adults from the target sample and the healthy adults from the baseline sample received the *adult version* of the questionnaire which was designed to estimate the household costs experienced by adults with or without (perceived) food sensitivities. The families with food allergic children received the *parental version* which was designed to provide the same estimates in households including children with or without food hypersensitivity. A household without a food hypersensitive child (control) reported the cost of the oldest child living at home.

3.2.2 Survey

The data was collected through a patient-based resource and expenditure cost survey footnote[2]. A detailed description of the development and validation of this questionnaire has been provided elsewhere (Fox et al., 2009; Voordouw et al., in press). The questionnaire used in this study gathered structured information on all aspects of health and social care resource use. To summarise, the questionnaire development was performed in three stages: (1) identification of cost items through a review of literature, patient organisations and focus groups; (2) formulation of the questionnaire; (3) pilot testing and validation. The results of the pilot testing and

[2] A copy of the "household costs of food allergy" questionnaire can be obtained on request from the authors.

validation have been described in Voordouw *et al.* (in press). The framework developed by Miles et al. (2005) was used to structure the questionnaire into the three cost sections. This study will analyse the direct and indirect costs of living and seeking healthcare for families with and without food-hypersensitive members.

The costs will be calculated using the Purchasing power parity (PPP) of the Geary-Khamis dollar with base line year 2007 to compare the costs across the different countries. PPP is a device which assumes that exchange rates between currencies in different states are in equilibrium when their purchasing power is the same (Ethier, 1995). The international Geary-Khamis dollar, often used together with PPP, is a hypothetical unit of currency with the same purchasing power as the US dollar at a given point in time.

A methodology which values the time loss of household production as a monetary value was used to calculate the indirect costs. In the *opportunity cost method* the individual's own market wage rate is used to evaluate the time loss or household production (Kooreman & Wunderink, 1997). In economic models used for analysing the choice between labour market participation and home production, it is frequently assumed that the value of the first hours spent on home production is higher than an individual's labour time in the job market (represented by their wage rate). The income the individual foregoes by spending time on home production is found by the multiplication of the wage rate by these hours. The opportunity cost method is widely used in the literature and is well-validated (Posnett & Jan, 1996). This method was used in the analysis of the indirect costs. When a person was not employed in paid work the minimum wage rate per country was used. When the person reported they were working but did not state their income, we used the national average wage rate. The direct cost was calculated by summing all out-of-pocket cost items from the questionnaire. When no direct or indirect cost was incurred zero cost was used in the analysis. If, in previous questions, it was stated that costs were made on a particular item without mentioning the amount, the cost item was entered as a missing value.

The direct costs included costs for medical treatment not covered by insurance and thus paid by the individual, travel costs to obtain medical treatment, costs for medication, including over-the-counter and prescribed medicines; costs of living, including food expenses, holiday expenses, costs during leisure activities, costs for equipment required to prepare safe meals, and domestic help. The indirect costs included lost working days, loss of education or working opportunities, lost earnings, lost human capital, time spent on searching for information on health related issues, and time spent obtaining medical treatment (e.g., travel time, consultation time).

3.2.3 Analysis

All significance tests have been conducted on the logarithms of the cost variables, in order to reduce the skewness of the cost distributions. Analysis of covariance (ANCOVA) with planned contrast and post-hoc tests using Bonferroni corrections were used to identify significant differences between cases and controls within countries and across the four countries. The logarithmic means of the cost variables were controlled for the following co-variables: age, gender, education, total working hours, household income, household composition, and severity and type of food allergy. The cross-country results were weighted by the ratio of the sample size to the population size of each country. The natural exponent of the difference in mean cost items between cases and controls will be reported to indicate the percentage difference of their respective geometric means. For example, if the difference in the average logarithmic costs was 0.48, the proportional difference equaled exp(0.48) = 1.62 resulting in 62% difference.

3.3 Results

The reported results are based on the pooled sample, including the adult version and parental version of the questionnaire, because the analysis on the separate samples did not show significant differences in cost items between the groups.

3.3.1. Direct costs

Contrary to expectations, the total direct costs in Poland, Spain and the UK were higher for the respondents asymptomatic to foods compared to the food hypersensitive respondents by 49% ($p<.01$), 73% ($p<.01$), 120% ($p<.01$), respectively, controlled for the influence of a number of co-variates. The total direct costs of food hypersensitive respondents and respondents asymptomatic to foods across all countries were significantly higher for respondents asymptomatic to foods than for food hypersensitive respondents by 62% ($p<.01$).

Within all countries and across all countries, the impact of cost of living was higher for respondents asymptomatic to foods than for food hypersensitive respondents (see Table 2a). In the Netherlands, the respondents asymptomatic to foods incurred 58.4% ($p<.01$) greater cost of living expenses compared to food hypersensitive respondents. In Poland the difference was 25.9% ($p<.01$), in Spain 31.0% ($p<.05$) and in the UK 60.0% ($p<.01$). Across all countries the costs for respondents asymptomatic to foods were 39.1% ($p<.01$) higher than for food hypersensitive respondents.

Table 2a. Analysis of variance of direct costs of cases and controls in four countries (logarithms)

		NL and case	NL and control	Poland and case	Poland and control	Spain and case	Spain and control	UK and case	UK and control	All cases	All controls
Cost of living	ln mean	**7.51**	**7.97****	**7.62**	**7.85****	**8.16**	**8.43***	**7.70**	**8.17****	**7.73**	**8.06****
	SE	**0.09**	**0.06**	**0.06**	**0.04**	**0.10**	**0.07**	**0.06**	**0.04**	**0.04**	**0.03**
Travel Cost to obtain health care	ln mean	**2.29**	**1.60****	**1.34**	**1.11****	1.46	1.36	**1.79**	**1.30****	**1.63**	**1.32****
	SE	**0.10**	**0.06**	**0.06**	**0.05**	0.11	0.07	**0.06**	**0.04**	**0.04**	**0.03**
Cost of consultation health professional	ln mean	**0.95**	**0.62***	0.87	0.72	**0.36**	**0.85****	**0.09**	**0.83****	**0.57**	**0.72***
	SE	**0.11**	**0.07**	0.07	0.05	**0.13**	**0.08**	**0.07**	**0.04**	**0.05**	**0.03**
Medicine (prescribed and OTC)	ln mean	2.65	2.67	**5.22**	**5.48***	3.62	3.63	3.03	3.16	3.74	3.75
	SE	0.16	0.10	**0.10**	**0.07**	0.18	0.12	0.10	0.06	0.07	0.05
Medical insurance	ln mean	2.39	2.37	2.91	2.97	**2.75**	**2.86***	**2.95**	**3.03***	2.86	2.91
	SE	0.04	0.02	0.02	0.02	**0.04**	**0.03**	**0.03**	**0.02**	0.02	0.01
Total direct costs	ln mean	7.14	7.26	**7.77**	**8.17****	**7.63**	**8.18****	**7.47**	**8.26****	**7.59**	**8.07****
	SE	0.11	0.07	**0.07**	**0.05**	**0.13**	**0.08**	**0.07**	**0.04**	**0.05**	**0.03**

Note. ** p<.01; * p<.05. Significant results in bold font

The ln is natural logarithm to the base e ($\ln(x) = \log_e(x)$).

However, in all countries except for Spain, the travel costs to obtain medical health care were on average 36.3% ($p<.01$) higher for food hypersensitive respondents than for respondents asymptomatic to foods: in the Netherlands by 99.4% ($p<.01$), Poland 25.9% ($p<.01$), UK 63.2% ($p<.01$). The costs of consultation with a health professional in the Netherlands were 39.0% ($p<.05$) higher for food hypersensitive respondents than for respondents asymptomatic to foods. The opposite was found in Spain and UK where the respondents asymptomatic to foods had 63.2% ($p<.01$) and 109.6% ($p<.01$) higher costs, respectively, than the food hypersensitive respondents for consultation with health care professionals. In Poland no significant differences were found in this respect. Across all countries the costs of consulting health professional were higher for respondents asymptomatic to foods compared to food hypersensitive respondents by 16.2% ($p<.05$).

The medication costs, either prescribed or over-the-counter, were 29.7% ($p<.05$) higher for respondents asymptomatic to foods than food hypersensitive respondents in Poland. In the other countries and in the across-country analysis no differences were observed. The costs of medical insurance for Spain and UK were 11.6% ($p<.05$) and 8.3% ($p<.05$) higher for respondents asymptomatic to foods compared to food hypersensitive respondents, respectively. In the Netherlands, Poland and in the across-country analysis no differences were observed in costs of medical insurance between food hypersensitive respondents and respondents asymptomatic to foods.

Table 2b shows the parameter estimates of the analysis of variance. Food hypersensitive respondents had lower total direct costs than respondents asymptomatic to foods with a beta coefficient of −.48 (based on logarithmic costs), indicating 62% difference in purchasing power adjusted costs. Those with severe reactions to food allergens incurred less costs than those with mild reactions to food allergens using the severity grading scale of Mueller (Mueller, 1966, 1990).

Regardless of food hypersensitivity, the sample that completed the adult version of the questionnaire had lower direct costs compared to the sample that completed the parental version. In addition, for both food hypersensitive respondents and respondents asymptomatic to foods, the direct costs were relatively high for households with a high educated respondents, higher household income and where longer hours were worked by the respondent. They were also higher if the respondent was older, and for households composed of with one adult (as compared to households with two adults and children). All of these variables are highly correlated with income (i.e., the older the person and the more educated they are the higher the income, not having children also frees people to enable working longer hours and

earning more money). Higher income means people have more disposal resources to spend on holidays and food. No significant differences were observed for the other variables included in the analysis.

Table 2b. Parameter estimates of analysis of variance on total direct costs

	Coeff.	**SE**	
Intercept	5.46	0.28	**
Very mild food allergy	*Reference group*		
Mild food allergy	−0.33	0.11	**
Moderate food allergy	−0.23	0.11	*
Severe food allergy	−0.11	0.14	
No adverse reactions to foods	−0.26	0.11	**
Parental version	−0.50	0.15	**
Adult version	*Reference group*		
University degree respondent	0.44	0.07	**
High diploma respondent	0.64	0.09	**
Secondary Education respondent	0.43	0.08	**
Missing data education level	−0.09	0.06	
Primary education respondent	*Reference group*		
Ln Working hours respondent	0.09	0.01	**
Ln Working hours partner/spouse	0.01	0.01	
Ln Household income	0.24	0.04	**
Missing data household income	1.28	0.28	**
Ln age adult in adults version	0.15	0.04	**
Ln age child in parental version	0.09	0.03	**
Missing data age	−0.05	0.15	
Gender adult female in adults version	−0.10	0.06	
Gender adult male in adult version	*Reference group*		
Gender child female in parental version	−0.10	0.07	
Gender child male in parental version	*Reference group*		
Household composition single adult	1.08	0.08	**
Household composition one adult and child/children	0.63	0.10	**
Household composition two adults without children	0.73	0.06	**
Household composition two adults and child/children	*Reference group*		
Chocolate and Sweets * case	0.69	0.09	**
Celery * case	0.23	0.12	*

Eggs * case	0.27	0.09	**
Fish * case	0.60	0.12	**
Fruit * case	0.35	0.07	**
Meat or poultry * case	0.55	0.18	**
*Milk and diary * case*	*Reference group*		
Mustard * case	−0.21	0.15	
Nuts * case	0.25	0.07	**
Sesame seed * case	0.02	0.14	
Shellfish and crustacean * case	−1.07	0.12	**
Soya * case	0.26	0.14	
Sulphites * case	−1.00	0.53	
Wheat and gluten * case	−0.54	0.12	**
Vegetables * case	−0.67	0.33	*
Other food allergy * case	1.04	0.34	**
Case	−0.48	0.07	**
Control	*Reference group*		

Note. F= 55.69; p<.01; adjusted R^2 = 0.15.
The ln is natural logarithm to the base e (ln(x) = $\log_e(x)$).

3.3.2 Indirect costs

The total indirect costs were largely influenced by the value of time associated with household tasks rather than value of time spent on health care, resulting in the total indirect costs for respondents asymptomatic to foods in the Netherlands being 37.7% (p<.01) higher than food hypersensitive respondents, 53.7% in the UK (p<.01) and 24.6% across all the four countries (p<.01) (Table 3a).

The indirect costs associated with the time spent on household tasks including cleaning, cooking, shopping, gardening, and childcare across all countries were higher for respondents asymptomatic to foods compared to food hypersensitive respondents by 30.1% (p<.01). In the Netherlands this figure was 47.7% (p<.01), 29.7% in Spain (p<.05), and 71.6% in the UK (p<.01). In Poland no significant differences were observed.

The costs of time spent on obtaining health care from a health professional across all countries was 43.3% (p<.01) higher for food hypersensitive respondents than for respondents asymptomatic to foods. Within-country analysis shows that food hypersensitive respondents in the Netherlands had 87.8% (p<.01) higher costs than respondents asymptomatic to foods, in Poland and Spain the difference was 50.7%

(p<.01). In the UK no differences were found. This was in line with our expectations that food hypersensitive respondents incur greater costs than respondents asymptomatic to foods, and is also consistent with the higher direct travel costs for food hypersensitive respondents in most countries (see Section 3.1).

The costs of time spent on obtaining health care in the hospital, and for family members to visit their hospitalized family member, was 61.6% (p<.01) higher for food hypersensitive respondents than for respondents asymptomatic to foods in Spain. In the other countries no differences were found between food hypersensitive respondents and respondents asymptomatic to foods. This could be due to the relatively low incidents of hospitalization that occurred in our sample of food hypersensitive patients.

The parameter estimates shown in Table 3b indicate that the greater the severity of food hypersensitivity the lower was the indirect costs. The household costs derived from the adult version were lower by 31% compared to the household costs of the parental version, either with or without a food hypersensitivity. The higher the educational level for food hypersensitive respondents and respondents asymptomatic to foods, the higher were the indirect costs, either with or without a food hypersensitivity. The working hours of the respondents, either cases or respondents asymptomatic to foods, were positively related to indirect costs whereas the working hours of the partner of the respondent were negatively related to the indirect costs. These higher costs associated with a higher educational level and working hours may also be due to the higher wage rate of these respondents as time was converted into monetary value using the respondents' wage rates. The younger the child, either with or without food hypersensitivity, the higher were the indirect costs. This could be due to the greater amount of time spent on care of young children compared to older children. For the respondent of the adult version, either case or control, the higher the age the higher were the indirect costs. This could be partly explained by a higher wage rate of respondents with more working experience as they become older. In the parent sample a gender effect was observed: girls had greater indirect costs than boys for either case or control. No gender effect was observed in the adult sample. Household composition seemed to influence the indirect costs. Namely, households with one adult incurred lower indirect costs compared to households with two adults and child or children, regardless of whether they had a food hypersensitive family member or not. Households with one adult and child or children incurred higher indirect costs compared to households with two adults and child or children, regardless of whether they included a food hypersensitive family member or not. The interaction effects of food hypersensitive respondents with allergies to chocolate and sweets, fish, fruit,

Table 3a. Analysis of variance of indirect costs of cases and controls in four countries (logarithms)

		NL and case	**NL and control**	**Poland and case**	**Poland and control**	**Spain and case**	**Spain and control**	**UK and case**	**UK and control**	**All cases**	**All controls**
Total value of time spent on household tasks	ln mean	**8.18**	**8.57****	7.76	7.74	**8.19**	**8.45***	**8.29**	**8.83****	**8.16**	**8.43****
	SE	**0.09**	**0.06**	0.06	0.04	**0.10**	**0.07**	**0.06**	**0.04**	**0.04**	**0.03**
Total value of time spent with and travelling to health professional	ln mean	**3.21**	**2.58****	**2.81**	**2.40****	**3.79**	**3.38****	2.64	2.55	**2.92**	**2.56****
	SE	**0.10**	**0.06**	**0.06**	**0.05**	**0.12**	**0.07**	0.07	0.04	**0.05**	**0.03**
Value of time spent by family members visiting family members in hospital	ln mean	0.36	0.32	0.77	0.64	**0.57**	**0.09****	0.94	0.80	0.76	0.64
	SE	0.12	0.08	0.08	0.06	**0.14**	**0.09**	0.08	0.05	0.06	0.03
Total indirect costs	ln mean	**8.27**	**8.59****	7.80	7.78	8.31	8.50	**8.41**	**8.84****	**8.24**	**8.46****
	SE	**0.08**	**0.05**	0.05	0.04	0.09	0.06	**0.05**	**0.03**	**0.04**	**0.02**

Note. ** p<.01; * p<.05. Significant results in bold font
The ln is natural logarithm to the base e (ln(x) = $\log_e(x)$).

meat, poultry, and sesame seeds showed a positive relation and nuts a negative relation with the indirect costs compared to the food hypersensitive respondents with allergy for milk and dairy products (reference group). Overall, the food hypersensitive respondents had lower indirect costs with a beta coefficient of −.22 compared to respondents asymptomatic to foods.

Table 3b. Parameter estimates of analysis of variance on total indirect costs

	Coeff.	**SE**	
Intercept	6.55	0.20	**
Very mild food allergy	*Reference group*		
Mild food allergy	0.25	0.08	
Moderate food allergy	−0.04	0.06	**
Severe food allergy	0.45	0.06	
No adverse reactions to foods	0.02	0.08	**
Adult version	−0.31	0.11	**
Parental version	*Reference group*		
University degree respondent	0.60	0.05	**
High diploma respondent	0.52	0.06	**
Secondary Education respondent	0.13	0.06	**
Missing data education level	−0.41	0.04	**
Primary education respondent	*Reference group*		
ln Working hours respondent	0.06	0.01	**
ln Working hours partner/spouse	−0.02	0.01	**
ln Household income	0.19	0.03	**
Missing data household income	1.05	0.21	**
ln age adult in adults version	0.12	0.03	**
ln age child in parental version	−0.02	0.02	
Missing data age	−0.19	0.11	
Gender adult female in adults version	0.00	0.04	
Gender adult male in adult version	*Reference group*		
Gender child female in parental version	0.16	0.05	**
Gender child male in parental version	*Reference group*		
Household composition single adult	−0.21	0.06	**
Household composition one adult and child/children	0.23	0.08	**
Household composition two adults without children	−0.04	0.05	
Household composition two adults and child/children	*Reference group*		

Chocolate and Sweets * case	0.16	0.07	**
Celery * case	0.08	0.09	
Eggs * case	−0.01	0.07	
Fish * case	0.18	0.09	*
Fruit * case	0.10	0.05	
Meat or poultry * case	0.66	0.14	**
*Milk and diary * case*	*Reference group*		
Mustard * case	−0.07	0.11	
Nuts * case	−0.10	0.05	*
Sesame seed * case	0.34	0.10	**
Shellfish and crustacean * case	−0.12	0.09	
Soya * case	0.05	0.10	
Sulphites * case	−0.11	0.39	
Wheat and gluten * case	−0.06	0.09	
Vegetables * case	−0.18	0.24	
Other food allergy * case	0.68	0.25	**
Case	−0.22	0.05	**
Control	*Reference group*		

Note. F = 13.12; p<.01; adjusted.R^2 = 0.18.
The ln is natural logarithm to the base e (ln(x) = $\log_e(x)$).

3.4 Discussion and conclusion

This study reports the differences in household costs associated with having a family member suffering from food hypersensitivity, compared to households without food hypersensitive members. Contrary to our expectations, the food hypersensitive respondents had significantly lower direct and indirect costs across all countries that household costs would be higher in the presence of food hypersensitivity. This may be explained by the routinisation of shopping and cooking due to the limited variety of foods people with a food allergy can safely consume, and by the avoidance of more expensive processed foods leading to less expenses on groceries and less time spent buying and preparing meals (Cornelisse-Vermaat, Voordouw, Yiakoumaki, Theodoridis, & Frewer, 2008; Voordouw et al., 2009). Moreover, families with food hypersensitive members also have restricted social and recreational activities where the food supply cannot be managed to an appropriate level (for example, going out for dinner, ordering takeaway food, or recreational travel) leading to less expenses

compared to a family without food hypersensitive members (see Cornelisse-Vermaat, Voordouw, Yiakoumaki, Theodoridis, & Frewer, 2008; Voordouw et al., 2009).

It is possible that food hypersensitive patients needed to travel further to seek a (food) allergy specialist due to the small number of clinicians with expertise in this area, resulting in higher travel costs. Once a food allergy patient has been diagnosed and is adequately informed about the avoidance diet and emergency treatments, patients will be monitored at least yearly with a follow-up consultation (some patients outgrow food allergy whereas others develop new allergies), leading to relatively low consultation costs compared to other chronic diseases which require regular check-ups by a specialist. The medication for food allergy is limited to emergency treatment, such as carrying an epinephrine auto-injector or oral antihistamines (Pumphrey, 2000; Thompson & Chandra, 2002). Again, these costs are relatively low compared to other chronic diseases requiring daily medication. The differences in health care insurance systems across the countries make it difficult to develop a sensitive measure to establish the impact of food hypersensitivity on health care insurance. However, taking into consideration the above (low consultation costs and low medicine costs), it may be concluded that food hypersensitive patients do not need more expensive health insurance than people without food hypersensitivity.

The most relevant finding of this study is that the greater the severity of the food hypersensitivity, the lower were the indirect and direct costs. The lower costs associated with a severe food hypersensitivity could be explained through the behavioural changes of the patients compared to food hypersensitive respondents with mild food hypersensitivity. Food hypersensitive respondents with severe food hypersensitivity have more restrictions associated with consumption in general, as well as consumption of expensive or exotic foods, eating out, and foreign travel and holidays, thus reducing expenditure of patients with severe food hypersensitivity as compared to mild food hypersensitive respondents. This illustrates that cost of living (measured as household spending) alone should not be seen as a measure of welfare and wellbeing. In a follow-up study the welfare and well-being of food hypersensitive suffers will be estimated.

Many patient interest groups working in the area of food allergy report anecdotal evidence that food allergic patients have very high costs associated with their disease (see, for example, Anaphylaxis Campaign (UK), 1 April 2010; Australasian Society of Clinical Immunology and Allergy, 1 April 2010; Consortium of Food Allergy Research (coFAR), 1 April 2010; European Federation of Asthma and Allergy Associations, 1 April 2010; Food Allergy and Anaphylaxis Network (FAAN) (USA) 1 April 2010; Global Allergy and Asthma European Network (GA_LEN), 1

April 2010; International Union of Immunological Societies (IUIS), 1 April 2010; World Allergy Organisation, 1 April 2010). However, the results presented here, derived from the analysis of extensive survey data collected in different European countries, and through application of a validated instrument do not support the contention that food allergy is associated with high costs at the household level.

Our study design may have had some methodological limitations. When a respondent was not in paid employment, the minimum wage rate used in the country under consideration was used to calculate the opportunity costs, because it was assumed that, regardless of educational level, the respondent could earn at least the minimum wage rate on the labour market. When respondents were employed, actual wage rates were used because the respondent has chosen household production over income he or she could have earned spending that time on the labour market. It could be argued that this assumption was inappropriate, as the unemployed individual could have earned more than the minimum wage if employed.

The sample collected in the UK was smaller in comparison to the samples collected in the other countries. This might have affected the results because, in the between-country analysis, the countries were weighted according to their population sizes, leading to a larger multiplication factor for food hypersensitive respondents in the UK as compared to other countries. Outliers may have had a relatively large impact on the results in this case.

3.4.1 Future research and implications

For policy makers, information about the cost at the household level as well as cost for the health sector and industry are important to develop adequate and cost-effective regulatory measures regarding consumer protection and provision of health care services. Since both direct and indirect costs of food hypersensitive respondents were lower than for respondents asymptomatic to foods, our results suggest that compensating cost measures for patients are not necessary.

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Chapter 4

The subjective welfare and well-being of food hypersensitive individuals in the Netherlands, Poland, Spain and United Kingdom.

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Abstract

Introduction

This study estimates the effects of food hypersensitivity on individuals' perceived welfare and well-being compared to non-food hypersensitive individuals in the Netherlands, Poland, Spain and UK.

Method

The difference in welfare between food hypersensitive respondents and those asymptomatic to foods was estimated using a subjective welfare approach, including income evaluation. Well-being was measured using the Cantril Ladder-of-Life Scale, and health status using the Self-Perceived Health Scale (SPH). The difference in well-being and health status between participant groups was explained further using a number of background variables.

Results

No significant within-country differences in welfare between food hypersensitive respondents and respondents asymptomatic to foods were found. In terms of well-being, adult food hypersensitive respondents and their spouses reported significantly less happiness than respondents asymptomatic to foods in the Netherlands and Poland. In Spain, only the spouses of the food hypersensitive respondents were significantly less happy than respondents asymptomatic to foods. The well-being of children did not significantly differ between groups. The degree of severity of food hypersensitivity was negatively related to overall health status. In Poland, food hypersensitive respondents reported worse health status compared to asymptomatic respondents. In Spain the converse was true.

Discussion and conclusion

Food hypersensitive respondents were generally less happy with their life as a whole than respondents asymptomatic to foods, presumably because they suffered more.

4.1 Introduction

Adverse reaction to food can be caused by food hypersensitivity. Food hypersensitivity includes both food allergic reactions and food intolerant reactions to foods (Patriarca et al., 2009). Individuals suffering from food allergy have inappropriate autoimmune system reactions to normally harmless food components. Food allergy is either IgE-mediated (e.g. food allergies) or non-IgE-mediated (e.g. celiac disease). In the case of food intolerance, the immune system is not involved (e.g., lactose deficiency). Food hypersensitivity is a disease for which no treatment is currently available, although research aimed at curing the disease is promising (Asero et al., 2007; Clark et al., 2009; Dutau & Rance, 2006). As a consequence, food hypersensitivity needs to be carefully managed by exclusion of problematic foods from the diet (Ewan & Clark, 2005; Thompson & Chandra, 2002). Therefore, people suffering from food hypersensitivity, as well as people providing or preparing food need to be alerted constantly for potentially problematic foods in the diet (Cornelisse-Vermaat et al., 2008; Joshi, Mofidi, & Sicherer, 2002). It has been suggested that the implementation of an avoidance diet may be costly in terms of time and money, for example in terms of information search and shopping (Cornelisse-Vermaat et al., 2008; Flabbee, Petit, Jay, Guenard et al., 2008; Voordouw et al., in press). Furthermore, socio-economic restrictions associated with allergen exposure may also result in a decreased quality of life (Flokstra-De Blok et al., 2010; Gowland, 2002). There is some evidence to suggest that food allergic patients may also self-report taking more time off work, perceive a lower income, and are more physically restricted compared to non-food allergic people (Knibb et al., 2000). Thus, the quality of life, financial situation and health status of people suffering from food hypersensitivity may be less positive from those asymptomatic to foods. The concepts of well-being and welfare capture these issues and make it possible to measure the impact of food hypersensitivity.

Well-being is defined as the overall life satisfaction or happiness of an individual (Antonides & Van Raaij, 1998; Van Praag & Frijters, 1999). Happiness is generally considered the ultimate goal of life (Frey & Stutzer, 2002). Several factors may influence overall well-being, for example, an individual's satisfaction with society, their financial situation and working status, and their environment, health, housing, leisure, friends, marriage and family situation (Kahneman & Krueger, 2006; Van Praag, Frijters, & Ferrer-i-Carbonell, 2003).

Although a recent study showed that the direct and indirect financial costs associated with food hypersensitivity at the household level, due to medical care and informal care were negligible (Voordouw et al., submitted), food hypersensitivity may

have an impact on the *subjective welfare*, defined as the individual evaluation of income (Antonides & Van Raaij, 1998; Van Praag & Frijters, 1999). The traditional approach to measuring welfare would be using objective methods assuming that consumers maximise the utility of their income (Van Praag & Frijters, 1999). However, consumers frequently show bounded rationality when it comes to maximizing utility and therefore their choices do not always reflect their true preferences (Gigerenzer & Selten, 2001). Here, we use the subjective welfare method which has proven its reliability in a number of studies (Clark, Diener, Georgellis, & Lucas, 2008; Kahneman & Krueger, 2006; Van Praag & Frijters, 1999).

In this study, the welfare and well-being of food hypersensitive patients in the Netherlands, Poland, Spain and UK were investigated by comparing clinically diagnosed food allergic and food intolerant patients with a sample of respondents asymptomatic to any food. To our knowledge, this issue has not been investigated before.

4.2 Method

4.2.1 Study population

Data from respondents in Poland and Spain were collected as part of the epidemiological study performed within EuroPrevall. The protocol on the sampling strategy has been described elsewhere (Kummeling et al., 2009; Mills et al., 2007). The epidemiological study was designed as a clinical case-control study to establish the prevalence of food allergy and food intolerance. In the Netherlands and UK, the protocol from the epidemiological study was used to select the patients with food allergy and food intolerance. Recruitment was conducted through hospitals and patient organisations. Respondents were included if they indicated having one or more allergies to the 14 food allergens listed in the EC Directive 2006/142/EC, *and* reported experiencing symptoms following accident ingestion of food allergens, *and* reported that they had been diagnosed as having food allergy by a health professional. A pre-analysis was performed to test whether the patients from each sampling method were comparable. The analysis of co-variance identified no significant differences between the recruitment methods. The target group of respondents with food allergy or food hypersensitivity and their families were compared to a baseline sample which consisted of respondents reporting that they and their families were asymptomatic to any type of food allergy. The baseline groups in Spain and Poland comprised respondents asymptomatic to foods as part of the epidemiological study. In the Netherlands and UK, the baseline samples were selected to be comparable to the

demographic characteristics of the target patient samples. Pre-analysis using analysis of co-variance showed that the baseline samples were not significantly different across all countries. The patients recruited through the epidemiological study were tested through double-blind placebo-controlled food challenges (DBPLCFC). The majority of the food hypersensitive respondents were classified as *food intolerant* and the minority as *food allergic*. Therefore, in this study we will use the broader term "food hypersensitivity," which includes all patients with food allergy or food intolerance.

The survey was conducted in the Netherlands, Poland, Spain and the UK. Welfare and well-being were estimated by comparing the differences between households with, and without, food hypersensitive members, enabling comparison of the target food hypersensitive group to the asymptomatic baseline sample. The participants received written information about the study, together with the questionnaire inquiring about the costs at the household level. Their participation was voluntary and had no consequences for their treatment. Participants did not receive any incentive for their contribution. The questionnaires were assigned unique codes to obtain a data set with anonymous records. Only the researcher could match the codes with the personal data of the participants. Ethical approval from the medical ethical committees in the participating hospitals, clinical centres and universities was obtained.

In total, 1592 respondents were included in this study (Table 1). The target sample comprised both food hypersensitive adults and children. In the case of the latter, (one of) the child's parent(s) completed the questionnaire. The food hypersensitive adults from the target sample and the healthy adults from the baseline sample received the *adult version* of the questionnaire, designed to estimate the welfare, well-being and health status experienced by adults with or without (perceived) food sensitivities. The families with food allergic children received the *parental version*, which was designed to provide the same estimates in households including children with or without food hypersensitivity. A household without a food hypersensitive child (asymptomatic baseline sample) reported the welfare, well-being and health status of the oldest child living at home.

4.2.2 Health, well-being and welfare scales

Various scales were used to measure self-reported health status, welfare and well-being. The five-point Self-Perceived Health (SPH) scale was included to enable assessment of subjective health status. Individuals rated their own current perceived health status from 'poor' to 'excellent' on a 5-point scale (Benyamini & Idler, 1999).

Table 1. Distribution of adult and parental versions of the questionnaire

		Adult version	Parental version	Total
Netherlands	Case	65	67	132
	Control	52	92	144
Poland	Case	97	149	246
	Control	224	163	387
Spain	Case	97	96	193
	Control	190	231	421
United Kingdom	Case	30	12	42
	control	20	7	27
	Total	775	817	1592

Well-being was assessed using the 'ladder-of-life' scale, in which respondents indicated on a 10-point scale representing a fictitious ladder how they evaluated their life as a whole (Cantril, 1965), the lowest step indicating the worst possible life and the highest step indicating the best possible life. The well-being measure assessed people's happiness across all life domains, including the economic domain, thus enabling the measurement of the impact of food allergy or food intolerance on life as a whole. The Cantril scale has been used in several sociological and psychological surveys (Van Praag & Frijters, 1999).

Income satisfaction or welfare was measured using the Leyden approach, including the income evaluation question (see Figure 1) (Van Praag and Frijters, 1999).The Leyden approach assumes, first, that individuals are able to evaluate income levels using verbal qualifiers ranging from "very bad" to "very good". These verbal qualifiers equal the utility levels of the respondent. The income evaluation question asks for a reverse evaluation, in which the respondent was asked to state an income associated with each of the presented evaluation levels. It assumes, second, that the verbal qualifiers can be transformed into a numerical [0,1] utility scale. Respondents tend to provide information spread evenly over the utility scale, such that each of the levels corresponds with a equal jump on the [0,1] welfare scale. Using six evaluation levels, each respondent provided six income levels connected to six utility levels. A lognormal distribution function (Λ) has been assumed to fit the stated incomes to the utility levels. The location parameter of the distribution, μ, can be interpreted by realising that Λ (e^{μ}; μ, σ) = 0.5. Hence, the income level e^{μ} is halfway between the lowest and highest possible utility levels and was estimated as the average of the log-

income answers. The parameter σ determines the slope of the welfare function and indicates the welfare sensitivity of the individual.

Question

Thinking of your present situation, what total monthly household income (adding your own and your spouse's/partner's income after tax and other deductions have been taken out) would you consider for your family to be……?

Please enter an amount on each line

Very bad? ……..

Bad? ……..

Insufficient? ……..

Sufficient? ……..

Good? ……..

Very Good? ……..

Figure 1. The income evaluation question

4.2.2.1 Severity scale of food hypersensitivity

Food hypersensitivity reactions can be classified into four categories of severity using the Mueller grading scale (Mehl, Wahn, & Niggemann, 2005; Mueller, 1966). Mild symptoms include skin rashes (grade 1). If gastrointestinal problems, (diarrhoea, or angio-oedema) also occur, severity is classified as moderate (grade 2). The next grade also includes problems with respiratory tract, such as tightening of the throat (grade 3). The most severe reactions include the cardiovascular system and potentially anaphylactic shock (grade 4).

4.2.3 Inclusion of type of food allergens

EU directive 2003/89/EC amending 2000/13/EC), effective from November 2005, made it mandatory for the food industry to list all 12 (currently 14) potential food allergens on product labels regardless of the quantity in the finished product (Cheftel, 2005; Hefle & Taylor, 2004; Hignett, 2002). The eight food allergens that contribute to 90% of the IgE-associated reactions are; milk, egg, soy, peanut, tree nuts, sesame, wheat, fish and shelfis. The food allergens listed in this directive were included in the questionnaire.

Allergic reactions associated with chocolate, meat, poultry are often caused by cross-contamination of other allergens like milk or nuts. The pilot study showed that respondents do not always contribute these allergenic reactions to cross-contamination of the real allergens responsible for the symptoms. They reported these products under *'other allergens,'* therefore; these products were taken up separately in the questionnaire and in the analysis.

4.2.4 Analysis

The difference in welfare, derived from the income evaluation question, between the food hypersensitive respondents and respondents asymptomatic to foods in each country was estimated using analysis of co-variance and Bonferroni *post hoc* tests. The difference in well-being, derived from the Cantril scale, between food hypersensitive respondents and respondents asymptomatic to foods was estimated using ordered probit analysis. The following demographic characteristics were used as co-variates in both analyses: age, gender, education, total working hours, household income, household composition, food allergy or food intolerance severity level, type of food allergy or food intolerance. The parent version and adult version were not highly correlated with the family composition; therefore, they were included as separate dummies in the analysis.

4.3 Results

4.3.1 Welfare

The welfare parameter μ was not significantly different between food hypersensitive respondents and controls in any of the countries (Table 2). However, both food hypersensitive respondents and respondents asymptomatic to foods who completed the adult questionnaire needed a significantly lower income to be equally satisfied with their income than the group of respondents who completed the parental questionnaire ($p<.05$), indicating higher welfare for patients than for patients' parents. An explanation could be that families with children need more income to compensate for a lower amount of leisure time than households without children.

Respondents with a university degree needed a significantly higher income to be equally satisfied compared to respondents with only primary education ($p<.01$). This could be explained by the higher aspirations of people with higher education levels (cf. Easterlin, 2001). Households composed of a single adult, or one adult and children, reported needing less income to be as equally satisfied as households comprising two adults and children (respectively, $p<.01$ and $p<.01$). This can be

explained by the number of people in the household and the resources needed to reach the same satisfaction level. The higher the household income, the higher the perceived welfare (p<.01), indicating a preference drift associated with household income level. These results are in line with earlier findings (Senik, 2009; Van Praag & Frijters, 1999).

Food hypersensitive respondents reporting nut, shellfish and crustacean hypersensitivity needed more income to be equally satisfied to respondents with milk hypersensitivity (respectively, p<.01, and p<.05). This could be explained by the fact that, for milk, many alternatives are available such as soymilk or goat's milk. However, for nut, shellfish and crustaceans, no real alternative is available. To compensate for this loss, more income is needed to be equally satisfied with one's dietary options. Furthermore, accidental reactions to nuts, shellfish and crustaceans are generally more severe than those exoerineed following exposure to milk.

Table 2. Parameter estimates of analysis of variance on welfare (μ)

	Coeff.	SE	
Intercept	4.27	0.17	**
Very mild food allergy	*Reference group*		
Mild food allergy	0.00	0.05	
Moderate food allergy	0.02	0.05	
Severe food allergy	0.02	0.06	
No adverse reaction to foods	0.00	0.05	
Parental version	*Reference group*		
Adult version	-0.20	0.09	*
University degree respondent	0.08	0.03	**
High diploma respondent	-0.05	0.04	
Secondary Education respondent	0.03	0.04	
Primary education respondent	*Reference group*		
Missing data education level	0.00	0.03	
Single adult	-0.23	0.05	**
One adult and child/children	-0.13	0.05	**
Two adults without children	-0.02	0.03	
Two adults and child/children	*Reference group*		
Chocolate and Sweets * case	-0.06	0.04	
Celery * case	0.02	0.07	
Eggs * case	-0.02	0.04	
Fish * case	0.04	0.06	
Fruit * case	-0.04	0.03	

Meat or poultry * case	0.15	0.10	
*Milk and diary * case*	*Reference group*		
Mustard * case	-0.03	0.07	
Nuts * case	0.12	0.04	**
Sesame seed * case	0.00	0.09	
Shellfish and crustacean * case	0.14	0.06	*
Soya * case	-0.08	0.07	
Sulphites * case	0.26	0.36	
Wheat and gluten * case	-0.02	0.08	
Vegetables * case	0.11	0.08	
Other food allergy * case	0.06	0.14	
Gender adult female in adults version	0.03	0.03	
Gender adult male in adult version	*Reference group*		
Gender child female in parental version	-0.02	0.03	
Gender child male in parental version	*Reference group*		
ln Working hours respondent	0.01	0.01	†
ln Working hours partner/spouse	0.01	0.01	
ln Household income	0.44	0.02	**
Missing data household income	3.46	0.16	**
ln Age of adult in adult version	0.02	0.02	
ln Age of child in parental version	-0.01	0.02	
Age Missing data dummy	0.02	0.08	
Netherlands	-0.08	0.04	
Spain	*Reference group*		
Poland	-0.26	0.03	**
UK	0.04	0.10	
Netherlands*Case	-0.08	0.07	
Poland*Case	0.04	0.04	
Spain*Case	0.03	0.05	
UK*Case	0.08	0.13	

Note. † p<.10; * p<.05; ** p<.01.
The ln is natural logarithm to the base e (ln(x) = $\log_e(x)$). Adjusted R^2 = .56.

4.3.2 Health status

The results for self-perceived health status are shown in Table 3. In Poland, patients reported significantly lower overall health status compared to respondents asymptomatic to foods (p<.05). In Spain food hypersensitive respondents had a significantly higher overall perceived health status compared to the respondents asymptomatic to foods (p<.01). No differences were observed in the Netherlands or

in the UK. In addition, participants with mild food hypersensitivity had worse perceived health status compared to respondents with a very mild food hypersensitivity (p<.05). Participants who completed the adult questionnaire reported better health status compared to respondents who completed the parental questionnaire (p<.01). Respondents with university level education reported better health status compared to the respondents in the reference group (primary education level) (p<.01). This corresponds to the results of previous research (Groot & Maassen van den Brink, 2007; Grossman & Kaestner, 1997).

Table 3. Ordered probit analysis of the self-perceived health scale

	Coeff.	**SE**	
Bad health	-1.00	0.44	*
Reasonable health	0.19	0.44	**
Good health	1.57	0.44	**
Very Good health	2.80	0.44	
Excellent health	*Reference group*		
Intercept	-0.05	0.13	
Very mild food allergy	*Reference group*		
Mild food allergy	-0.32	0.14	*
Moderate food allergy	-0.23	0.17	
Severe food allergy	0.08	0.13	
No adverse reaction to foods	-0.37	0.21	
Adult version	0.26	0.09	**
Parental version	*Reference group*		
University degree respondent	0.31	0.12	**
High diploma respondent	0.09	0.10	
Secondary Education respondent	-0.08	0.08	
Primary education respondent	*Reference group*		
Missing data education level	-0.50	0.19	**
Single adult	0.11	0.12	
One adult and child/children	0.08	0.09	
Two adults without children	-0.15	0.12	
Two adults and child/children	*Reference group*		
Chocolate and Sweets * case	-0.32	0.16	*
Celery * case	-0.34	0.12	**
Eggs * case	-0.33	0.15	*
Fish * case	-0.07	0.09	
Fruit * case	-0.25	0.26	

Meat or poultry * case	0.37	0.19	
*Milk and diary * case*	*Reference group*		
Mustard * case	0.01	0.10	
Nuts * case	-0.01	0.22	
Sesame seed * case	0.12	0.16	
Shellfish and crustacean * case	0.41	0.17	*
Soya * case	-0.62	0.59	
Sulphites * case	-0.17	0.19	
Wheat and gluten * case	-0.26	0.24	
Vegetables * case	0.17	0.37	
Other food allergy * case	-0.08	0.08	
Gender adult female in adults version	-0.11	0.08	
Gender adult male in adult version	*Reference group*		
Gender child female in parental version	0.02	0.02	
Gender child male in parental version	*Reference group*		
ln Working hours respondent	0.00	0.02	
ln Working hours partner/spouse	0.26	0.05	**
ln Household income	2.09	0.41	**
Missing data household income	-0.15	0.06	**
ln Age of adult in adult version	-0.06	0.05	
ln Age of child in parental version	-0.39	0.17	*
Missing age dummy	0.12	0.14	
Netherlands	-0.15	0.10	
Poland	0.13	0.14	
Spain	*Reference group*		
UK	0.21	0.29	
Netherlands*Case	0.08	0.11	
Poland*Case	-0.21	0.09	*
Spain*Case	0.63	0.22	**
UK*Case	-	-	

Note. † p<.10; * p<.05; ** p<.01.
The ln is natural logarithm to the base e ($\ln(x) = \log_e(x)$).
Nagelkerke $R^2 = .28$

Food hypersensitive respondents reporting allergies for chocolate, celery, or eggs had a worse health status compared to those with milk hypersensitivity (respectively, p<.05, p<.01, p<.05). However, respondents sensitive to meat, poultry, shellfish or crustaceans had a better health status compared to food hypersensitive respondents sensitive to milk (p<.05 and p<.05). The consumption of meat and

poultry in large quantities can increase the risk of diseases like, cancer or cardiovascular disease (Sandhu, White, & McPherson, 2001). Avoiding these products in the diet might contribute to better health status.

The more (paid) hours the participant's partner worked, and the higher the household income, the higher was reported health status ($p<.01$ and $p<.01$). Income inequalities are often highly correlated with health status (Wilkinson & Pickett, 2006). The younger the child suffering from a food hypersensitivity, the worse the health status indicated by the parents ($p<.05$). For adults no differences were observed.

4.3.3 Well-being

The results of the well-being analysis are shown in Table 4. The results for repondents, their spouses and children were very similar. In the Netherlands and Poland, food hypersensitive respondents reported lower well-being compared to respondents asymptomatic to foods in each country for both respondents and spouses (Dutch respondents $p<.01$; Dutch spouses $p<.05$; Polish respondents $p<.05$; Polish spouses $p<.05$). In Spain, spouses of food hypersensitive respondents reported lower levels of well-being compared to spouses of respondents asymptomatic to foods ($p<.01$). For children, no effects of food hypersensitivity on well-being were observed. The severity and type of food hypersensitivity did not show significant effects on well-being.

Respondents ($p<.01$), spouses ($p<.05$) and children ($p<.05$) of parents with a university degree reported a higher well-being compared to respondents with only primary education. Households comprising one adult, either with or without food hypersensitivity, reported higher well-being than households with two adults and children ($p<.05$). The higher the respondent's income level ($p<.01$) and hours worked ($p<.05$), the higher was the perceived level of well-being.

Table 4. Ordered probit analysis of the Cantril ladder of life scale for respondents, spouses and children

	Respondent			Spouse			Child		
	Coeff.	**SE**		**Coeff.**	**SE**		**Coeff.**	**SE**	
Ladder of life step 0	0.53	0.44		-0.30	0.54		-1.70	0.66	**
Ladder of life step 1	0.76	0.43	†	0.07	0.52		-1.22	0.62	*
Ladder of life step 2	0.94	0.43	*	0.36	0.51		-0.66	0.60	
Ladder of life step 3	1.46	0.42	**	0.80	0.51		-0.22	0.60	
Ladder of life step 4	1.91	0.42	**	1.26	0.51	**	0.30	0.60	
Ladder of life step 5	2.58	0.42	**	1.89	0.51	**	0.71	0.60	
Ladder of life step 6	3.08	0.42	**	2.41	0.51	**	1.37	0.60	*
Ladder of life step 7	3.88	0.42	**	3.17	0.51	**	2.14	0.60	**
Ladder of life step 8	4.77	0.43	**	4.07	0.51	**	2.84	0.60	**
Ladder of life step 9	5.37	0.43	**	4.66	0.51	**	0.24	0.16	
Ladder of life step 10			*Reference group*						
Very mild food allergy			*Reference group*						
Mild food allergy	0.17	0.13		0.12	0.14		-0.21	0.18	
Moderate food allergy	0.00	0.13		0.06	0.15		-0.36	0.22	†
Severe food allergy	-0.04	0.16		-0.04	0.19		-0.02	0.16	
No adverse reaction to foods	0.01	0.13		-0.12	0.14		-0.14	0.64	
Adult version			*Reference group*						
Parental version	0.15	0.20		0.21	0.26		0.12	0.12	
University degree respondent	0.27	0.08	**	0.23	0.10	*	0.32	0.16	*
High diploma respondent	0.17	0.11		0.21	0.13	†	0.40	0.14	**
Secondary Education respondent	0.17	0.09	†	0.25	0.11	*	-0.05	0.11	
Primary education respondent			*Reference group*						
Missing data education level	0.05	0.08		0.04	0.09		-0.36	0.26	
Single adult	0.29	0.13	*						
One adult and child/children	0.02	0.11		0.32	0.21		-0.02	0.57	
Two adults without children	0.10	0.08		-0.01	0.10		0.02	0.14	
Two adults and child/children			*Reference group*						
Chocolate and Sweets * case	0.10	0.11		0.21	0.13	†	0.02	0.22	
Celery * case	0.00	0.16		-0.06	0.19		-0.11	0.13	
Eggs * case	-0.03	0.11		0.01	0.13		-0.15	0.21	
Fish * case	0.01	0.14		0.30	0.17	†	0.12	0.12	

Fruit * case	0.07	0.09		-0.02	0.10		0.05	0.36	
Meat or poultry * case	-0.24	0.24		-0.25	0.28		-0.21	0.30	
*Milk and diary * case*			*Reference group*						
Mustard * case	-0.33	0.18	†	-0.34	0.23		0.12	0.14	
Nuts * case	0.18	0.10	†	0.26	0.11	*	-0.04	0.28	
Sesame seed * case	0.07	0.21		-0.09	0.24		0.14	0.24	
Shellfish and crustacean * case	0.10	0.16		-0.01	0.20		-0.10	0.22	
Soya * case	0.29	0.16	†	0.27	0.20		-0.42	1.18	
Sulphites * case	-0.97	0.55	†	-1.00	0.62		-0.01	0.29	
Wheat and gluten * case	0.06	0.19		0.07	0.23		0.07	0.50	
Vegetables * case	-0.15	0.23		-0.30	0.27		-0.36	0.44	
Other food allergy * case	-0.22	0.35		-0.67	0.43		0.37	0.41	
Gender adult female in adults version	0.00	0.08		-0.04	0.10		0.03	0.08	
Gender adult male in adult version			*Reference group*						
Gender child female in parental version	0.01	0.07		-0.01	0.08		0.00	0.03	
Gender child male in parental version			*Reference group*						
ln Working hours respondent	-0.02	0.02		-0.05	0.02	*	-0.01	0.03	
ln Working hours partner/spouse	0.01	0.02		0.04	0.02	*	0.26	0.07	**
ln Household income	0.44	0.05	**	0.37	0.06	**	2.08	0.58	**
Missing data household income	3.59	0.39	**	3.06	0.48	**	-0.02	0.17	
ln Age of adult in adult version	-0.08	0.06		-0.10	0.07		-0.09	0.06	
ln Age of child in parental version	-0.02	0.05		-0.03	0.05		-0.35	0.14	**
Missing age dummy	-0.32	0.18	†	-0.32	0.22		0.00	.	
Netherlands	0.28	0.10	**	0.21	0.12	**	-0.60	0.13	**
Spain			*Reference group*						
Poland	-0.09	0.08		-0.25	0.10	**	0.06	0.44	
UK	0.23	0.20		0.39	0.25		-	-	
Netherlands*Case	-0.42	0.16	**	-0.42	0.18	*	0.00	0.14	
Poland*Case	-0.22	0.10	*	-0.24	0.11	*	-0.35	0.19	†
Spain*Case	-0.09	0.14		-0.39	0.15	**	-0.31	0.55	
UK*Case	-0.33	0.27		-0.40	0.32		-	-	

4.4 Discussion and conclusion

The aim of this study was to investigate the impact of food hypersensitivity on subjective welfare and well-being in the Netherlands, Poland, Spain and UK. This was accomplished by comparing clinically diagnosed patients hypersensitive to foods with a sample of respondents asymptomatic to any food.

In general, patients with food hypersentivity, either food allergy or food intolerance, reported reduced well-being compared to the healthy control group. Since well-being was positively related to income, an income supplementation may compensate for food allergy. Other measures may also be considered (e.g., counseling, provision of safe food). In this study no differences in welfare were found between clinically diagnosed food hypersensitive respondents and the asymptomatic baseline sample. Similar results were found in a study on perceived food intolerance sufferers for lifestyle, welfare and dietary practices of perceiving food intolerance, in a community sample in Ireland (Knibb et al., 2000). Health-related quality of life (HRQL) can be defined as the perceived effect by the patients of an illness and its consequent therapy (Meltzer, 2001), and is a sub domain of general well-being (Antonides & Van Raaij, 1998). Several studies investigated the HRQL associated with chronic diseases, such as allergic diseases. HRQL is impaired in patients with food allergy compared to the general population; furthermore, research shows that the magnitude of food allergy is intermediate compared to diabetis mellitus type 1 and asthma, irritible bowel syndrome and rheumatoid arthritis (Flokstra-De Blok et al., 2010). Although the direct and indirect costs of patients with food hypersensitivity and subjective welfare were not affected by the disease compared to a healthy control sample, this study confirms previous findings that food allergy negatively affects the well-being of patients. This important finding could be used to prioritise resources for the development of new food allergy management strategies, and could help to inform legislation in this area.

The results also suggest that food hypersensitivity does not have an impact on perceived health status. This may be because, under circumstances where dietary management is effective, patients do not suffer illness in the course of their daily life. Accidental exposure to problematic foods may result in a negative effect on health status, but this may be infrequent. It is important to note that perceived health status does not necessarily correlate with anxiety associated with the development of an allergen avoidance strategy and allergen management stategy (DunnGalvin & Hourihane, 2007; DunnGalvin & Hourihane, 2008).

4.4.1 Future research and implications

Patients suffer from a loss of well-being; future research may focus on the development of well-being over time, and by comparing situations before and after clinical testing for food allergy or food intolerance.

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Chapter 5

Food allergic consumers' preferences for labelling practices: A qualitative study in a real shopping environment

This chapter is based on the following publication: Voordouw, J., Cornelisse-Vermaat, J.R., Yiakoumaki, V., Theodoridis, G., Chryssochoidis, G., & Frewer, L.J. (2009). Food allergic consumers' preferences for labelling practices: A qualitative study in a real shopping environment. *International Journal of Consumer Studies, 33*(1), 94-102.

Abstract

Food allergy is a chronic disease which can only be managed through avoidance of problematic proteins in the diet. Inappropriate communication about food allergens can cause stress and insecurity, which may have a negative impact on quality of life. The aim was to investigate whether information provided through current labelling practices meets the need of food allergic consumers. A total of forty participant (20 adult food allergy suffers and 20 parents of food allergic children) were recruited from 2 different European countries (Greece and the Netherlands), and interviewed whilst shopping in a supermarket. Participants were asked to purchase 15 potentially problematic food items as if for their own household. Their information search behaviour was observed, and participants were questioned about their preferences for food allergen information provision.

Participants reported experiencing problems associated with current food allergy information provision. It was reported that inappropriate use of fonts, colours and languages, application of precautionary labelling, and lack of harmonisation in labelling practices across countries can cause (un)necessary dietary restrictions for food allergic consumers. Research is needed to investigate the feasibility and implementation possibilities for new information delivery strategies and amendments to existing European labelling policy.

5.1 Introduction

Food allergy sufferers may experience a range of symptoms after consuming problematic foods which range from uncomfortable (e.g. itching, rashes) to potentially fatal (e.g., anaphylactic shock) (Buttriss, 2002). Food allergy has potential to detrimentally affect the quality of life experienced by food allergic sufferers (De Blok, Vlieg-Boerstra et al., 2007). It is estimated that around 5-8% of children and 1-2% of adults are affected by different food allergies (Buttriss, 2002; Sicherer, Noone, & Munoz-Furlong, 2001). However, the prevalence of *self-reported* food allergy is much higher in adults, with an estimated 12 % to 22 % of the population perceiving allergic responses to problematic foods (Wood, 2002; Woods et al., 2002). The current management of food allergy is to completely avoid problematic food allergens in the diet (Dutau & Rance, 2006; Estelle & Simons, 2006; Gowland, 2002; Jackson, 2003; Kapoor et al., 2004; Sampson, 2001). This potentially has a secondary affect on the quality of life and economic functioning of other family members, as well as those with responsibility for food provision (Miles, Valovirta, & Frewer, 2006).

Given that avoidance of target foods by food allergic individuals is the only treatment for food allergy, effective communication about the presence of potentially allergenic ingredients in different foods is essential. There is, however, evidence to suggest that information provision in the retail environment is ineffective (Miles, Valovirta, & Frewer, 2006). Ineffective communication by governments can lead to inadequate labelling due to lack of knowledge on the part of manufacturers. For example, Joshi et al. (2002) report that the parents of food allergic children are confused by the complexity and ambiguity of the allergen information provided by food manufacturers (Joshi, Mofidi, & Sicherer, 2002), which could result in accidental ingestion of unlabelled allergens or unnecessary restrictions in the child's diet (Hourihane, 2001; McCabe, Lyons, Hodgson, Griffiths, & Jones, 2001).

Food allergy sufferers perceive that there is a lack of information about the inclusion of food allergens in specific products (ACNielsen, 2005; Joshi, Mofidi, & Sicherer, 2002; Mills et al., 2004). The terminology used is perceived to be too complex for consumers to efficiently interpret the information supplied with foods (ACNielsen, 2005; Joshi, Mofidi, & Sicherer, 2002; Mills et al., 2004). There are profound individual differences in terms of foods which provoke allergic reactions, as well as individual sensitivities to these allergens (Buttriss & Schenker, 2002).

As of November 25th 2005, the new EU-directive ("Directive 2003/89/EC of the European parliament and the council of 10 November 2003 amending Directive 2000/13/EC as regards indication of the ingredients present in foodstuffs") EU

directive 2003/89/EC amending 2000/13/EC) became effective, which made it mandatory for the food industry to list twelve potential food allergens on product labels regardless of the quantity in the finished product (Cheftel, 2005; Hefle & Taylor, 2004; Hignett, 2002). In order to avoid litigation associated with accidental ingestion of a food allergen (for example, as a consequence of cross-contamination in the factory), many producers use precautionary "may contain" labelling, which further reduces the choices available to food allergy sufferers (Mills et al., 2004). A few Dutch manufacturers have introduced symbols on food packages which indicate the presence or absence of food allergens in the food product, although whether this practice facilitates food choices of food allergic consumers is not understood. Research is therefore needed to understand what constitutes optimal food labelling practices from a consumer perspective. An additional level of complexity regarding the optimisation of a pan-European allergen labelling policy is the possibility that cross-cultural differences exist regarding food choices and labelling preferences (Gracia & Albisu, 2001; Trichopouloua, Naskaa, Costacoua, & Group, 2002). The research conducted in the present study was conducted in two European countries with different traditions of dietary choice, the Netherlands, where consumers traditionally prefer a northern European diet, and Greece, which is typically "Mediterranean". There is evidence to suggest that Greek food consumers may purchase fewer processed foods (Garcia-Closasa, Berenguera, & Gonzáleza, 2006; Simopoulos, 2001). Furthermore, there are differences in the extent to which consumers trust upon the regulatory system, and their perceptions of the efficacy of the food risk management practices employed by industry and regulatory authorities (Van Kleef et al., 2006; Van Kleef et al., 2007; Krystallis et al., 2007), which may have implications regarding the extent to which consumers are confident about labels.

The objectives of the research presented here were to investigate the attitude and preferences of food allergic consumers towards current labelling practices, and to explore how information delivery regarding allergen information might be improved. In addition, the research aimed to understand whether the new labelling legislation provided sufficient information for the food allergic consumer to be able to make safe food choices and to reduce the health risk. A further research aim was to identify the preferences, information needs and preferred information delivery formats of food allergic consumers with different levels of severity of food allergy regarding allergenic ingredient labelling in two different countries, the Netherlands and Greece, in order to compare the information needs of food allergic consumers in cultures with different dietary intakes. A previous publication has summarised the policy implications of (part of) this research (Cornelisse-Vermaat, Voordouw, Yiakoumaki, Theodoridis, &

Frewer, 2007). In this paper, the methodology and results will be discussed in an in-depth and detailed analysis, and the underlying values which determine consumer responses and perceptions will be analysed.

The preferences of food allergic consumers for information about food allergens can only be understood if information about *how* they search for information located on the product itself (label), as well as in the retail environment (e.g., information on shelf, information from personnel, leaflets in the shop) is collated. In addition, the question arises as to whether they can find the relevant information, and how much effort and time is invested in this activity. It is also important to investigate whether consumers trust existing information on food labels. For example, most labels contain an information service telephone number, which consumers can use to get more information, but it is unclear whether food allergic consumers make use of this. It is preferable to investigate these preferences in a shopping situation where food allergic consumers are confronted with realistic product choices as this reflects "real life" food choice situations, and facilitates identification of concerns and preferences in a "real time" context (Burke, Harlam, Kahn, & Lodish, 1992; Campo, Gijsbrecht, & Guerra, 1999).

5.2 Method

Participants in Greece and the Netherlands were recruited through local news paper advertisements and through patient group websites. Participants were included on the basis of self-reported perceived or diagnosed allergies to 3 possible foods; namely, milk, egg and/or tree nuts or peanuts. These food allergies were selected from the EU-list of 12 potential food allergens (EU directive 2003/89/EC amending 2000/13/EC)[3]:, and were included because milk allergy is very common in children, and egg and/or tree nuts or peanuts are common food allergies in adults (Rona et al., 2007).

In total, 20 participants in each country were recruited into the study. More women than men were included in the participant sample as they tend to have greatest responsibility for the grocery shopping (Aylott & Mitchell, 1999; Twiggs, McQuillan, & Ferree, 1999). Half of the samples in each country were adults who suffered from single or multiple food allergies, and half of the samples were parents of food allergic children. To measure the severity of food allergy symptoms, the Mueller scale was used, which asks food allergic individuals about the symptoms experienced after ingesting problematic foods. These symptoms are categorised into four levels ranging

[3] This study was carried out before more potential food allergens were added to this list.

Table 1. Demographic characteristics of the study population

Characteristics	**Category**	**N (NL)**	**% (NL)**	**N (GR)**	**% (GR)**
Gender	Male	6	30	6	30
	Female	14	70	14	70
	Total	*20*	*100*	*20*	*100*
Age	18-24	3	15	5	25
	25-34	5	25	2	10
	35-44	8	40	11	55
	45-54	2	10	1	5
	55-64	2	10	0	0
	>65	0	0	1	5
	Total	*20*	*100*	*20*	*100*
Working status	Full-time	4	20	9	45
	Part-time	4	20	3	15
	Unemployed	0	0	0	0
	Pensioner	1	5	1	5
	Student	2	10	5	25
	Homemaker	5	25	2	10
	On disability allowance	2	10	0	0
	Other	2	10	0	0
	Total	*20*	*100*	*20*	*100*
Education level	Low	2	10	1	5
	Medium	9	45	4	20
	High	9	45	15	75
	Total	*20*	*100*	*20*	*100*
Allergy*	Milk	10	50	11	55
	(pea)Nuts	13	65	13	65
	Egg	9	45	4	20
Household Income	< 750 Euro per month	0	0	3	15
	750-1500 Euro per month	4	20	2	10
	1500-2250 Euro per month	6	30	4	20
	2250-3000 Euro per month	5	25	6	30
	> 3000-3750 Euro per month	4	20	5	25
	undisclosed	1	5	0	0
	Total	*20*	*100*	*20*	*100*

Note. * multiple allergies in one person are calculated as separate cases.

from mild to severe reactions (Mueller, 1966, 1990). The severity of symptoms caused by food allergy experienced by these participants varied from mild to extremely severe and potentially life threatening. In Table 1 the demographic characteristics of the study population are shown. The sample size is appropriate for an in-depth exploratory investigation with a small number of participants (Elliott & Jankel-Elliott, 2003).

The study of food allergic consumers' behaviour in a real shopping environment, and the in-depth interviews conducted during the course of participants shopping activities[4], were used to identify what constitutes their "daily routine" and the kind of problems experienced by food allergic consumers when trying to protect their health, or the health of their children, through appropriate food selections. Although it cannot be guaranteed that the presence of the interviewers did not affect the shopping behaviour of participants, the face validity of the results suggests that this effect is minimal. Low, middle and high priced supermarkets were included in the total study design, and participants were assigned supermarket with price levels similar to the ones they used in their normal habitual shopping activities.

Participants were handed a shopping list of 15 possible problematic food items[5], and were asked to buy these as if they were making purchases for their own household. In addition, they were also asked to buy a different product type or brand to the one they would normally buy to avoid habitual behaviour. If there was not a safe product available for purchase with respect to the particular food allergy of concern, they could omit that particular food product from their shopping activity. The interviewers paid for the groceries and the participants could take the groceries home if they so desired, this was not known to the participants be forehand. This was done to avoid the potential influence on participant food choices which might result from the possibility of receiving free groceries.

Several food products normally used for preparation of breakfast, lunch and dinner, as well as snacks, were included in the shopping list. The list was composed in such a way that the products included needed some careful consideration with respect to the inclusion criteria of the food allergies of the participants. A dietician with expertise on food allergy was consulted in order to facilitate the development of the list.

A pilot survey (n=4 food allergic consumers) was conducted before the study itself was initiated to check if the study design was appropriate to the study objectives. Following the pilot survey, only minor changes were made to the shopping list. Two

[4] Questions asked during the interview available on request.
[5] List of food items available on request.

products were replaced by other products to improve variety. The study design itself did not need further amendments.

The study was conducted in the Greece and the Netherlands in February 2006, (Monday- Saturday daytime). No unusual media attention relevant to the issue of food allergy occurred during this period. The interviews and discussions in the shop with the participants were audio taped on a voice recorder. The audio tapes were transcribed into English for the purpose of analysis.

The transcripts of the interviews were analysed using the software package Atlas Ti 5.0. (a software package which facilitates the analysis of qualitative data) (Scientific Software Development, 2004). To make the analysis comparable between countries the research team first developed a coding scheme (Stemler, 2001). The English transcripts were coded with the final coding scheme (11 codes) by a researcher from the country in which the interview was held. A cross-check was performed to assess whether the codes attached to the quotes were assigned the same code by different researchers individually to ensure reliable and consistent results (inter-coder reliability)[6]. The predetermined inter-coder reliability was aimed at minimum of 70% (Lombard, Snyder-Duch, & Bracken, 2002). The cross check was performed on a random sample of 4 transcripts and fulfilled the reliability requirements.

5.3 Results

5.3.1 Label appearance and content

In general, the food allergic consumers reported that they were not satisfied with the way in which the allergen the information was presented on the label. In both Greece and the Netherlands, participants described problems regarding the readability of the label. These include, for example, the font size used on the label

> P 6 NL (male): *"….what's written on there is almost unreadable, you almost need a magnifying glass …….*"

Moreover, the contrast of the label was reported to be low (e.g. dark letters on a dark background), which resulted in problems interpreting fonts. Furthermore, the materials used in packaging was sometimes shiny or glossy, and many food allergic consumers reported that the use of such materials made the label very difficult to read.

[6] More information about the method and the coding scheme is available on request.

P17 GR (female): "*It [the package] is transparent and it [the text] is written in white letters, so it is difficult to read. … I like information to be in tables, to be easy to read and eye-catching.*"
P 6 NL (male): "*Well, as long as the letters are readable, this one is difficult because it's so shiny.*"

Some participants suggested that the allergen information should be presented in bold letters compared to the other ingredients. This would enhance the readability and would allow the food allergic consumers to find the relevant information faster.

Some Greek participants suggested that the relevant information should be in a frame or box. Furthermore, participants indicated that they would like an ingredient list and allergen information written in a specific standardised colour. They considered that this would facilitate the process of information search.

The Dutch participants suggested a standard location for the allergen information (for example, *above* the ingredient list). During the study, several participants were observed to read the ingredient list completely before they discovered the allergen information on the label. In most cases this was written at the bottom of the back label.

P18 NL (female): *"…it is extra information. But it doesn't really stand out from the rest. Now I know where it's written it does, but otherwise I wouldn't have seen it."*
P9 NL (female): *"I have to search the package carefully, to see where information relevant to me is located."*

In both countries, most of the food allergic participants were not satisfied with the information provision on the existing labels. The information provided was considered insufficient for the food allergic consumers to make a decision about product safety. Most participants reported that the ingredient list presented on the label was incomplete and not sufficiently specific. For example, vegetable oil can be derived from various sources, such as sunflowers, peanuts, sesame seeds. Specific information about the origin of the ingredients is of vital importance for food allergic consumers. An example is starch used as an ingredient which is often not specified by source.

P3 NL (female): *"...I don't know whether it is potato, corn or wheat starch…they don't specify it…"*

P17 GR (female): "*For example, it mentions milk proteins, but it doesn't say which milk proteins. Lactose is one of the milk proteins that I am allergic to.*"

In addition, food additives (e.g. preservatives, emulsifiers, stabilisers, taste/flavour enhancers, and antioxidants) and E-numbers appeared to cause a lot of confusion among food allergic consumers. The terminology used to describe the additives was perceived to be difficult to interpret in terms of implications for the food allergic consumer. Furthermore, participants found it difficult to recognise 'hidden' ingredients.

P25 NL (female): *"On both [products available] aromas are listed for flavouring, so both have a chance of containing something that isn't allowed. Well I think I would want to know what the aromas are exactly……..*"
P18 NL (female): *"I discovered later that whey powder was a milk product."*

In general, most participants expressed preferences for inclusion of separate allergen information on the label next to the ingredient list. There were still a large group of sufferers who did not completely rely on the allergen information without recourse to additional scrutiny of the ingredients list. Most participants tended to use the allergen information as *exclusion* rather than *inclusion* criterion. For example, they would first look at the allergy information to determine whether they could purchase the food product. If the information indicated the food selected was problematic, they would place it back on the shelf. However, if the (specific) allergen information did not indicate that the food contained the allergen, the participants would read the whole ingredient list to be sure it was not present in the chosen food product, thus severely increasing time spent on shopping.

P4 NL (female): *"Well, if milk was listed in the allergen information, then I wouldn't take it anymore, but if it was listed on the allergen information that is not there, then I would still check myself just to make sure."*
P1 GR (female): *"But, I don't know whether it means that it contains milk or not. I would prefer it if there was an X on it. The way I see it now, it seems as though it means that it contains milk."*

Most Dutch participants liked the indicative symbolic representations for potentially allergenic ingredients on the package. For example, the drawing of a glass of milk together with the head of a cow indicated that cow's milk was present in the

product. However, Greek participants commented that such symbols were not used in Greece. Both Dutch and Greek participants indicated that they would prefer the allergen information to exist in *addition* to symbolic representation of allergen information. Nonetheless, some symbols were reported to be ambiguous. For example, a few participants wondered if a symbol of an egg on the label would imply that the product *does* or *does not* contain egg. Others suggested that the symbols should be placed on the front of the package to facilitate rapid search of information. In the Netherlands, where symbolic allergen labelling is being trialled, the symbols are placed close to the ingredient list. Moreover, symbolic allergen information was reported to be most effective if participants could identify it on the packaging without first removing the product from the shelf.

> P18 NL (female): *"If there is a picture then I will check to see what exactly it contains… it would save a bit time if you knew the pictures and what they meant by heart."*
> P2 GR (female): "*It would be good if there were an asterisk that explained whether these ingredients are vegetables, chemicals, or something else. … an asterisk or brackets*"

The number of languages on the label was a source of irritation to many of the participants, although it was understood that for foreigners the inclusion of other languages would be quite useful. Clearly not all languages used internationally can be included on the label. A solution suggested by the participants was to put the text in the language of the country in which the product was being purchased at the top of the label, possibly followed by other languages. However, some labels did not even have the information in national language of consumers. In the Netherlands these products tended to be available in lower priced supermarkets. In Greece, products without information in Greek also exist. A further problem was reported to be that discrepancies exist between what information is available according to which language information is presented. To increase clarity, and to prevent information overload, some participants suggested putting a limited number of languages on the label.

> P20 NL (female): *"…English or Dutch, but not such a long list of all those languages, so I really have to look for the Dutch one. No I don't like that!"*
> P8 GR (female): "*Here, for example, in this language the nuts that have been used are described precisely, while they are not described in Greek. It only says 'traces of nuts."*"

In both Greece and the Netherlands, participants reported discrepancies between the general description of the product (e.g. preparation methods, storage

advice) and the analytical and chemical description in the ingredients list. The general description on the front of the package was not in line with the ingredients list. In this process, the product loses credibility.

> P15 GR (female): "*-On the front of the package it says that the crisps are fried in 100% olive oil and at the back it says that it contains 28% olive oil! -Does this make you doubt the reliability of the info label? -Yes, now that I've seen it.*"
> P3 NL (female): *"for this product it's interesting because you see that normally I would have chosen this product seeing as there is no wheat listed in the ingredient list, but then in the allergen information you see the heading that it contains wheat….. So then what can I trust? Because normally I would have blindly trusted the ingredient list, and I would have bought it."*

Participants reported experiencing precautionary labelling more frequently than in the past, prominent examples including 'may contain traces of nuts' or 'produced in a factory where nuts are processed'. Participants claimed that they believed the warnings were inaccurate and unnecessarily restricted their choices. Moreover, the participants indicated that the abuse of these warnings may lead to a decrease in credibility of the warning, product, and the brand.

> P11 GR (female): *"Yes, the [label] says 'It may contain traces of peanuts, nuts and soy'. I would like to know that for sure. When an industrial firm uses peanuts, it's final. I cannot understand this 'may'."*

Food allergic consumers find the information on existing labels overwhelming. However at the same time, the participants would like a complete and specific ingredient list.

> P4 GR (male): *"Chicken soup with rice. Ingredients: rice, salt… Well, half of them are unknown again…. Well, it has too many things. I might not even bother to read this label because I know that I will have to spend too much time [reading the label]."*

5.3.2 Practices to reduce health risk

An important factor in determining food allergic consumers' information preferences was the variability in susceptibility to problematic allergen according to allergy type. For some sufferers, a trace of an allergen can potentially cause an allergic reaction,

while for others their threshold for reaction is higher. Therefore, study participants, particularly in Greece, suggested it would be useful to mention the *percentages* or *quantities* of all the ingredients, particularly those to which consumers were allergic.

> P17 GR (female): "*But, it doesn't give any percentages. The quantity of nuts or eggs used could be small, and I could possibly consume it. But, it doesn't say anything, so I cannot risk it.*"
> P5 GR (male): "…*walnut... this is the ingredient that isn't good for me. It doesn't mention any percentages. …It is one thing to contain just traces and a different thing to contain a larger quantity of nuts. We have to know the percentage.*"

In both the Netherlands and Greece, participants reported that they avoided asking the personnel in the retail environment for help, because they did not trust the expertise of the shop personnel regarding allergy advice.

Dutch participants reported that there are often changes in recipes used to make products and assortments. In the Netherlands supermarkets frequently rearrange the shop, perhaps every two months, as well as replace products by other brands, or even alter the type of products available in the retail environment. Dutch participants reported that they find this very irritating and annoying. Specifically, they reported that products that were previously safe to consume may suddenly contain food allergens, or products that were safe to consume are suddenly not available anymore.

> P6 NL (male): *"See, this one* [food product] *we usually have, but the package has changed. So, now I'm extra careful about reading the ingredients again to make sure they haven't changed that all again."*
> P8 NL (male): *"The biggest problem is that the packages are constantly changing without knowing whether the content is changed. And then there is the trend of putting 'new' or 'renewed' on every package. We cannot be sure anymore what it is made of."*

The Dutch participants reported that they sometimes obtained additional information by emailing, writing or phoning the food producer, making use of using the contact details on the package. The Greek participants reported that they only used these contact details if 'really necessary'. Several allergic consumers resort to practices such as home study or personal search, whereby they seek access to all possible available sources of information on food allergy, either in printed material or on the internet.

P6 NL (male): *"Sometimes I call up the producers and I ask if it (*the allergic ingredient*) is in there* (a particular product*), they will look at the list and tell you it is not in there, then I will continue asking where they bake it ….and then sometimes they call back a day later and tell me that the oil (*in which it is baked) *contains something."*
P2 GR (female): *"You know, I usually buy products and then I go home and check the ingredients using the lists that I have. …In the past I used to bring these lists with me in the supermarket."*

A common practice for both Greek and to lesser extent Dutch, participants was to prepare many food dishes at home. This reflected the preference on the part of participants for increased certainty regarding the safety of food ingredients, which can only be provided by home preparation. In addition, participants reported that dietary variation was also increased as a result of preparing many food dishes at home, as many complex food products, e.g., ready-to-eat meals which are available in the retail environment contain food allergens. Variation in the diets of food allergic consumers was reported to be dependent on the severity of participants' allergy, as well as if participants suffered from multiple allergies. In general, people with more severe food allergies or multiple food allergies reported having less variation in their diets. People having severe allergic reactions to food allergens were very risk adverse, whereas people with less severe allergic reaction were willing to take more risks, (for example, they are more likely to consume products with precautionary warnings). In general, most participants did not experience limited dietary variation as a burden. They reported that they were used to dietary limitations, and had no other choice than to accept reduced variation in their diet. Participants reported that the most difficult products to buy were complex food products containing many different ingredients. These were also the dishes that were most frequently prepared at home by food allergic consumers themselves.

Neither Greek nor Dutch participants expressed a preference for purchasing A-brands over B-brands (cheaper, less known brands, such as the "own brands" of supermarket chains). Some participants reported that they had more *trust* in A-brands because of the well-established name, quality and labelling practices. However, it was also mentioned that cheaper brands tended to contain fewer additives than leading A-brands. The participants were concerned and considered that many additives exist in food products, which was seen as a reduction in the food products' safety perceived by the participants.

At the same time, the food allergic consumers included in the study tended to be more health oriented and environmentally conscious than non-food allergic

consumers. Some participants reported that healthy and environmentally friendly food products are less likely to cause food allergic reactions as 'natural' products are likely better accepted by the body. With 'natural' food products, consumers meant food products that contained very few additives and preservatives. Moreover, participants believed that biological or organic food products are more natural products than those containing conventionally produced ingredients. The participants further tried to avoid complex food products that contain many ingredients, additives and preservatives whereas paying increased attention to the nutritional value of the food products. They looked at the fat and sugar contents, and the amount of calories contained in a food product.

> P8 GR (female): "*In general, I don't buy biscuits. And this is not only because of allergies, but also because of the oils and stuff they contain.*"
> P12 GR (female): "*The nutritional value of these biscuits is minimal. You just eat it for pleasure. ……Hydrogenated vegetable oils equal 'plastic' for me. These are the worst oils one can find. So, I wouldn't buy this product.*"

The personal experience participants in the study have had with particular food products has been very important for them when assessing whether the food product is safe for them to consume, especially if insufficient information is provided on the label. Participants reported that, if they had had an allergic reaction to a product in the past, they would not buy it again for a long period of time, if at all. They feared reoccurrence of the hazardous incident. Only young adolescents were willing to "take the risk".

> P5 NL (male): *"Principally I don't eat anything of Milka* [a brand of chocolate] *either. Even if it is not listed on there I'll have problems with it anyway. I know this from my childhood already that I can never eat Milka chocolate."*
> Interviewer: *"Do you take risks?"*
> P5 NL (Male): *"Yes, why not, you need to live. Otherwise you really can't do anything anymore."*

5.3.3 Loss of time and money

Most of the participants in Greece and the Netherlands believed they spent much more time on shopping in comparison to consumers who were non-food allergic, or who did not perceive responsibility for food allergy prevention in their households.

Participants reported having to read all the labels carefully every time to check if the product was (still) safe for them to consume. Additional time was also needed to check the safety of products which they had not purchased before. Participants with the most severe food allergies reported reading the label most carefully and systematically. Interestingly, Dutch participants reported frustration with the increased time spent on shopping, but this was reported as being much less of a problem for the Greek participants. In both countries, participants mentioned that they often repeatedly buy the same product once they have established that it is safe, and eventually develop routine shopping patterns which reduce the time burden of shopping.

> P17 GR (female): "*I just buy pasta that doesn't contain eggs. I buy a certain brand of penne that I know I won't have a problem with. I buy certain products so that I will not have to spend too much time searching and I won't have to take any risks.*"

In the Netherlands, participants reported that they spent *less* money on groceries compared to non-food allergic consumers. In particular, they claimed that, as a consequence of omitting potentially problematic ingredients, food products such as candy, cookies and other snacks were not purchased, and they perceived that this resulted in a lower total groceries cost. Greek participants reported that they believe they spent *more* money on groceries to avoid food allergens and to increase the variety in their diet.

In both countries, participants indicated that they were willing to pay more, (reported to be up to twice as much), for allergen-free food products. In particular, parents of food allergic children were willing to pay more as they do not want their children to consume a diet which is over restricted. One Dutch participant mentioned that she buys goat's milk for her child which is seven times more expensive than cow's milk, but was also safe for the child to consume.

> P10 GR (male): "*Yes, since it would be a matter of health, I wouldn't mind paying more money.*"
> P16 GR (female): "*Yes, you pay much money. I had to spend a whole salary for my child in the early years mainly. We couldn't find something that he could eat. He didn't eat much, he ate very little, but he required a whole salary to be able to eat the essentials.*"

5.4 Discussion and conclusion

The objective of this study was to investigate the attitude and preferences of food allergic consumers towards current labelling practices (following the new EU-directive) in a realistic shopping environment, as well as explore how information delivery regarding labelling of allergen information might be further improved in order to reduce health risk. In general, the results show that food allergic consumers are still not satisfied with the current labelling practices. Furthermore, the results indicate that the information needs of the food allergic consumers included in this study are not satisfied by the information supplied on the label. Improved information provision has the potential to provide a positive impact on the quality of life of food allergic consumers. The results suggest that further refining of food policy designed to protect food allergic consumers is needed. In particular, the results suggest that the new labelling regulations are still insufficient for food allergic consumers to be able to make safer food choices. For example, the new legislation has been perceived to have lead to an increase of warnings presented on labels. Participants often questioned whether these warnings were precautionary or genuine, and expressed the view that they lead to unnecessary restrictions in the diets of food allergic consumers. One policy implication could be to label threshold levels for cross contamination of allergens in a food product. If the potential for cross contamination exceeds the threshold level it should be indicated on the label. When the potential for cross-contamination is below the threshold level, a general warning is sufficient. Furthermore, information regarding ingredients percentages of food allergens could be beneficial to food allergic consumers. Because the threshold level at which a food allergic reaction occurs differs between individuals, the food allergic consumers can decide if this is an acceptable level allowing safe consumption of the food product. The development of individual "customisable" sensitive detection methods to measure these amounts of allergens in food products may represent a separate line of investigation. If improved detection ultimately leads to safer food products, and, as a consequence, increases the "brand loyalty" of food allergic consumers will potentially incentivise industry to provide further information regarding the traceability of potential allergens in the food chain.

The results of this study demonstrate that food allergic consumers would like to have a complete ingredient list, written allergen information and allergy symbols, explanation of difficult terminology, high contrast labelling and a readable font size provided as minimum requirements for effective communication about the presence of potential allergens as food ingredients. Whilst written allergen information is reported as useful by food allergic consumers, they expressed a preference for

inclusion of a complete ingredient list in order to judge the allergen content themselves. Showing the percentages of allergens enables food allergic consumers to better evaluate the safety of food products. Next to the written allergen information, participants in this study expressed a preference for inclusion of allergen symbols on the package, although these would need to be harmonised internationally if confusion regarding the interpretation of symbolic information was not to occur, in order to facilitate uniform and unambiguous interpretation of the symbols. Food allergic consumers preferred the symbols to be located on the front of the package, to facilitate the rapid identification of safe or dangerous products on the supermarket shelves.

Under existing information strategies, food allergic consumers report experiencing difficulties in understanding terminology, and not trusting the information on the label and credibility of the information. Participants, including those who had attained high levels of education, were confused by the terminology currently used to identify ingredients and allergen information on packaging. Furthermore, the format and location of the allergen information differed between different products and brands, making it unnecessarily confusing for consumers. This would suggest amendments should be made in the legislation on a standard location, format of allergy information, and allergen symbols to be included on the label.

The use of "precautionary" labelling was reported to be problematic. Food production lines are often used to produce several different food products, and there is a high risk of cross-contamination during the production process itself. As a consequence, many companies include "may contain" labelling as a precautionary measure, which may be of limited utility in identifying allergens. Precautionary labelling is a burden for the food allergic consumer because it restricts the food included in their diets unnecessarily. "May contain" labelling should only be used if the risk of cross contamination is significant, and only after complete assessment of the production lines. In other words, manufacturers should incorporate strategies to assess the risk of cross-contamination of the production lines and production processes, and should only use the "may contain" labelling when there is a realistic chance on a risk.

Only Dutch participants were concerned about the frequent alteration in the assortment and recipes available the Netherlands. This might be because the assortment and recipe changes in Greece might be comparatively infrequent, and therefore go unnoticed by the participants, although this cannot be concluded form the current analysis. The allergen information on the label was reported to be absent in Greece. This was probably a consequence of new legislation, the EU directive 2003/89/EC amending 2000/13/EC, being implemented for only three months at the

time of data collection, with the result that the new packages were not yet being available. The allergen symbols which were present on some products in the Netherlands were not shown on the Greek products. Nonetheless, the Greek participants reported that they would like to have such symbols on food labels. Participants in both countries reported that they spent more time shopping as a consequence of their condition. However, only the Dutch participants report this to be problematic. This may be due to different perceptions of national food risk management system. These food risk management systems entail protocols that manufacturers incorporate to cope with allergens in their production processes. These protocols help manufacturers to avoid unnecessary cross-contamination and adequately label the allergens present their products.

Greek participants may perceive greater individual responsibility for their own health protection, whereas Dutch participants are more reliant on institutionalized risk management systems. This is supported by the general preference for home food preparation in order to exclude potential allergens. An apparent cultural difference related to the perceived costs of having a food allergy, or preparing food for someone with a food allergic condition. The Dutch participants reported that they spend less money on the grocery shopping, while the Greek reported that they spend more. Dutch participants report this to be due to reduced variation in their diet. Against this, Greek participants highlighted their efforts to preserve the variety in their diet. By preparing homemade sweets, candies, and cakes, they consumed a safe and varied diet. In contrast, the Dutch participants tended to avoid consuming foods in these categories. This is more important for food allergic children's parents, who reported that they try to make their children feel better, especially in a school environment, where children are more exposed to challenges and risks Dutch parents were willing to spend more money in these food categories to be able to give their children a dietary pattern which closely resemblances that of other children without food allergy in the same age range, so their children do not feel left out. The Greek parents, however, make more snack products themselves to give to their children.

To summarise, while Greek and Dutch participants report that their food allergy increases the time spent shopping, this was only problematic in the Netherlands. Both Greek and Dutch consumers favoured symbolic labelling of allergens. However, Greek participants perceived the primary responsibility for health protection to lie with the individual, whereas Dutch participants perceived this to lie primary on institutionalised responsibility level.

To implement the changes suggested by these results, amendments in food policies need to be made at an European level. However, national differences in

implementation may also be required, in particular when legislation comes down to implementation by national environments. For example, difference in communication practices may reflect the local requirements of citizens of EU member states, over and above the minimal requirements of the European legislative framework. Nevertheless, uniform EU regulations and policies are necessary to guarantee food safety for food allergic consumers.

The results of the research presented here have potential to improve the quality of life of food allergic consumers through improved consumer protection. However, there are important implications for industry labelling practices. Food allergy can be life threatening and adequate food labelling is of utmost importance if food allergy is to be effectively managed; the development of an effective food labelling strategy must be a priority within Europe. The new EU-directive (EU directive 2003/89/EC amending 2000/13/EC) does not provide sufficient basis for food allergic consumers to be able to make safe food choices. Further changes in EU regulations and policies are needed. To reduce health risk and improve the quality of life of food allergic consumers *clear* and *adequate* labelling is required. Traceability is the first step in developing adequate labelling, especially concerning food allergens. Traceability of all ingredients throughout the whole production process is of utmost importance. Labels should have all ingredients written out in comprehensible national language. Furthermore, the ingredient list and allergens information should have a standardized format which facilitates the decision making process. Symbols facilitate quick interpretation and decision-making processes regarding the allergen information, as well as overcoming language barriers sand therefore represent an important aspect of clear labelling. The usage of standardized unambiguous symbols should be harmonised on international level through food policies. Labelling policies and practise should be harmonised at least at national level and if possible preferably at international level.

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Chapter 6

Preferred information strategies for food allergic consumers: A study in Germany, Greece, and the Netherlands

This chapter is based on the following publication: Voordouw, J., Cornelisse-Vermaat, J.R., Pfaff, S., Antonides G., Niemietz D., Linardakis M., Kehagia O., and Frewer L.J. (accepted subject to revision). Preferred Information Strategies for Food Allergic Consumers: A Study in Germany, Greece, and the Netherlands. *Food Quality and Preferences.*

Abstract

Information provided on food packaging is currently the most important method enabling food allergic consumers to eliminate allergens from their diet. This study aimed to identify the preferences of food allergic consumers regarding different information provision scenarios. Respondents (N=291) filled out a web-based questionnaire on their preferences regarding a food label, an in-store booklet, and an ICT-solution. ICT methods will not replace effective food labelling, but may be used to supplement information provided by labels. Recommendations for information delivery to food allergic patients in the form of labels and booklets, as well as personalised (novel ICT) approaches, are provided.

6.1 Introduction

There is evidence to suggest that the incidence of (some) food related allergies may be increasing (Rona et al., 2007). Given that avoidance of allergens is the only way to prevent an allergic reaction (Munoz-Furlong, 2003), the provision of effective information about potentially allergenic foods and ingredients is a priority, particularly when contextualised by the potential severity associated with a reaction (Buttriss, 2002). The aim of the research reported here was to identify the usefulness of specific characteristics and means of information provision for food allergic consumers.

EU directive 2003/89/EC amending 2000/13/EC), effective from November 2005, made it mandatory for the food industry to list all 12 (currently 14) potential food allergens on product labels regardless of the quantity in the finished product (Cheftel, 2005; Hefle & Taylor, 2004; Hignett, 2002). The directive is clear about the need to label potentially problematic ingredients, but there is no clarity regarding precautionary labelling.

One effect of legislative change is that manufacturers are adopting *precautionary labelling,* rather than face possible legal action in the event of small amounts of undeclared allergens being discovered in their products. Rather than helping the allergic consumer cope with their condition, such labelling restricts food choices further. There is also evidence that food allergic consumers may regularly ignore precautionary labels, putting themselves at risk and further devaluing food label information(Cornelisse-Vermaat et al., 2008; Hefle et al., 2007; Van Hengel, 2007).

Joshi et al. (2002) report that only 10% of those avoiding milk in processed foods were able to spot the "milk words" in a label-reading task. Similarly 54% of those avoiding peanuts correctly identified peanuts on labels and 22% correctly identified soy (Joshi, Mofidi, & Sicherer, 2002). Consumers are wary of using lists of commercially prepared "safe" foods, because manufacturers may change the ingredients contributing to specific products without warning (Mofidi, 2003). As a consequence, food allergic consumers, or those responsible for their care, must read the ingredient statements for all products each time they shop, which is time consuming and has a detrimental effect on quality of life and welfare (De Blok, Vlieg-Boerstra et al., 2007; Knibb et al., 2000; Primeau et al., 2000).

Recent research has suggested that current food allergy coping strategies are inadequate. To some extent, allergic reactions were attributed to *misunderstanding label terms* and to inclusion of *non-specific terms* in the ingredients list (Elinor, Weiss, & Furlong, 2005). The requirement for more information is at odds with providing food labels with clarity and is compounded by many labels appearing in multiple languages and in very small type, making them difficult to read which, in addition to incomplete

allergen detection, may lead to unnecessary restrictions on dietary choices (Joshi, Mofidi, & Sicherer, 2002).

Consumers frequently call manufacturers to assess the safety of the products, despite changes in labelling legislation (Mofidi, 2003). Whilst most large manufacturers willingly provide this information (Munoz-Furlong, 2003), the additional burden in terms of time and inconvenience this places on the consumer is unacceptable.

Information delivery *via* the product label is not the only feasible approach. The improvement of information supply for food allergic consumers might be strengthened if new Information and communication technologies (ICT) were used (Cornelisse-Vermaat, Voordouw, Yiakoumaki, Theodoridis, & Frewer, 2008).

Improved information delivery to food allergic consumers is a policy priority. The aim of the study reported here was to identify the usefulness of specific characteristics and means of information provision for allergic consumers through different information delivery scenarios.

6.2 Method

Adult food allergic consumers, and the parents of food allergic children, were recruited through advertisements in national newspaper or e-letters from national patient groups in Germany, Greece, and the Netherlands. Participants were also recruited through advertisements published in newspapers and trade magazines to include respondents without internet access. Two hundred and ninety two participants were included on the basis of self-reported perceived or actual allergies to three possible foods, i.e., milk, egg and/or tree nuts or peanuts. These food allergies were selected from the EU list of 14 potential food allergens, and were included because milk allergy is very common among children, and egg and/or tree nuts or peanuts are common adult allergies.

A number of possible information scenarios were developed based on previous research (Cornelisse-Vermaat et al., 2008; Cornelisse-Vermaat, Voordouw, Yiakoumaki, Theodoridis, & Frewer, 2008; Voordouw et al., 2009). Effective labelling on packages, ICT approaches including a "Personal Shopping Assistant" (where the bar code of individual products could be scanned and a warning signal was provided if the product contained the allergenic ingredients to which the consumer was allergic), and an information terminal (providing similar information to the "personal shopping assistant", but not requiring the consumer to purchase or borrow a hand-held scanner) were identified as potentially effective information sources for consumers, together with more traditional media such as information booklets.

Three main information scenarios were selected as the preferred candidates for delivering allergen information: a) Label - standardised label with symbols; b) Booklet - with allergen information; c) Information Communication Technologies (ICT) - such as a small personal shopping assistant, an information terminal, a handheld scanner, or an internet shop.

The most important attributes of each of the different information scenarios were also identified. Five different attributes of food labels, 5 for ICT tools, and 4 for the booklet were selected (see Table 1).

Table 1. Attributes for the Label, Booklet, and ICT scenarios

Attribute	**Attribute levels**	**Option evaluated**		
		Food label	**Booklet**	**ICT**
Glossary	1. none 2. ability to look up explanations for difficult terms or ingredients	n.i.	√	√
Ingredients information (Percentages)	1. does not show percentages at all 2. show percentage of allergens in product 3. show percentages of all ingredients in product	√	√	√
Personal warning systems	1. none 2. visual 3. audio 4. visual and audio warning	n.i.	n.i.	√
Additional information	1. no additional information 2. precautionary labeling to indicate that a product 'may contain traces of the allergen' 3. specific production details about how allergens are managed within a factory	√	√	√
Standardized format	1. no box 2. eye-catching box with standardized allergy information	√	n.i.	n.i.

Standardized allergen symbols	1. none 2. at the front 3. at the back 4. at the back and the front	√	n.i.	n.i.
Information Service	1. none 2. telephone hotline 3. website address 4. both hotline and website	√	n.i.	n.i.
Booklet Format	1. allergen free products- per food category 2. allergen containing products- per food category 3. allergen containing products 4. allergen free products	n.i.	√	n.i.

Note. √ attribute included in the option evaluated, n.i. not included in the option evaluated

Participants were initially presented with images of the information delivery systems, as well as brief explanations regarding each information "attribute". Respondents were then asked to rate the information scenarios using a seven-point Likert scale. An example of an information scenario profile is shown in Figure 1. Conjoint analysis of the ratings was employed to evaluate the relative preference for each information attribute for the three information types. Separate analyses were conducted for the Label, Booklet, and ICT information delivery approaches.

There were many possible combinations of attribute levels for each information delivery approach (288 for Label + 72 for Booklet + 72 for ICT). A fractional factorial design was employed to minimize the number of profiles presented to respondents. Orthogonal designs of attribute level combinations were generated by SPSS 15.0 for each information approach, which resulted in sixteen profiles for each of the three conjoint experiments. To reduce experimenter concerns regarding participant fatigue, each participant rated half of the profiles, involving 8 questions per information scenario (Label, Booklet, ICT) or a total of 24 different profiles. Additionally, two holdout profiles were included for each information scenario (one for each set of 8 questions), which was excluded from the conjoint analysis and later used to evaluate the model reliability. After the rating task, several questions

concerning demographics were asked (gender, age category, educational level, specific allergy, allergy severity), together with items about previous experience with ICT tools.

Scenario option 1. In addition to the current food labelling requirements *this label* will provide:

Percentages	**Additional info**	**Format allergy information**	**Allergy symbols**	**Information service**
A list of percentages of *allergens* contained in the product	specific production details about how allergens are managed within a factory	*Not applicable*	*Not applicable*	A *telephone hotline number* and *website address* which can be used to obtain additional information.

Please rate the combined information option described above

Dislike very much						Like very much
1	2	3	4	5	6	7

Figure 1. Example of an information scenario

The questionnaire was piloted in English with students from the three participating countries. Feedback regarding the questionnaire explanations, content and structure was incorporated into the design. The final English questionnaire was translated and back translated into German, Dutch, and Greek. Any remaining inconsistencies were resolved. The final online survey took approximately twenty minutes to complete.

Data from Germany (N=55), Greece (N=69), and the Netherlands (N=167) were pooled for each conjoint analysis. A generalised linear model with repeated measures for subjects was estimated. The relevant attributes and a country variable were included as fixed variables. For the ICT conjoint analysis, an additional covariate

was included based on a factor analysis of five questions related to previous experience with ICT tools (the factor explained 83% of the item variance). For all of the conjoint analyses, pairwise comparisons were conducted which were adjusted for multiple comparisons using Fisher's least significant difference. Summaries of the results are presented in Tables 2–4. For each conjoint analysis, if four or more of the responses were missing then the data for that respondent was excluded from the analysis. For the ICT conjoint analysis, any respondents that did not complete the five experience questions were excluded from the analysis. This procedure resulted in 287 observations for Labels, 292 for Booklets, and 255 for ICT.

6.3 Results

6.3.1 Label

Results from the conjoint analysis for the label ratings indicated that significant differences were observed between levels of each attribute ($p<.05$) (see Table 2). Cross-country differences were detected, such that the Dutch ratings were significantly more positive about all label attributes compared to the Greek and German responses.

In terms of the optimal strategy to present the ingredients on the label for food-allergic consumers, the pairwise tests indicated that the option to *show the percentage of allergens* was rated significantly higher than either showing percentages of all ingredients, and not showing percentages. Similarly, the pairwise tests revealed significant differences between the type of precautionary information that was favoured for the label, where *specific details on allergy management* was rated significantly higher than providing notification that a food product *may contain traces of allergens*. Both of these options were preferred compared to providing *no precautionary information*. The results also supported the use of an *eye-catching box with standardised allergy information* versus *no box*.

Moreover, a standardised symbol representing allergy information at the *front and back* of the food product was preferred. Beyond the information provided directly on the package, the results indicated that services to provide additional allergy information should be offered through a *hotline*, which was rated significantly higher than through a *website*, *hotline and website*, or not at all. However, there was no significant difference between the *website* or combined option of a *hotline and website*, while providing *no* information service was only significantly lower compared to the *hotline* and combined *hotline and website* alternative and did not differ significantly from the *website* option. Apparently receiving information from a real person about the food products was preferred to finding information on a website.

Table 2. Results of label conjoint analysis

Label	Attribute levels	Mean	SE
Percentages**	none	3.89[A]	0.08
	show percentage of ingredients	4.36[B]	0.08
	show percentage of allergens	4.60[C]	0.07
Precaution**	none	3.85[A]	0.08
	may contain traces allergens	4.41[B]	0.08
	specific details on allergy mgt	4.59[C]	0.08
Allergy info**	no box	3.87[A]	0.07
	eye-catching box with standardized info	4.69[B]	0.07
Symbols**	no symbol	3.80[A]	0.08
	symbol at back	4.23[B]	0.08
	symbol at front	4.47[C]	0.08
	symbol at back and front	4.64[D]	0.08
Info service**	none	4.09[A]	0.09
	website	4.24[AB]	0.08
	hotline and website	4.27[B]	0.08
	Hotline	4.54[C]	0.09
Country**	Germany (n= 55)	4.12[A]	0.14
	Greece (n=65)	4.24[A]	0.10
	Netherlands (n=167)	4.49[B]	0.08

Note. [ABC] Different superscripts within a label mean that the respective estimates were significantly different at the 5% level (within a label). Same superscripts within a label mean that the respective estimates were not significantly different.

6.3.2 Booklet

The results of the booklet conjoint analysis indicated significant differences between levels of each attribute (see Table 3). Therefore, the use of a glossary in the food allergy booklet was supported by the results. The only exception was the country variable, showing no significant differences between the ratings across countries.

Table 3. Results of booklet conjoint analysis

Booklet (n=292)	**Attribute levels**	**Mean**	**SE**
Percentages**	none	3.68[A]	0.09
	show percentage of ingredients	4.43[B]	0.10
	show percentage of allergens	4.48[B]	0.08
Precaution**	none	3.75[A]	0.08
	specific details on allergy mgt	4.36[B]	0.10
	may contain traces allergens	4.48[B]	0.09
Glossary**	no glossary	3.85	0.08
	glossary	4.54	0.08
Format**	allergen free products per food category	4.09[A]	0.09
	allergen free products	4.18[A]	0.09
	allergen containing products	4.19[A]	0.09
	allergen containing products per food category	4.33[B]	0.08
Country	Netherlands (n=164)	4.14[A]	0.10
	Germany (n=55)	4.20[A]	0.17
	Greece (n=69)	4.25[A]	0.10

Note. [ABC] Different superscripts within a cell mean that the respective estimates were significantly different at the 5% level (within a cell). Same superscripts within a cell mean that the respective estimates were not significantly different.

In terms of the remaining attributes with multiple levels, the pairwise tests suggested several significant differences. Providing *no* percentage breakdown of allergens or ingredients resulted in significantly lower ratings compared to both of the alternatives, although there was no significant difference between *showing the percentage of allergens* versus *showing the percentage of ingredients*. Similarly, although participants expressed a preference for precautionary information compared to providing *none*, there was no significant different between specifying the food product *may contain traces allergens* versus providing *specific details about allergy management*. Nonetheless, in terms of the format of the booklet, there was a clear preference for information to be *specified according to products containing allergens and divided into categories per food categor*y, which was rated significantly higher compared to all the other options. However, this information

is not currently supplied in retail outlets. Booklets are often ordered by allergen-free products.

6.3.3 Information Communication Technologies

At least some levels of each attribute in the ICT conjoint analysis were significantly different from one another at the five percent level (see Table 4), although the variables representing country and respondent experience with ICT were not significant. Since ratings for glossary were significantly higher than without glossary, this result supported the inclusion of a food allergy glossary in any ICT approach to information delivery.

The pairwise tests indicated many of the levels for each attribute were not significantly different from each other. For the percentage breakdown options in the ICT conjoint, there was no significant difference between the options to *show the percentages of allergens* versus *the percentage of ingredients*, although both of the options were rated significantly higher compared to providing no percentage breakdowns. Likewise, in terms of food allergy warnings provided through ICT, *no warning* was significantly lower than the other options, although there was no significant difference between the other 3 options: visual warning, audio warning, or audio and visual warning.

Lastly, in terms of the kind of precautionary information provided, there was no significant difference between ICT that advises that a food product *may contain traces of allergens* versus one which specifies *details regarding allergy management*, although both of these options were rated significantly higher compared to providing *no* precautionary information.

In the analysis of the holdout profiles, we compared the ratings predicted by the estimated model with the actual ratings of the holdout profiles by the participants. For five holdout profiles, the predicted ratings were less than 7% off the actual ratings, and the differences were not significant in a t-test. For one Booklet holdout profile, the difference was 16% ($t=2.41$, $p<.05$).

On the basis of the overall ratings of the respective profiles, an indication regarding participant preferences for label versus booklet versus ICT could be obtained. All three conjoint analyses were repeated, including interaction effects between the attributes and country. Using the results from these analyses, the overall ratings for each device was calculated for each country. Participants in all countries gave the highest average preference ratings to an adjusted label on the 7-point scale (Netherlands: 6.13, s.e.=0.27; Greece: 5.88, s.e.=0.28; Germany: 5.75, s.e.=0.22). Participants in the Netherlands (5.48, s.e.=0.29) and Greece (5.40, s.e.=0.29) rated ICT as the second best solution and the booklet as the least preferred solution on

average (Greece: 5.30, s.e.=.29; Netherlands: (5.19, s.e.=.32). German participants preferred the booklet (5.25, s.e.=0.25) more than the ICT solution (5.20, s.e.=0.24).

Table 4. Results of ICT conjoint analysis

ICT (n=217)	Attribute levels	Mean	SE
Percentages**	None	3.33[A]	0.09
	show percentages of all allergens	4.43[B]	0.08
	show percentages of all ingredients	4.46[B]	0.08
Warning**	None	3.49[A]	0.09
	Audio	4.22[B]	0.09
	Visual	4.24[B]	0.08
	audio and visual	4.34[B]	0.09
Glossary**	no glossary	3.75	0.08
	Glossary	4.40	0.07
Precaution**	None	3.47[A]	0.07
	specific details on allergy mgt	4.36[B]	0.09
	may contain traces of allergens	4.39[B]	0.09
Country	Germany (n=50)	3.89 [A]	0.15
	Greece (n=62)	4.13 [A]	0.10
	Netherlands (n=143)	4.21 [A]	0.09
Experience Factor	Co-variate coefficient	0.11	0.07

Note. [ABC] Different superscripts within a label mean that the respective estimates were significantly different at the 5% level (within a label). Same superscripts within a label mean that the respective estimates were not significantly different.

6.4 Discussion and conclusion

Adults from three different EU countries were surveyed regarding the allergy management of the most severely food-allergic member of their family (themselves or another family member). A summary of the findings is given in Table 5.

Most respondents preferred a label containing a box with standardised food allergy information. Respondents preferred a standardised symbol (indicating the allergens) both at the back and the front of food packages. Furthermore, the results suggested that the label should show the percentages of the allergens in the food product, as well as provide specific details about allergy management in the food chain, displayed in an eye-catching box with standardised information, and located in a standard place on the label. The respondents preferred to have a hotline (telephone number), rather than a website address placed on the label.

One solution could be a mandatory safety warning of major allergenic food ingredients, as defined by Directive 2000/13/EC, on every foodstuff package, without any exceptions based on the size of the product or the presence of secondary packages. Due to space limitations on small packages and the large number of European languages, this safety warning could be a unique European symbol to warn and inform food-allergic individuals (Buhl, Kampmann, Martinez, & Fuchs, 2008). It is notable that particular groups within the population (in this case food allergic adolescents) were five times more likely to use the front label/nutrient claims than nutrient labels (McCullum & Achterberg, 1997) and so if a choice needs to be made between labelling on the front of packaging, and the back, the front should be prioritised.

The results of the study show that the participants preferred a glossary in the *booklet* that explains complicated terms. The booklet should also show the percentages of the allergens and contain a "may contain" warning. Contrary to the Netherlands and Greece, in Germany the booklet was preferred above an ICT-solution.

The analyses of the results focused on the *ICT-solution* showed that a device was preferred that would show the percentages of all ingredients (or at least those of the allergens), have audio and visual warnings, a "may-contain" warning (if applicable), and a glossary explaining complicated terms. One advantage of using ICT approaches is the flexibility which they confer in terms of personalising information, which is a common requirement for food allergic consumers or their care givers (Hu, Grbich, & Kemp, 2007).

The preferences regarding a standardised label differed between participants in the Netherlands and those in Greece and Germany. As a consequence, it will be difficult to develop very specific recommendations regarding the appearance of the food label, which can be adopted throughout Europe. General guidelines could be set out (for example, including a symbol on the package), which could then be adapted to consumer needs in specific countries. However, it is of interest to note that the participants in the three countries included in the study did not differ in their preferences regarding the information which should be included in a booklet.

The same was true for the proposed ICT-solutions. However, given the different socio-political context of different European member states, it is difficult to provide generic pan-European policy recommendations over and above the *de minimis* requirements regarding allergen information provision.

Table 5. Summary of results conjoint analysis

Attribute	Attribute levels	Preferred level number		
		Food Label	Booklet	ICT
Ingredients information (Percentages)	1. does not show percentages at all 2. show percentage of allergens in product 3. show percentages of all ingredients in product	2	2*	2*
Additional information	1. no additional information 2. precautionary labeling to indicate that a product 'may contain traces of the allergen' 3. specific production details about how allergens are managed within a factory	3	2*	2*
Standardised format	1. no box 2. eye-catching box with standardized allergy information	2		
Standardised allergen symbols	1. none 2. at the front 3. at the back 4. at the back and the front	4		
Information service	1. none 2. telephone hotline 3. website address 4. both hotline and website	2		
Glossary	1. none 2. ability to look up explanations for difficult terms or ingredients		2	2
Booklet format	1. allergen free products- per food category 2. allergen containing products- per food category 3. allergen containing products 4. allergen free products		2	
Personal warning systems	1. none 2. visual 3. audio 4. visual and audio warning			4**

Note. *no significant differences were detected between options 2 and 3. Therefore the results of the analyses including interaction effects were used to choose the option which was most preferred for each separate country, **no significant difference was detected between options 2, 3, and 4. The analysis including interaction effects did not confirm either of the options. Therefore, the highest overall preference was taken from the pooled analysis.

Effective implementation of systems is contingent not only on consumer preferences for information delivery, but also whether such systems can be effectively and safely implemented throughout the food chain (for example in terms of ingredient traceability and information delivery in the retail environment, such as the may contain labelling). Whilst new developments in ingredient traceability, such as RFID tagging, improve identification of particular ingredients in a given food chain, other factors such as the efficiency and reliability of traceability systems, or the cost of implementation, may make their adoption unfeasible (Davies, Van Rijswijk, Frewer, Luijckx, & Ward, 2008).

One question not addressed by this research is whether symbolic labelling should indicate whether the product actually contains this allergen or is free of this allergen. Further research is required to clarify this issue. A further problem in terms of public health relates to the fact that children and adolescents in unfamiliar surroundings do not always have access to the outer packages of foodstuffs, or the types of information delivery utilised at point of sale, to assess the safety of foodstuffs. Finally, the non-declaration of individually wrapped foodstuffs with outer packages and the general exclusion of the labelling of products whose largest single surface area falls below 10 cm^2 are legally allowed in the EU and elsewhere. As a consequence, small-sized foodstuffs may represent a potentially fatal hazard to vulnerable consumers, but nonetheless remain unlabelled under current legislative frameworks. Further refinement of existing legislation is required, contextualised by parallel research to determine optimal information delivery strategies for these consumers.

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Chapter 7

Optimising the delivery of food allergy information: An assessment of food allergic consumer preferences for different information delivery formats

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Abstract

In this study food allergic consumer preferences for different prototype information delivery tools was examined with the aim to improve informed product choices. Sixty-two self-reported food allergic participants from the Netherlands and Germany used three prototype information delivery tools (food label, handheld electronic scanner, and information booklet) to access the allergy information. Participants rated each tool in terms of their perceived convenience, usefulness and confidence. Principal Component Analysis indicated that convenience and usefulness loaded on one construct functionality. The impact of information delivery tool and country on functionality and confidence was analysed with two repeated measures GLM. The results indicated that perceived functionality was rated higher for label followed by electronic scanner and thereafter booklet. While food allergic consumers were confident about using all three tools, confidence did not statistically distinguish between the information delivery tools. No differences in perceived functionality or confidence were identified between countries. To conclude, consumer rating of functionality indicated label was the most preferred tool for delivering allergy information. The information delivery of prototype tools were sufficient for food allergic consumers to make informed food choices. The results have implications for developing new policies and legislation concerning information provision to food allergic consumers.

7.1 Introduction

Adverse reactions to food, such as food allergy, can trigger the body's immune system such that it responds to harmless proteins (Buttriss, 2002). This response, mediated by the immune system, can result in a range of symptoms, extending from uncomfortable skin reactions to anaphylactic shock (the latter of which can be potentially fatal). At the present time, the only strategy available to manage food allergy involves removing problematic food allergens from the diet of those experiencing allergic responses, as there is no treatment for the condition (Dutau & Rance, 2006; Eigenmann, 2001; Munoz-Furlong, 2003). The need for continuous vigilance, insomuch as food allergen avoidance is concerned, has the potential to negatively affect the quality of life of food allergic consumers and their families (De Blok, Vlieg-Boerstra et al., 2007; Sicherer, Noone, & Munoz-Furlong, 2001), as well as the economic functioning of individuals, their families, the health services and all actors involved in the agri-food sector (for example the food industry) (Miles, Valovirta, & Frewer, 2006).

The prevalence of clinically diagnosed food allergy is estimated to be 1–2 % in adults and 5–8% in children (Mills et al., 2007; Pereira et al., 2005). However, the prevalence of self-reported *undiagnosed* food allergy is much higher in adults, with an estimated 3–35% of the population reporting allergic responses to foods (Rona et al., 2007). There is some evidence suggesting that the prevalence of some food allergies may be increasing, although the evidence is equivocal (Grundy, Matthews, Bateman, Dean, & Arshad, 2002; Rona et al., 2007). However, taking the diagnosed and perceived food allergy rates together implies that a substantial percentage of the population may be affected by the issue of food allergy, and in some way restrict their behaviour in concordance with this.

The EU directive 2003/89/EC, which came into operation in November 2005, requires that the food industry lists 14 potential food allergens on pre-packed food labels regardless of the quantity in the finished product. The aim of the directive was to facilitate consumer identification of food allergens in food products. It is important to note that, in addition to the obligatory declaration of food allergens on the label, many food manufacturers also provide voluntary allergen advisory statements, which provide information about possible unintended cross-contamination between the food product and a food allergen ("precautionary labelling"). The purpose of the advisory statements is to alert food allergic consumers to the possible food allergens in the food product. However, these advisory statements may result in confusion on the part of the food allergic consumer (Simons, Weiss, Furlong, & Sicherer, 2005).

Cornelisse-Vermaat et al. (2008) conducted a stakeholder analysis to identify the different technical possibilities for information delivery regarding the presence of

food allergens in food products. An important conclusion was that the information supply for food allergic consumers might be improved if new Information and Communication Technologies (ICT) were developed specifically with the aim of improving information delivery, although such methods of communication were unlikely to replace product labelling. It was, however, concluded that such tools might provide an additional information "stream," which would provide additional information focused on facilitating safe food choices on the part of food allergic consumers (Cornelisse-Vermaat et al., 2008).

Resulting from the stakeholder analysis three information scenarios were selected as being the preferred candidates for delivering allergen information to consumers. These were, firstly, a Label (in the format of a standardized label with food allergy symbols; it is important to note that including specific food allergens in the list of ingredients is legally required in the EU. There is no legislation or advice concerning the use of symbols); secondly, an information Booklet with allergen information about specific products available in the retail environment; thirdly, a handheld electronic "scanner" — in this case a small information terminal with bar-code scanner — which could be used to identify potential allergens through scanning the ingredient traceability information provided by the bar code. The different information delivery scenarios were assessed by (self-reported) food allergic consumers in the Netherlands, Greece and Germany using an web-based online survey to identify preferences for the different characteristics within each type of information delivery tool (Voordouw et al., accepted subject to revision). The information scenarios were described to the participants rather than presented for real. The results suggested that participants in all countries gave the highest average preference ratings to an adjusted label. Participants in the Netherlands and Greece rated ICT as the second-best solution, and the booklet as the least preferred solution, German participants preferred the booklet over and above the ICT solution. The research also identified an "ideal format" for information delivery for each of the information tools developed.

The research presented here aimed at understanding the preferences of (self-reported) food allergic consumers regarding the actual use of "prototypes" of each of the three information delivery tools (Cornelisse-Vermaat et al., 2008; Voordouw et al., submitted), delivering food allergen information in the form and content previously identified as being preferred by food allergic consumers.

The aim of this research was to identify overall consumer preferences for the different information delivery tools in a consumer experiment, and to confirm if the additional attributes of the prototype tools are sufficient for food allergic consumers

to make informed product choices. The results will contribute to the development of the optimal strategy for conveying information about food allergens to food allergic consumers and other end-users.

7.2 Method

7.2.1 Study sample

The participant sample consisted of food allergic adults or their spouses, or the parents of food allergic children. Participants were recruited through advertisements published in national newspapers, on patient organisation websites and nutritionist. In total, 62 participants (24 in Germany, 38 in the Netherlands) were included in the sample on the basis of their self-reported perceived or diagnosed food allergy to at least one of the following foods: milk, egg, tree nuts, peanuts, and gluten. The food allergies were selected on the basis of their relatively high prevalence in the Netherlands and Germany (Mills et al., 2007; Pereira et al., 2005; Rona et al., 2007). Fifty participants in the study reported suffering from food allergy themselves, 6 participants had a partner with self-reported or diagnosed food allergy and 18 participants had a child suffering from self-reported or diagnosed food allergy. Some participants fell into two or more of these categories. The participants each were given a voucher worth 25 euros and their travel expenses were covered. The Netherlands and Germany were included in this study because the results of the previous study indicated the adjusted label was preferred in both countries, followed either by ICT (in the Netherlands) or Booklet (in Germany). Greece was excluded in the current study because in the previous study, the preference order was similar as in the Netherlands. The demographic characteristics of the study sample are provided in Table 1. Time Budget Research (TBO) data from the Netherlands showed that, although males take on more household tasks, the females are mostly responsible for the grocery shopping for the household (Sociaal Cultureel Planbureau, 2006). This is in line with the findings of a study done in 22 countries by Batalova and Cohen that women do more domestic task than men in all 2 countries (Batalova & Cohen, 2002). For this reason our study population consist for the majority of females. Although female might have different preferences and perceptions than male we believe that this study population is representative for the consumers responsible for the food shopping for a food allergic family member.

Table 1. Demographic characteristics of the sample

	N	%
Female	53	85
Age groups		
18–35	13	21
36–45	18	29
46–55	13	21
56–65	9	15
66 or older	7	11
Level of education		
Primary education	61	98
Secondary education	57	92
Commercial or technical education	12	19
University	15	24

Note. Of two participants the age was missing.

7.2.2 New information delivery tools

The attributes of the new information tools are provided in Table 2. In addition to the standard information presently required by existing food regulations, the "ideal format" of the label included the ingredient list showing allergen percentages indicated between brackets. Below the ingredient list the allergy information was provided in an eye-catching box. Below this box, specific details concerning allergy management in the factory was provided (e.g., "Processed in a facility that also processes [allergen], or "Processed in a factory which was [allergen] free"). Furthermore, allergen symbols were provided on both the front and the back of the package. These included a symbolic representation of an egg, peanut, walnut, udder, and a wheatear, respectively indicating the presence of hen's egg, peanuts, tree nuts, cow's milk, and gluten. Below the allergen information, a customer service telephone number was provided for additional information requests.

To make the "ideal format" of the ICT scanner ready for operation, a database was created containing the ingredient list, the allergen information, and information about allergen management in the factory. The data base was linked to the ICT device via wireless Internet access. The data base could be activated by the participants by scanning the barcode of the product, after which the information appeared on the screen. This information consisted of an information field providing details of the

ingredient list. Participants had the option to click on underlined terms, (i.e., E-numbers, herbs or spices, chemical names, and aromas), and were subsequently provided with more information about these issues. For example, if the participant clicked on "starch" or "oil" a new field opened providing information about the origin of the starch, for example corn starch or sunflower oil. If a ingredient in the food is derived from, or contains ingredients derived from allergenic sources, they need to be included with specific names in the list of ingredients by the manufacturer according to current legislation. Despite this legislation food allergic consumers would need information on all sources of the ingredients as lack of knowledge about the ingredients gives the food allergic consumers feeling of insecurity. Therefore, food allergic consumers desire to be fully informed about the content of a food product and the origin of additives. Allergenic ingredient content, expressed as a percentage, were again provided between brackets. The allergen information was provided in a different field below the ingredient list. The latter field indicated whether the allergens requiring labelling according to the EU directive were present in the product. The field remained empty if the product was free from these allergens. When an allergen containing product was scanned using the ICT scanner, an audio warning sound was produced. The last field contained information about allergen management used in the factory in which the product was produced (i.e., "processed in a facility that also processes [allergen]").

The "ideal format" of the booklet provided the percentages of the allergen content in the ingredient list between brackets, and specific details concerning allergen management in the factory. The booklet included a glossary explaining "difficult" terminology (e.g., chemical names, E-numbers). The innovative aspect of the information booklet was that it showed allergen-containing products by product category. For example, the booklet listed all allergen-containing food products in the category "biscuit." If a particular product was not listed, the implication was that the product was allergen free and safe to eat. For each food containing allergens a special form for the booklet was filled. The booklet had the advantage of the same information structure irrespective of the type or size of the food product.

The study was performed in the National language, either German or Dutch. The materials, ICT scanner, booklet and Labels, as well as the questionnaire were all translated into the National language.

Table 2. "Ideal" attributes of the prototype information delivery tools

Attribute	Label	ICT scanner	Booklet
Percentage of allergen content	x	x	x
Specific details on allergen management in the factory	x	x	x
Eye-catching "box" on the packaging with standardized allergy information format	x		
Allergen symbol provided on the back and front of the package	x		
Telephone number for consumer service hotline	x		
Glossary of technical terms		x	x
Audio and visual warnings		x	
Allergen containing products by food category			x

7.2.3 Food products

To assess consumer preferences for the new information delivery tools, fictitious food products were developed by using empty packages with labels manipulated to provide information according to the 'ideal format' resulting from the previous research. Three different categories of food products were included, namely, ready-made meals, snacks, and pre-prepared salads. In each product category, two fictitious food products were provided, one containing an allergen, and one allergy free. The "allergenic" food products (lasagne Bolognese, milk biscuits, and American coleslaw) contained *all* of the following allergens: milk, egg, peanuts, tree nuts, and gluten. The "allergen free" products (lasagne Verdi, biscuits, and vegetable salad) did not contain *any* of the 14 allergens legally required to be specified in the list of ingredients. The products were chosen after consulting the Dutch Nutrition Centre (In Dutch: Voedingscentrum) as these products all could contain the food allergens included in this study.

7.2.4 Study design

Participants were asked to use each of the three information delivery tools to assess whether the different food products (two food products of one category *per* information delivery tool) were safe for them, or their family members, to consume. To randomize the interaction effect of the food product and the information delivery tool a Latin Square Design was used. Three versions of the assignment were developed, differing in the tool—product combination (e.g., "label" either with

lasagne, biscuits or salads). To randomize the order effect of the tools in each version of the questionnaire the tools were rated in a different order (see Table 3).

After this assignment, the respective questionnaire asked the participants to rate each of the three information delivery tools on seven-point scales concerning 'convenience' (anchored by "very inconvenient" and "very convenient"), 'usefulness' (anchored by "very useless" and "very useful"), and 'confidence' (anchored by "low confidence" and "high confidence"). Finally, the participants completed a five-item 7-point ICT self-efficacy scale to estimate their experience with ICT, adapted from Eastin and LaRose (2000).

Table 3. Latin square design of the information delivery tools and fictitious food products

Assignment	Tool × product
Version A	Label+cookies, ICT+lasagne, book+salad
Version B	ICT+salad, book+cookies, label+lasagne
Version C	Book+lasagne, label+salad, ICT+cookies

Participants were free to fill out their comments on the questionnaire. The written comments by the participants about each tool were also analysed qualitatively by coding all quotes and assigning them into categories. A code was developed if at least two participants mentioned the topic.

The questionnaire was piloted in the Netherlands with three respondents. They suffered from (self-reported) peanut, nut and sesame seed allergies. These respondents provided feedback leading to the re-phrasing of a few questions in the final questionnaire.

7.3 Results

Data analysis comprised three parts, to be described below: quantitative analysis concerning data reduction and analysis of variance, and qualitative analysis of the participants' written comments.

7.3.1 Quantitative analysis

A principal components analysis was performed on the three ratings concerning 'convenience,' 'usefulness,' and 'confidence.' A one-component solution yielded loadings of, respectively, .87, .82, and .62, with a cumulative explained variance of 60.1%. To investigate further whether the items formed a single construct a reliability test was performed, resulting in an alpha of .67. To improve reliability, item deletion was applied. The scales of 'convenience' and 'usefulness' were taken together as one

construct named 'functionality' with an alpha of .73. 'Confidence' was treated as a single-item construct.

Table 4. Mean distribution of the ICT self-efficacy scale

ICT self-efficacy scale	Mean (SD)
Confidence with terms concerning computer hardware	4.9 (1.7)
Confidence with terms concerning computer software	4.9 (1.7)
Confidence with computer problems	4.2 (1.9)
Confidence in explaining why a task will not run	4.1 (1.8)
Confidence in learning advanced skills within specific computer program	4.9 (1.8)

Note. Adopted from Eastin and Larose (2000)

The results of the ICT self-efficacy scale, relating to the experience of the participants with ICT, is shown in Table 4. Pearson bi-variate correlation analysis showed that ICT experience was positively correlated with the overall preference for the prototype ICT scanner ($r=0.21$, $p<.05$). Therefore a factor analysis was performed on the ICT experience scale and the factor scores were used as a co-variate in a Generalised Linear Model (GENLIN) with repeated measures.

All respondents were able to select the food product in the experiment they could safely eat (taking their food allergy into account). The main effects of the model are shown in Table 5. The main effects of the new information tools on functionality ($p<.01$) and the effect of ICT self-efficacy on functionality ($p<.05$) were significant, the main effects on confidence were not significant.

Table 5. Model effects with Wald chi-square of main effects of tools and co-variants country and ICT experience (χ^2 (df))

	Tools	Country	ICT self-efficacy scale
Functionality	41.120 (2)**	.121 (1)	3.950 (1)*
Confidence	1.450 (2)	.005 (1)	0.450 (1)

Note. *p<.05, **p<.01

The post-hoc analysis showed that there were no significant differences between the countries on the 'functionality' and 'confidence' scales (see Table 6). The data was therefore pooled in subsequent analyses.

Table 6. Preferences for the information tools per country (mean (SE))

	Netherlands	**Germany**
Functionality	5.7[a] (.13)	5.6[a] (.16)
Confidence	6.0[a] (.16)	6.0[a] (.02)

Note. [a] For each row different superscripts indicate that the respective estimates were significantly different at the 5% level. Same superscripts in each row indicate that the respective estimates were not significantly different.

Table 7 shows the ratings of the information tools on the two scales. Perceived functionality was rated significantly higher for the label compared to the booklet ($p<.01$) and ICT scanner ($p<.05$). The ICT scanner was rated as significantly more functional compared to the booklet ($p<.05$). The mean functionality score for the booklet was relatively low compared to label and ICT scanner. Overall, the participants reported (similar) high levels of confidence for all three information delivery tools.

Table 7. Preferences for the new information tools (mean (SE))

	Book	**Label**	**ICT scanner**
Functionality	4.9[a] (.21)	6.3[b] (.10)	5.7[c] (.16)
Confidence	5.9[a] (.18)	6.0[a] (.16)	6.1[a] (.16)

Note. [abc] For each row different superscripts indicate that the respective estimates were significantly different at the 5% level. Same superscripts in each row indicate that the respective estimates were not significantly different.

7.3.2. Qualitative analysis

The participants were given the opportunity to provide commentary and feed back on the different tools if they wished. Thirty-two Dutch (NL) and 17 German (D) participants provided written feedback.

7.3.3. New designed label

Some participants indicated their appreciation of the symbols, with the caveat that the symbols needed explanation before they were able to use them correctly.

> *P24 NL (female): "The symbols are very useful. Although, explanation of the symbols is necessary. Symbols are fast to read."*
> *P38 NL (female): "I am very pleased with the symbols."*

However, some participants indicated that the symbols could lead to confusion as to whether or not the allergen was contained in the product.

P1 D (female): "For me the symbols are a bit confusing however after getting used to the symbols it will be very informative."

Many participants appreciated the new label design.

P25 NL (female): "Once I know that all information is on the label, the font size is readable and the symbols are included, my personal preference would be the label because of its consumer friendly design."
P6 D (female): "I do not buy a product before consulting the label. I feel unsecure if it states "modified starch" Because I always want to know what kind of starch it is. On this label the allergen reference takes away this unsecure feeling. Furthermore, the allergen management information is fantastic!"

There was some evidence suggesting that the provision of details regarding the conditions in the factory was very informative.

P8 D (female): "The allergy management information is very useful; it gives me more trust in the brand."
P4 NL (female): "…also very useful the difference between produced in a allergen free environment or possible presence of allergens in the products."

7.3.4. ICT scanner

In general, participants indicated that the information provided by the ICT scanner was detailed enough to make a safe food choice. Furthermore, the glossary function was reported to be informative and enhanced the participants' trust in the product. Against this, some German participants reported that the scanner was not "user friendly" enough. In particular, they reported that the menu system was too complex, and the speed of information provision was too slow. Additional concerns were raised about the costs of the scanner.

P12 NL (female): "I believe when I am used to this device it will be very helpful…"
P6 D (female): "….If the screen turns red there are allergens in the product. For a reasonable price I would consider buying this device, but than it needs to be made more practical."

Additional concerns were raised about the potential for social exclusion of particular groups in the population, who are less comfortable about using modern ICT technologies.

P4 NL (female): "This is not appropriate device for technophobic people like my mother."

Other concerns were voiced about pragmatic difficulties in using the scanner (for example, in terms of its pragmatic use in the shopping environment, or the extra time needed to use it when shopping). Safety concerns were related to the accuracy of the ingredient traceability data base rather than the scanner itself.

7.3.5. Booklet

Some participants reported that the booklet was too laborious, time consuming and impractical to use in a retail environment. Furthermore, concerns were raised about the reliability of the booklet, given the need to frequently update the information it contained.

P27 NL (female): "The information in the booklet is good although this is not practical in the store […] If a product is not in the booklet, meaning it is allergen free, I would not trust the information and I will still look at the ingredient list on the label."

However, some participants reported that the information in the booklet was adequate for making safe food choices.

P33 NL (female): "Looks very complete and clearly ordered with valuable information. More and completer information than the label. If I would want more information I would use the scanner."

Generally, the comments served to further understand consumer preferences identified in the quantitative part of the research.

7.4. Discussion and conclusion

The aim of this study was to investigate whether the prototype information delivery tools, based on the preferences of food allergic consumers identified in previous research (Cornelisse-Vermaat et al., submitted), enabled food allergic consumers to make safe food choices when applied in an experimental shopping environment. Consumer assessments of the functionality of the different information delivery tools,

together with ratings of their confidence in using them to make safe food purchases from the perspective of allergy avoidance, were also assessed.

The results show that there were no significant differences between the Netherlands and Germany in terms of consumer assessments of functionality of, and their confidence in, the three information tools.

The perceived functionality of information delivery devices is important and enables food allergic consumers to utilise them in a retail environment. This study showed that the label and ICT scanner scored relatively high in terms of functionality. The booklet was judged to be less functional. Since food allergic consumers were equally highly confident in the information provided by the different tools (scoring around 6 on the 7-point scale), one might conclude that preferences were determined more by the functionality of the tools than the reliability of the information about allergens they provided. These finding are in line with the study done by Cornelisse et al. (submitted) as the highest preference was for label, second ICT and third booklet.

Most respondents indicated that the product label was the most functional source of allergen information. In part, this may reflect the potential lack of availability of the electronic scanner, or the fact that the use of the ICT scanner and the booklet was time consuming. Participants also expressed the view that the meaning of "symbolic" allergen labelling should be explained before food allergic consumers can optimally use them. This is in line with previous research indicating the need for clear, unambiguous and uniform symbols (Cornelisse-Vermaat, Voordouw, Yiakoumaki, Theodoridis, & Frewer, 2008). Communication and education strategies about symbols and product information on packages might solve these issues. Previous research indicated that the ingredient list was not always understood because of the terminology used (Voordouw et al., 2009). The labels included in this study tried to address this issue by placing the lay explanation of difficult (chemical) terminology between brackets, an addition viewed positively by the participants.

Although labelling was found to be the preferred information strategy by food allergic consumers, the use of ICT devices such as the electronic scanner merits further exploration. For example, ICT has the advantage of being able to deliver up-to-date allergen information relatively quickly (for example, should accidental contamination of a specific product line occur, or when product recipes change). Indeed, the electronic scanner utilised in the current research, when connected to an online data base, can provide far more information than can be indicated by a label

with limited space. The scanner can make use of a "layered menu[7]", such that consumers can choose whether they want or need specific food-related information (for example, about a specific range of potential allergens, or combinations of allergen and other food-related information, such as production methods, sustainability, or nutritional issues, or even product alternatives). It is suggested here that the use of an electronic scanner may be used in addition to food allergy labelling (see also (Cornelisse-Vermaat, Voordouw, Yiakoumaki, Theodoridis, & Frewer, 2008). Given the flexibility of the consumer information provided, the approach may also be useful in developing competitive advantage in the retail sector. The use of the ICT scanner as an additional information source, rather than as the only information source, is essential if social exclusion of some less-computer-literate segments of the population is to be avoided.

In conclusion, the food allergic consumers in this study preferred clear and unambiguous labelling on product packaging, although the functionality of the electronic scanner was appreciated. Whilst the use of allergen labelling of food products remains an important consumer priority, additional information provision through the application of novel ICT technologies seems highly relevant (not the least from the retailer perspective of potentially delivering competitive advantages in terms of facilitating consumer choice).

The results of this study are important for developing new policies and legislation concerning information provision to food allergic consumers, for example developing and implementing a harmonised international symbolic allergen strategy, associated with effective communication about how such labels should be interpreted. These results could also directly be used by manufacturers to develop new labelling or ICT scanners to improve their service to clients in the store and thereby their market position.

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[7] Layered menu means that with each additional click on the screen you get more detailed information.

Chapter 8

General discussion

8.1 Introduction

In this final Chapter, some concluding remarks will be made with regard to the findings in the different chapters of this thesis. The objective of this thesis is to obtain better understanding of the impact of food allergy and food hypersensitivity on households with food allergic member(s). In particular, the thesis aimed at gaining more insight into the economic problems with respect to welfare and well-being, financial costs and information delivery strategies, which food allergic consumers and their families encounter.

Food allergy is an important health issue as no general cure is at present available (Munoz-Furlong, 2003), and the only proven treatment is to strictly avoid the problematic food allergens in the diet (Ortolani & Pastorello, 2006). Moreover, the need for continuous vigilance, regarding dietary exclusion has the potential to negatively affect the psychological and social functioning of food allergic individuals and their families (Baiardini, Braido, Brandi, & Canonica, 2006; Flokstra-De Blok, 2009; Primeau et al., 2000).

To develop adequate guidelines focused on optimising consumer protection, regulators need objective information about the extent to which food allergy represents a major public health problem, as well as having a negative impact on quality of life of food allergic consumers. Therefore, it is important to know the prevalence of food allergy, as well as the economic costs and the impact on quality of life. In addition, policy makers, regulators and the food industry need tools to effectively manage food allergies and hypersensitivities across Europe. Effective

management of food allergy can deliver an improved quality of life to food allergic consumers and their families.

The burden on health care services associated with chronic diseases leads to an increased interest in their economic impact. In making decisions about optimal allocation of health care resources, it is important to consider the economic effects of chronic diseases, such as food allergy. Evidence is needed regarding the relative importance of food hypersensitivity, including food allergy and food intolerances, compared to other chronic diseases to justify the economic cost for development of new legislation or policies (for example, in terms of food and ingredient labelling, food production or investment in formal diagnosis within the health care system (Pfaff et al., submitted).

8.2 Summary and conclusions

Although estimated costs for several non-food related allergies have been provided (UCB, 1997), similar data is not available for food allergy. The main objective of the research described in **Chapter 2** was to develop a questionnaire which can be used to assess the economic costs of food allergy at both the individual and household level across different countries and population groups, and to conduct an exploratory analysis of the potential economic impact of food allergy. The study confirmed that the "household costs of food allergy" questionnaire produced plausible results and provided appropriate data to estimate costs of households both with and without food allergic family members. Taking the results into account, the "household costs of food allergy" questionnaire was simplified by creating closed questions with "tick boxes", removing unnecessary questions, and including simple filter instructions to skip non-applicable questions. In this exploratory study, both self-reported clinician diagnosed food allergic consumers were included in the sample. This could potentially lead to a dilution of the results, assuming that self-diagnosed consumers will have lower costs for health service usage compared to clinician-diagnosed consumers. Despite these limitations, the "household costs of food allergy" questionnaire captured some differences in economic functioning between food allergic individuals and controls. These differences related primarily, although not exclusively, to negative affect on indirect costs and intangible costs.

Chapter 3 reports the use of the "household costs of food allergy" questionnaire in a large sample of clinician-diagnosed food hypersensitive patients to confirm these cost effects, and to test hypotheses about costs experienced within different countries to extend the findings to a broader cross-national context. This study was part of an epidemiological study to investigate the prevalence of food allergy

and food intolerance in four European countries, data were collected in The Netherlands, Poland, Spain and the United Kingdom. The respondents in this broader study were either diagnosed with food allergy or food intolerance. For the purposes of this discussion, the term food hypersensitivity to indicate both diseases. Contrary to our expectations, the food hypersensitive respondents had significantly lower direct and indirect costs across all countries compared to households without food hypersensitive members. The direct cost of living was higher for respondents asymptomatic to foods than for food hypersensitive respondents. In general, the travel costs to obtain medical health care and the costs of consulting health professional were higher for food hypersensitive respondents than for respondents asymptomatic to foods.

The indirect costs of time spent on obtaining health care from a health professional across all countries was higher for food hypersensitive respondents than for respondents asymptomatic to foods. In contrast, the indirect costs associated with the time spent on household tasks including cleaning, cooking, shopping, gardening, and childcare across all countries were higher for respondents asymptomatic to foods compared to food hypersensitive respondents. The most important finding in this study is that food hypersensitive patients with severe reactions to food allergens incurred *less* indirect and direct costs than those with mild reactions to food allergens, where severity was assessed using the Mueller severity grading scale for fiood allergy (Mueller, 1966, 1990)

Although Chapter 3 reported that the direct and indirect financial costs associated with food hypersensitivity at the household level were not greater than for non-food hypersensitive individuals, conga to expectations, it is possible that food hypersensitivity may have an impact on *subjective welfare*, defined as the individual evaluation of income (Antonides & Van Raaij, 1998; Van Praag & Frijters, 1999). Furthermore, socio-economic restrictions associated with allergen exposure may also result in a decreased health related quality of life, (HRQoL) (Flokstra-De Blok, 2009; Gowland, 2002). HRQoL is closely related to well-being. This concept captures the overall life satisfaction or happiness of an individual, whereas HRQoL focuses on an individuals satisfaction with their health status. **Chapter 4** describes the impact of food hypersensitivity on subjective welfare and well-being. No differences in welfare between food hypersensitive respondents and respondents asymptomatic to foods were found. However, adult food hypersensitive respondents and their spouses reported significantly less happiness than respondents asymptomatic and their spouses to foods. Moreover, the well-being of children did not significantly differ between

groups. Another result of this study was that the degree of severity of food hypersensitivity was negatively related to overall health status.

The impact of food hypersensitivity primarily affects the well-being of food allergic individuals, but and has very limited financial effects or impact on subjective welfare. Consequently, measures need to be implemented which have the potential to improve the well-being of food allergic patients. Given that avoidance of target foods by food allergic individuals is the only treatment for food allergy, and food hypersensitivity, effective communication about the presence of potentially allergenic ingredients in different foods is essential. There is, however, evidence to suggest that existing strategies to improve information provision in the retail environment is ineffective (Miles, Valovirta, & Frewer, 2006). Therefore, research reported in **Chapter 5** focuses on understanding food allergic consumer perceptions of the efficacy of existing labelling practices, and their preferences for improvements in information delivery. Moreover, research reported in Chapter 5 aimed to understand whether the new labelling legislation, being developed and implemented at the time the research was being conducted, provided sufficient information for the food allergic consumer to be enabled to make safe food choices and to optimise risk management. At the time the research was conducted, food legislation had been developed to facilitate management of food allergens in order to protect food allergic, rather than food intolerant patients. For this reason, the research was confined to the study of the information needs of food allergic patients, and how this related to the current legislative situation. Participants reported experiencing problems associated with existing food allergy information provision. The analysis of the results suggest that that inappropriate use of small fonts, low contrast of colours between the package and text and many languages and inconsistencies between languages in the ingredient declaration, application of precautionary labelling, and lack of harmonisation in labelling practices across countries can result in unnecessary restrictions in the diet of food allergic consumers. For example, the ingredient list and allergen information should have a standardised format which facilitates the decision making process. Moreover, symbols facilitate quick interpretation and decision-making regarding the allergen information, as well as overcoming language barriers and therefore represent an important aspect of adequate labelling. Given that food allergy can be potentially life-threatening, at least in severe cases, adequate food labelling is of utmost importance if food allergy is to be effectively managed; the development of an effective food labelling strategy must be a priority within Europe.

The research reported in **Chapter 6** aimed to identify the usefulness of specific characteristics and means of information provision for allergic consumers through

different information delivery scenarios. Based on the results from Chapter 5 information delivery scenarios were developed, namely; a) Label - standardised label with symbols; b) Booklet - with allergen information; c) Information Communication Technologies (ICT) - such as a small personal shopping assistant, an information terminal, a handheld scanner, or an internet shop. The results suggested that the label should show the percentages of the allergens in the food product, as well as provide specific details about allergy management in the food chain, standardised symbol (indicating the allergens), displayed in an eye-catching box with standardised information, and located in a standard place on the label. Furthermore, the respondents preferred to have a hotline (telephone number), rather than a website address placed on the label. In addition, to the preferences indicated for the label the participants preferred the glossary in the *booklet* that explains complicated terms. The analyses of the results focused on the *ICT-solution* showed that especially the audio and visual warnings of a personalised message were an advantage of ICT above the label and booklet. ICT methods will not replace effective food labelling, but may be used to supplement information provided by labels.

Chapter 7 reports research which builds on the results of research reported in Chapter 6. Prototype information delivery tools are developed from the results, in line with the preferences of food allergic consumers. The aim of this research was to identify overall consumer preferences for the different information delivery tools. A consumer experiment, was conducted to understand if the information delivery was in fact optimal, and to confirm if the additional attributes of the prototype tools are sufficient for food allergic consumers to make informed product choices. Participants rated the different information delivery tools in terms of functionality, and their confidence in using them to make safe food purchases from the perspective of allergy avoidance. The results indicated that perceived functionality was rated higher for label followed by electronic scanner and thereafter booklet. While food allergic consumers were confident about using all three tools, confidence ratings different between the information delivery tools were not statistically different. Consumer ratingsof functionality indicated that the label was the most preferred tool for delivering allergy information. The results contribute to the development of an optimal strategy for conveying information about food allergens to food allergic consumers and other end-users. Furthermore, the results are important for developing new policies and legislation concerning information provision aimed at optimising health protection of food allergic consumers.

8.3 Discussion

8.3.1 Financial impact of food hypersensitivity

This thesis provides insight into the financial impact of food allergy to the individual and their household. Contrary to expectations, the food hypersensitive respondents had significantly lower direct and indirect costs across all countries compared to households without food hypersensitive members. This may be explained by the routinisation of shopping and cooking due to the limited variety of foods people with a food allergy can safely consume, and by the avoidance of more expensive processed foods leading to less expense on grocery purchase and reduced time spent buying and preparing meals (Cornelisse-Vermaat, Voordouw, Yiakoumaki, Theodoridis, & Frewer, 2008; Voordouw et al., 2009). Moreover, families with food hypersensitive members also restrict their social and recreational activities under circumstances where the food supply cannot be managed to an appropriate level (for example, eating outside of the home, ordering takeaway foods, or recreational travel), leading to less food-related expenditure compared to a family without food hypersensitive members (Cornelisse-Vermaat, Voordouw, Yiakoumaki, Theodoridis, & Frewer, 2008; Voordouw et al., 2009)

The higher travel costs of food hypersensitive patients incurred during consultations with (food) allergy specialists could be explained by the availability of a small number of clinicians with expertise in this area, resulting in further travelling to seek diagnosis and medical advice, and thus higher costs. However, once a food allergy patient has been diagnosed and is adequately informed about the requirements of an avoidance diet and emergency treatments if an adverse reaction should occur, patients will be monitored at least yearly with a follow-up consultation (some patients outgrow food allergy whereas others develop new allergies), leading to relatively low consultation costs compared to other chronic diseases which require regular check-ups by a specialist. The medication for food allergy is limited to emergency treatment, such as carrying an epinephrine auto-injector or oral antihistamines (Pumphrey, 2000; Thompson & Chandra, 2002). Again, these costs are relatively low compared to other chronic diseases requiring daily medication.

The results of the consumer preferences studies, which focus on optimising allergen information delivery to consumers, could also directly be used by manufacturers to develop new labelling or ICT scanners to improve their service to clients in the store and thereby their market position.

To conclude, the results presented here, derived from the analysis of extensive survey data collected in different European countries, and through application of a

validated "household costs of food allergy" questionnaire to measure costs, do not support the contention that food allergy is associated with high costs at the household level. The costs of food allergy to society or the health care system might be higher compared to the general population, and this is an interesting topic for future research.

8.3.2 Intangible impacts of food hypersensitivity

The intangible impact of food hypersensitivity was measured in the research reported in this thesis as the impact on the subjective well-being and subjective welfare. No differences in welfare between clinically diagnosed food hypersensitive respondents and the asymptomatic baseline sample were observed. Similar results were found in a study on perceived food intolerance sufferers for lifestyle, welfare and dietary practices of perceiving food intolerance, in a community sample in Ireland (Knibb et al., 2000). This also provides evidence that the intangible impact of food allergy may not be as large as believed.

In contrast to subjective welfare, subjective well-being was reduced for food hypersensitive patients compared to control group. This result is line with previous findings that food allergic patients experience a reduced quality of life due to the illness (Baiardini, Braido, Brandi, & Canonica, 2006; Flokstra-De Blok et al., 2010; Primeau et al., 2000; Sicherer, Noone, & Munoz-Furlong, 2001). Since well-being was positively related to income, an income supplementation may compensate for food allergy.

The results also suggest that food hypersensitivity does not have an impact on perceived health status. This may be because, under circumstances where dietary management is effective, patients do not suffer illness in the course of their daily life. Accidental exposure to problematic foods may result in a negative effect on health status, but this may be infrequent. None-the-less, adoption of efficacious avoidance strategies may be perceived as difficult, or result in stress and anxiety.

8.3.3 Impact of food allergy on information strategies

In general, this thesis provides evidence that the current labelling is inadequate for the food allergic consumers to be able to make safe food choices. Inappropriate communication about food allergens can cause stress and insecurity, which may have a negative impact on well-being. Thus, to reduce health risk and improve the well-being of food allergic consumers *clear* and *adequate* labelling is required. The EU directive 2003/89/EC amending 2000/13/EC was designed to improve the information to the allergic consumers. However, many food manufactures place precautionary warnings on their food products to avoid any law suits about allergenic reactions. Food allergic

consumers often questioned whether these warnings were precautionary or genuine, and expressed the view that they lead to unnecessary restrictions in the diets of food allergic consumers. Food manufacturers should incorporate strategies to assess the real risk of cross-contamination of the production lines and production processes, and should only use the "may contain" labelling when there is a realistic possibility of risk. Whether such changes in labelling practice is enforceable by law is another question, and beyond the scope of discussion in this thesis.

To be able to incorporate such strategies all ingredients need to be traced throughout the whole production process. Therefore, traceability is the first step in developing adequate labelling, especially concerning food allergens. Whilst new developments in ingredient traceability, such as RFID tagging, improve identification of particular ingredients in a given food chain, other factors such as the efficiency and reliability of traceability systems, or the cost of implementation, may make their adoption unfeasible (Davies, van Rijswijk, Frewer, Luijckx, & Ward, 2008).

Many food allergic consumers report that they have difficulties in finding the appropriate information on food labels (Elinor, Weiss, & Furlong, 2005; Joshi, Mofidi, & Sicherer, 2002; Sakellariou, Sinaniotis, Damianidou, Papadopoulos, & Vassilopoulou, 2009; Simons, Weiss, Furlong, & Sicherer, 2005; Van Hengel, 2007). The usage of standardised, and unambiguous, symbols could solve this problem. Labelling policies and practise should be harmonised at international level or at least at the national level, and if possible, preferably at an international level, although a barrier to such international harmonisation in regulation may be agreement regarding the form such labelling should take. In an era where increased globalisation has resulted in human mobility and higher levels of international travel, it is arguable that such harmonisation is a priority for legislative bodies and indeed may be an important agenda item for international agencies concerned with the security of food supply, and regulations associated with the implementation of food safety strategies.

Although labelling was found to be the preferred information strategy by food allergic consumers, the use of ICT devices, such as the electronic scanner, merits further exploration. For example, ICT has the advantage of being able to deliver up-to-date allergen information relatively quickly (for example, should accidental contamination of a specific product line occur, or when product recipes change). Furthermore, ICT has the possibility to personalise information, which is a common requirement for food allergic consumers or their care givers (Hu, Grbich, & Kemp, 2007). These results could also directly be used by manufacturers to develop new labelling or ICT scanners to improve their service to clients in the store and thereby their market position.

8.4 Recommendations for future research

The empirical studies in this thesis have a number of limitations, which were discussed in Chapters 2, 3, 4, 5, 6, and 7. This section will identify the most important limitations of the research thus far conducted and, from this, will provide some advice regarding future research.

For policy makers, information about the costs at the household level as well as costs for the health sector and industry are important to develop adequate and cost-effective regulatory measures regarding consumer protection and provision of health care services. The "household costs of food allergy" questionnaire developed to measure the economic costs associated with food allergy could be used for many purposes, for example, to measure the cost effectiveness of diagnostic methods or counselling strategies. The costs of developing diagnostic methods may be evaluated as being too great if the advantages they confer are not profitable to the health care system and society. In addition, the "household costs of food allergy" questionnaire may be used to assess the (changes in) the well-being of food allergy patients before and after clinical diagnosis, including in the long-term. After diagnosis of food allergy for certain allergens and adequate information through clinicians, the avoidance diet may exclude less or more food allergens from the diet leading to a change in well-being.

Further research could be performed to determine the difference in expenditure between self-diagnosed and clinician diagnosed patients. The prevalence of self-reported food allergy is much higher than that associated with clinician-diagnosed patients. This could be a consequence of difficulties experienced in obtaining formal diagnosis. While both self- and clinician- diagnosed patients exclude certain foods from their diet, it is not known what the effect on household costs and economic functioning will be between these groups. The "household costs of food allergy" questionnaire could also be applied to measurement of the impact on well-being after interventions aiming to reducing the burden of food allergy on the patients.

To avoid unnecessary precautionary warning on food labels, manufacturers should incorporate food risk management systems, which entail protocols that manufacturers apply to cope with allergens in their production processes. These protocols help manufacturers to avoid unnecessary cross-contamination and adequately label the allergens present their products. Research might usefully investigate how these protocols could be implemented (for example, through employee training) and enforced (for example, through changes in legislation).

8.5 Key findings

This section will discuss *in short the key findings* of this thesis and stress the importance of this research.

The first key finding of this thesis is the development of the "household costs of food allergy" questionnaire, which was designed to measure the financial impact of food allergy, and the larger survey across Europe using this "household costs of food allergy" questionnaire to collect information. To our knowledge, such an instrument has not been hitherto developed, and therefore its development was timely and necessary. For regulators and policy makers this "household costs of food allergy" questionnaire can be used to prioritise healthcare resources, as well as test the effectiveness of policy interventions. In particular, when used in combination with existing subjective welfare and well-being scales applied to assess the welfare and wellbeing of food hypersensitive and allergic patients. Although, the results show that food hypersensitivity was not affecting the direct, indirect and subjective welfare, it did show a negative effect on subjective well-being. Thus, food hypersensitive patients suffered from their disease, as they were less happy with their life as a whole compared to people asymptomatic to foods. Another important finding was that the milder the severity of the food allergy, the higher were the direct and indirect costs were. In contrast, quality of life decreased as disease severity increased. Therefore, it is important that policy makers, regulators and others involved in protecting food allergic patients do not only rely on cost analysis but also on the psychological impact of food allergy and food hypersensitivity when considering policy measures aimed at mitigation. The combination of research on economic, subjective welfare, subjective well-being impact and information preferences on individuals suffering from food hypersensitivity makes this thesis of great relevance and importance. Finally yet importantly, the results presented in this thesis do not support the commonly held belief of lobbyists that all food allergies incur high costs to the individual.

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Summary

Adverse reactions to food can be caused by food hypersensitivity. Prominent examples include food allergy or food intolerance. Patients suffering from food hypersensitivity have inappropriate autoimmune system reactions to potentially harmless food components. Symptoms can vary from uncomfortable skin rashes to cardiovascular problems such as anaphylactic shock. To date, no general cure is available. As a consequence, the management of food allergy consists of allergen avoidance, which may cause negative consequences in terms of patient anxiety and their experience of quality of life. Furthermore, implementation of dietary restrictions can have a negative effect on the quality of life and economic functioning of not only the food allergic patient but also their family members.

An important issue in the assessment of the impact of food hypersensitivity and food allergy is the assessment of the economic costs that accrue to afflicted consumers. This information will contribute to the prioritising of healthcare resources, as well as developing effective policies to insure consumer protection. It is also important to evaluate whether wellbeing and welfare are affected. If this is indeed the case, a question arises as how to best manage dietary avoidance strategies. The aim of the research reported in this thesis is to provide information salient to the assessment of the impact of food hypersensitivity and allergy on households with respect to costs (time and money), welfare, well-being, and information search strategies.

A systematic review of the existing literature revealed that researchers had not yet developed and validated an instrument to measure the individual and household costs of food hypersensitivity and/ or allergy. This thesis describes the development of the "household costs of food allergy" questionnaire and the exploratory analyses applied to validate the instrument. Thereafter, the "household costs of food allergy" questionnaire was used on a large sample of clinician-diagnosed food hypersensitive patients to confirm these cost effects. This study was part of an epidemiological study to investigate the prevalence of food allergy and food intolerance in four European countries, data were collected in The Netherlands, Poland, Spain and the United Kingdom. The respondents in this study were either diagnosed with food allergy or food intolerance. For the purposes of this discussion, the term food hypersensitivity will be used to indicate both diseases. Contrary to expectation, households with food hypersensitive respondents had significantly lower direct and indirect costs across all

countries compared to households without food hypersensitive members. In addition, no differences in welfare between food hypersensitive respondents and respondents asymptomatic to foods were found. However, adult food hypersensitive respondents and their spouses reported significantly less happiness than respondents, or their spouses, who were asymptomatic. Thus, the results presented in this thesis do not support the commonly held belief of clinical researcher and patient organisations that all food allergies incur high costs to the individual.

Given that an individual's experience of quality of life is negatively impacted by food hypersensitivity, it is feasible that this might be improved by the implementation of more effective management strategies. As the primary viable management strategy involves avoidance of problematic foods, facilitating consumer choice in the retail environment may optimise risk management. The labelling preferences of food allergic consumers were investigated in two European countries, The Netherlands and Greece. At the time the research was conducted, food legislation had been developed to facilitate management of food allergens in order to protect food allergic consumers, rather than food intolerant consumers. For this reason, the research was confined to the study of the information needs of food allergic patients, and how this related to the current legislative situation. The research utilised ethnographic interviews with food allergic consumers during the course of shopping in a supermarket. The results suggest that current labelling practice is perceived to be inadequate for food allergic consumers if safe food choices are to be made. This is due to inappropriate use of fonts, colours with low contrasts and inconsistencies in the different languages, application of precautionary labelling, and lack of European and international harmonisation in labelling legislation. Based on these results, new information scenarios, such as uniform labelling, information booklet and ICT solutions, were developed and tested through an online survey. The results were used to develop prototype information delivery tools. An experiment was conducted to understand if the information delivery was in fact optimal, and to confirm if the additional attributes of the prototype tools were sufficient to facilitate allergen avoidance. The results suggested that the label should show the percentages of the allergens in the food product, as well as provide specific details about allergy management in the food chain, and use standardised symbols and standardised location of allergy information on the package. Additional visual and auditory warnings were also treated as being important for the ICT driven information delivery approaches, the results indicated that ICT methods are not appropriate replacements for effective food labelling on packaging, but may be used to supplement information provided by labels.

To conclude, this thesis provides insight in the financial impact of food hypersensitivity, as well as the welfare and well-being. The "household costs of food allergy" questionnaire can be used by regulators and policy makers to prioritise healthcare resources, as well as to test the effectiveness of policy interventions. Limitations in current risk management strategies based on consumer information were also identified. The results of the consumer preferences studies can be used by policy makers and food industry to optimise the information delivery to food allergic consumers and therewith improve their quality of life. The combination of economic research and consumer research is relevant to investigate the dynamic impact of food allergy on individuals and their families.

Samenvatting

Ongewenste reacties op voedsel kunnen worden veroorzaakt door voedselovergevoeligheid. Belangrijke voorbeelden zijn voedselallergie of voedselintolerantie. Patiënten die lijden aan voedselovergevoeligheid hebben abnormale reacties van het auto-immuun systeem op potentieel onschadelijke voedselcomponenten. De symptomen kunnen variëren van huiduitslag tot aan cardiovasculaire problemen, zoals anafylactische shock. Tot op heden is er geen algemene behandeling beschikbaar. Als gevolg daarvan, is de enige behandeling strikte vermijding van de allergenen, dit kan negatieve gevolgen hebben voor de patiënten, zoals het ontwikkelen van angst en een verandering van de patiënts beleving van hun kwaliteit van leven. Bovendien kan het implementeren van dieetbeperkingen een negatief effect hebben op de kwaliteit van leven en het economisch functioneren van niet alleen de voedselallergische patiënt, maar ook van hun familieleden.

Een belangrijk aspect bij de beoordeling van de invloed van voedsel overgevoeligheid, is de beoordeling van de economische kosten die dit met zich mee brengt voor de voedselovergevoelige consument. Deze informatie kan bijdragen aan de prioritering van middelen in de gezondheidszorg, evenals de ontwikkeling en waarborging van een effectief overheidsbeleid ter bescherming van de voedselovergevoelige consument. Daarnaast is het belangrijk om te evalueren of subjectieve welzijn en welvaart worden aangetast. Indien dit inderdaad het geval is zal de vraag ontstaan hoe de vermijdingsstrategieën van voedingsmiddelen het beste kunnen worden gemanaged. Het doel van het onderzoek beschreven in dit proefschrift is informatie te verstrekken die belangrijk is voor de beoordeling van de invloed van voedselovergevoeligheid en voedselallergie op een huishouden ten aanzien van de kosten (tijd en geld), welvaart, welzijn en strategieën naar het zoeken van informatie door de voedselallergische consument.

Uit een systematische literatuur review is gebleken dat er nog geen wetenschappelijk instrument is ontwikkeld en gevalideerd om de individuele en huishoudelijke kosten van voedselovergevoeligheid en voedselallergie te meten. Dit proefschrift beschrijft de ontwikkeling van een vragenlijst om de huishoudelijke kosten van voedselallergie te meten en de verkennende analyses om het instrument te valideren. Daarna is de "Huishoudelijke kosten van voedselallergie vragenlijst",

toegepast op een grote steekproef waarin door artsen gediagnosticeerde patiënten met een voedselovergevoeligheid, om deze effecten op de kosten te kunnen bevestigen. Deze studie was onderdeel van een grotere Europese epidemiologische studie naar de prevalentie van voedselallergie en voedselintolerantie in vier Europese landen, in Nederland, Polen, Spanje en het Verenigd Koninkrijk. De respondenten in deze studie werden gediagnosticeerd door een arts met een voedselallergie of voedselintolerantie. Voor deze discussie, wordt de term voedselovergevoeligheid gebruikt om beide ziekten aan te duiden. In tegenstelling tot de verwachting, hadden de huishoudens van respondenten met een voedselovergevoeligheid aanzienlijk lagere directe en indirecte kosten in alle landen in vergelijking met huishoudens zonder voedselovergevoelige gezinsleden. Bovendien, werd er geen verschil gevonden in subjectief welzijn tussen voedselovergevoelige respondenten en de respondenten die asymptomatisch voor voedingsmiddelen. Echter, volwassen respondenten met een voedselovergevoeligheid en hun echtgenoten rapporteerden een aanzienlijk lagere gelukbeleving dan de respondenten, of hun echtgenoten, die asymptomatisch waren voor voedingsmiddelen. De resultaten die gepresenteerd zijn in dit proefschrift ondersteunen niet de algemene overtuigingen van klinische onderzoekers en patiëntenorganisaties dat alle voedselallergieën hoge kosten tot gevolg hebben voor het individu.

Gezien het feit dat de respondenten ervaarden dat hun kwaliteit van leven negatief werd beïnvloed door voedselovergevoeligheid, is het mogelijk dat deze kan worden verbeterd door de invoering van doeltreffende strategieën van informatie voorzieningen om de ziekte te managen. Aangezien de meest doeltreffende strategie voor het managen van voedselovergevoeligheden het vermijden van problematische voedingsmiddelen is, zou het faciliteren van de keuzes van de consument in de detailhandel het risicomanagement kunnen optimaliseren. De voorkeur van allergische consumenten betreffende etikettering van voedingsmiddelen werd onderzocht in twee Europese landen, Nederland en Griekenland. Op het moment dat het onderzoek werd uitgevoerd, was een voedselwet ontwikkeld om voedselallergenen te managen in de voedselketen met als doel om mensen met een voedselallergie te beschermen, maar niet de mensen met een voedsel intolerantie. Om deze reden is het onderzoek beperkt tot het bestuderen van de behoefte aan informatie van voedselallergische patiënten, en hoe dit gerelateerd was aan de huidige regelgeving. In dit onderzoek is gebruik gemaakt van etnografische interviews met voedselallergische consumenten tijdens het winkelen in een supermarkt. De resultaten suggereren dat de huidige etikettering als onvoldoende werd ervaren om veilige voedselkeuzes te kunnen maken als voedselallergische consument. Dit is te wijten aan ongepast gebruik van lettertypen,

kleuren combinaties met weinig contrast en inconsistenties tussen de verschillende talen, de toepassing van waarschuwingen op het etiket en gebrek aan harmonisatie van Europese en Internationale regelgeving voor etikettering. Gebaseerd op deze resultaten, werden nieuwe informatie-scenario's, zoals uniforme etikettering, een informatie-boekje en ICT-toepassingen, ontwikkeld en getest door middel van een online enquête. De resultaten werden gebruikt om prototypen te ontwikkelen die de gevraagde informatie konden leveren. Waarna een experiment werd uitgevoerd om te onderzoeken of de levering van informatie daadwerkelijk optimaal was, en om te bevestigen dat de extra kenmerken van het prototypen voldoende waren om het vermijden van allergenen te faciliteren. De resultaten suggereerden dat op het etiket de percentages van de allergenen in het voedingsmiddel vermeldt dienden te worden, evenals het vermelden van specifieke details over het managen van allergenen in de voedselketen, en het gebruik van gestandaardiseerde symbolen en een gestandaardiseerde locatie voor allergie informatie op de verpakking. Extra visuele en auditieve waarschuwingen werden aangeduid als belangrijke optie mogelijkheid voor de ICT gedreven informatie leveringsmethoden. De resultaten toonden aan dat de ICT-toepassingen niet geschikt was als vervanger van effectieve etikettering van voedingsmiddelen op verpakkingen, maar wel gebruikt kan worden om aanvullende informatie te leveren naast het etiket.

Concluderend geeft dit proefschrift geeft inzicht in de financiële gevolgen van voedselovergevoeligheid, evenals de subjectieve welvaart en het welzijn van voedselovergevoelige consumenten. De "huishoudelijke kosten van voedselallergie vragenlijst vragenlijst", kan worden gebruikt door regelgevers en beleidsmakers om de middelen die beschikbaar zijn in de gezondheidszorg te prioritiseren, maar ook kan de vragenlijst gebruikt kan worden om de effectiviteit van beleid interventies te testen. Ook werden er beperkingen geïdentificeerd in het risicomanagement van de voedselallergische consument ten aanzien van de informatie voorziening in detailhandel. De resultaten van de preferentie studies kunnen ook worden gebruikt door beleidsmakers en de voedingsmiddelen industrie om de informatievoorziening voor voedselallergische consumenten te optimaliseren en daarmee de kwaliteit van leven van deze groep te verbeteren. De combinatie van economisch onderzoek en consumenten onderzoek is relevant voor de dynamische impact van voedselallergie op individuen en hun families te onderzoeken.

Acknowledgements

When I started my job as a researcher in the EU project Europrevall I did not imagine that this would results in a PhD thesis. Working in a large project like Europrevall was a real privilege. The half yearly congress trips in the nicest cities across Europe were a wonderful experience for me, as well as working together with the leading experts on food allergy research.

Engaging in scientific research and writing a thesis is not something I did alone, and I find it is a pleasure to thank those who made this thesis possible. First of all I would like to thank my supervisors. I would like to express my gratitude to Professor Lynn Frewer, my promoter, for giving me this opportunity. Your scientific insight and support were very valuable for writing this thesis. It helped me to become a better researcher. I admire your dedication and vision for science.

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I would like to give a special thanks as well to my co-promotor Dr. Judith Cornelisse-Vermaat. Despite the fact you left the project a year early your input was indispensible. Dear Judith, working with you was a great pleasure and I believe we made a good team. Without your confidence in me, words of encouragement and support along the way this thesis would not have been possible.

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The development of the 'household cost of food allergy' questionnaire and the data gathering across Europe was an immensely big job, which I did not do alone. Therefore, I would like to thank Professor Miranda Mugford and Margaret Fox for their help. As well, many thanks to my Spanish and Polish colleagues for gathering the economic data. In particular, I would like to thank Inma and Javier for their help with the preparation of the data set and the analysis.

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Although I did not have an office at the Economics of Consumers and Households group I was always very welcome there. Therefore, I would like to thank all my colleagues at this group. Annelies and Margaret, thank you for your secretarial assistance. Marleen, I enjoyed our lunch dates and coffee breaks very much. Your "west-Frisian" down-to-earthiness has put my thoughts in perspective especially in the last phase of my project.

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I want to dedicate this thesis to my grandfather. Dear Opa, I cannot express in words how important you are to me. You are like a father to me and I am proud to say you are my best friend and my true soul mate. I love you infinitely.

Jantine Voordouw

About the author

Curriculum Vitae

Jantine Voordouw was born in Zaandam on 11th of July 1980. She finished her secondary education (vwo) at the Pascal College in Zaandam in 2000, after which she started to study Human Nutrition and Health at Wageningen University. She obtained a Bachelors of Science degree in 2004 after completing a bachelor thesis on ´Review of screening methods for malnutrition in institutionalised elderly´. In the same year she started the master program of Human Nutrition and Health for which she obtained a Master of Science degree in 2005 after completing one master thesis on ´Categorisation of meat and meat substitutes by consumers´ and one thesis on ´The health effects of Salmon consumption and barriers limiting fish consumption in the Netherlands´ commissioned by Nutreco Holding NV. In addition, she completed her internship at VU University Medical Center in Amsterdam where she was involved in clinical research. She specialised her study in Disease Prevention and Dietary Behaviour and Consumer Behaviour, which illustrates her affinity with both the natural sciences and the social sciences. In September 2005 she began as junior researcher at the Marketing and Consumer Behaviour group at Wageningen University in the sixth framework EU project Europrevall. In April 2007 she started with her PhD project continuing her work within Europrevall. Within this project she had a leading role in the development of an instrument to assess the household economic cost of food allergy, and the subjective welfare and well-being of people suffering from food allergies. Furthermore, she studied the labelling preferences and preferred information strategies of food allergic consumers. The results of this research are described in this thesis. She presented her work at several national and international conferences. She followed an intensive summer school on psychology, economics, law and statistics at the International Max Planck Institute in Jena Germany. During her PhD project she also was involved in teaching activities in the Bachelor course 'Consumer and Market' and the Master course 'Statistics in Consumer Research'. She assisted students in their practical work in which they could prepare exercises to get more familiar with the theory.

List of Publications

Peer reviewed journal papers

Pfaff S., Wilson E.C.F., Frewer L.J., Mills E.N.C., Flokstra-de Blok B., **Voordouw J.**, Mugford M. (submitted). Food industry and trade implications of food allergy: a discussion of results from a European socioeconomic research programme.

Hoek A.C., Boekel M.A.J.S., **Voordouw J.**, Luning P.A. (submitted). Identification of new food alternatives: how do consumers categorise meat and meat substitutes?

Voordouw J., Antonides G., Cornelisse-Vermaat J.R., Pfaff S., Niemietz D. & Frewer L.J. (accepted subject to revision). Optimising the delivery of food allergy information. An assessment of consumer preferences for different delivery formats. *Health Communication*

Voordouw J., Cornelisse-Vermaat J.R., Pfaff S., Antonides G., Niemietz D., Linardakis M., Kehagia O. & Frewer L.J. (accepted subject to revision). Preferred information strategies for food allergic consumers. A study in Germany, Greece, and the Netherlands. *Food Quality and Preference.*

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Book chapter (non refereed)

Cornelisse-Vermaat, J.R., Fischer, A.R.H., Kleef, E. van, Rijswijk, W. van & **Voordouw, J.** (2007). Gérer les informations sur une alimentation saine aux Pays-Bas. Quels sont les rapports entre l'industrie, les pouvoirs publics et les consommateurs dans la gestion des informations et leur utilisation? In T. Beaufils (Ed.), *Boire et manger aux Pays-Bas. De la sacro-sainte pomme de terre à la purée de piment* (DESHIMA. Revue française des mondes néerlandophones, 1, 209-226). Strasbourg, France: Fr: Département d'études néerlandaises, Université Marc Bloch.

Non refereed journal papers

Voordouw, J. & Cornelisse-Vermaat, J.R. (2008). Onderzoek naar voorkeur voedselallergische consument voor etikettering. Klant wil duidelijker etiket. *Overgevoeligheden,24*(3), 4-6. and *GAAF patiëntenblad Constitutioneel Eczeem, 17*(3), 14-15.

Cornelisse-Vermaat, J.R. , Botjes, E., Frewer, L., & **Voordouw, J** (2007). The importance of accurate and understandable food allergen labelling for food-allergic consumers. AgroFood industry hi-tech. September/October 18(5), 25-27.

Voordouw, J. & Cornelisse-Vermaat, J.R. (2006). Gezond eten in Nederland: heeft etikettering van levensmiddelen een positief effect op het voedingspatroon van consumenten? *Denkwijzer, 6*(3), 12-13.

Completed Training and Supervision Plan

Jantine Voordouw
Mansholt Graduate School of Social Sciences (MG3S)

Description	Institute	Year	ECTS
Courses:			
Mansholt introductory course	MG3S	2005	1.0
Academic writing II	CENTA	2006	1.5
Techniques for writing and presenting a scientific paper	MG3S	2008	1.2
Scientific writing	CENTA	2008	1.8
Career perspectives	WGS	2009	1.6
Summer school 'Adapting behaviour in a fundamentally uncertain world', Jena, Germany	IMPRS	2007	12.0
Quantitative research methodology	MG3S	2007	4.0
Behavioural economics	MG3S	2009	0.4
Food risk analysis	MG3S	2009	3.0
Presentations at conferences and workshops:			
Mansholt multidisciplinary seminar		2007	1.0
98th EAAE conference 'Marketing dynamics within the global trading system: new perspectives', Chania, Greece		2006	1.0
Allergy Consortium Wageningen PhD day		2006	1.0
Workshop FSA and ILSI 'Approaches to risk assessment in food allergy', Madrid, Spain		2007	1.0
Seminar Sweden 'Food allergy network' Lund, Sweden		2008	1.0
EuroPrevall conferences at; Athens, Greece; Lo-skolen, Denmark; Doorwerth, The Netherlands; Madrid, Spain; Warsaw Poland; Berlin, Germany; Vienna, Austria, Prague Czech; Vienna, Switzerland; Florence, Italy		2005-09	3 .0
WEVO seminar, Deurne, the Netherlands		2006	1.0
Teaching and supervising activities:			
Advisor 'Academic Master Cluster' YAM 60312, ACW	WU	2006	1.0
Teaching assistant during practical MCB-30306 Consumer Behaviour	WU	2007- 09	1.0
Teaching assistant during practical ECH-10805 Consumer and the Market	WU	2007- 09	1.0
Total (minimum 30 ECTS*)			**38.5**

*One ECTS on average is equivalent to 28 hours of course work

Abbreviations
MG3S stand for Mansholt Graduate School of Social Sciences
CENTA stands for Languages Services Wageningen
WGS stand for Wageningen Graduate Schools
IMPRES stands for International Max Planck Research School
EAAE European Association of the Agricultural Economists
FSA stands for Food Standards Agency
ILSI stands for International Life Sciences Institute
WEVO stands for Working Group Nutrition Behaviour (in Dutch: Werkgroep Voedingsgewoonten)
WU stands for Wageningen University

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