

APPENDIX A METHODOLOGY REPORT

**QUANTITATIVE CONSUMER SURVEY ON
ALLERGEN LABELLING: BENCHMARK 2003**

REPORT ON SURVEY DESIGN

C02039

March 2003

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REPORT ON SURVEY DESIGN



Prepared by



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APPENDIX A: QUESTIONNAIRES (DOCUMENTS NOW ELSEWHERE IN APPENDICES)

APPENDIX B: FIELD DOCUMENTS (DOCUMENTS NOW ELSEWHERE IN APPENDICES)

1 BACKGROUND

1.1. Introduction

Anaphylactic reaction to allergens in food products is a serious health issue that affects around one percent of adults and less than ten percent of young children (FSANZ 2002).

Such a reaction can occur as a result of exposure to substances such as:

- Crustacea and their products;
- Egg and egg products;
- Fish and fish products;
- Milk and milk products;
- Nuts and sesame seeds and their products; and
- Peanuts and soybeans and their products.

The new *Australia New Zealand Food Standards Code* (the Code) was fully effective from 20 December 2002, and specifies three levels of advice for consumers:

- Mandatory warning statements;
- Mandatory advisory statements; and
- Mandatory declarations of certain substances in food (allergen labels are an example of this requirement) that apply when the sorts of particular ingredients defined above are present as:
 - an ingredient;
 - an ingredient of a compound ingredient;
 - a food additive or component of a food additive; or
 - a processing aid or a component of a processing aid.

The objective of the mandatory declarations, warning statements and advisory statements are to provide consumers with sufficient information such that they and / or their carers can avoid potentially life-threatening adverse reactions to food or an ingredient in food.

Many food manufacturers have been in the process of bringing their food product labels into alignment with the new Code since it was first introduced in December 2000.

Food Standards Australia New Zealand (FSANZ), through its established Evaluation Strategy 2001-03, is therefore in the process of assessing through this research, how well the regulatory arrangements of the Code are working in terms of the allergen labelling requirements (*Standard 1.2.3*).

This research with consumers is to collect baseline data against which comparisons can later be made, in charting the effects of the introduction of the labelling changes for allergens on those 'at risk' of anaphylactic reaction to foods.

Research objectives

The research aims outlined in the Request for Tender (RFT) were to:

- **Assess the level of awareness and knowledge of consumers** ‘at risk’ of an anaphylactic reaction and their carers (if relevant) of the labelling provisions that cover allergens;
- **Assess the ability** of those ‘at risk’ (if relevant) or their carers **to successfully identify those foods** that contain the pertinent allergens;
- **Understand the existing behaviours** of ‘at risk’ consumers (where relevant) or their carers in regard to food selection; and
- Identify whether a **lack of understanding of the allergen labelling** of foods contributes to the occurrence of anaphylactic reaction in those affected, and to what degree.

The evaluation described herein is the first part of what is intended to be a two-part process to measure the impact of the new labelling requirements.

This first phase is described as the **benchmark survey**. The survey is therefore referred to throughout as the Quantitative Consumer Survey on Allergen Labelling: Benchmark 2003.

It is planned to conduct a second phase of research at some time in the future to track changes in awareness, knowledge and behaviours when compared to the measures that are established by the benchmark survey based on the aims listed above.

This has an implication for the methodology selected in that it must be able to be replicated, a key requirement for ensuring reliability.

1.2. Target groups

The target groups for the proposed research were originally identified as:

- those at risk of anaphylactic reaction to certain foods or food ingredients; and
- their carers.

Food-induced anaphylactic reaction was defined in the RFT as a ‘reaction that involves one or more of the following symptoms: difficulty breathing or throat swelling, generalised urticaria (hives) and/or faintness or collapse (FSANZ 2002).

Originally, participants to be included in the research were those who have already had an anaphylactic reaction, or who have been identified as ‘at risk’ of food allergies by medical specialists, or their carers in those instances where the person is a child aged 14 or under.

However, during the development of the questionnaire, the defined target group was broadened to the following definition:

By serious food allergy we mean a reaction that involves one or more of the following symptoms due to exposure to a particular food or food ingredient:

- **difficulty breathing or throat swelling,**
- **swelling or itching of lips or tongue,**
- **hives, skin rashes or eczema,**
- **stomach cramps, vomiting or diarrhoea, or**
- **faintness or collapse**

This broader definition was adopted in order to attain a wider cross-section of participants who may be assessing food labels critically, because of concerns about the presence of allergens, so it is not canvassing a truly anaphylactic population.

It should be noted that this survey is not intended to measure the prevalence of food anaphylaxis in Australia and / or New Zealand.

The questionnaire was eventually designed to be answered by the **main grocery buyer**, as it was deemed that they would be the most knowledgeable and appropriate person in the household to answer questions about food labels and food selection.

This report details the survey design and data collection procedures for the Quantitative Consumer Survey on Allergen Labelling: Benchmark 2003.

2 SURVEY DESIGN

2.1. Overall survey design

To address the requirements of the project in the most cost-efficient and appropriate manner possible whilst maximising the participation rate, a **self-completion** methodology was designed.

The methodology adopted comprises three data collection avenues:

- Medical institutions (clinics at hospitals);
- Private specialists in private practice; and
- Support groups.

The first two of these avenues are expected to provide a more 'balanced' sample in that those who are invited to participate will be selected by allergy specialists/immunologists according to an established selection protocol. Participants attained via the allergy support groups will be self-selecting and hence are likely to have a particular interest in or concern with the topic through their own or a family member being affected.

Each of these individual collection avenues is further discussed in sections 3 and 4, however the following note is made about a significant variation to the methodology as defined in the RFT documents:

The prescribed methodology was based on getting personnel from medical clinics to administer questionnaires to patients. It was suggested by NFO Donovan Research that a more appropriate (less onerous) approach would be to pay medical institutions a nominal amount to distribute the questionnaires to selected patients. This was subsequently the methodology adopted, and that is what is described herein.

The rationale for utilising this particular methodology (over the original one) was that:

- It minimised the level of involvement, or burden, required by selected hospitals or clinics with the aim of increasing their likelihood to participate;
- It had the capacity to include a larger proportion of respondents who have been aware of their own or their child's condition for a longer period, and hence have been exposed to labelling issues for a longer period;
- It minimised the potential muddying of data by having a relatively short data collection period;
- It preserved the privacy of respondents because the research agency does not come in contact with their contact details, and responses would be truly anonymous;
- It increased the randomness of the sample by reducing potential selection bias;

- It increased the representativeness of the sample by allowing more medical institutions across Australia and NZ to be included;
- It preserved quality standards; and
- It was cost-effective in that the cost of getting the agency to mail out the questionnaires is markedly reduced compared to having hospital personnel administer it (adjusted to compensate for non-responses with the preferred method).

A note on benchmarking

Ideally benchmark data should have been obtained prior to any changes to food labelling regulations. As it is, the new Code was in the process of implementation from December 2000 to December 2002, and hence some manufacturers had made changes to their labels in line with the new Code prior to December 2002. The data collected therefore cannot be truly defined as 'benchmark', but are really a snapshot of the situation at the time of recording.

2.2. Sample size

Sample size is usually based on the level of sub-group analysis that is required. In this instance FSANZ indicated that they would not be seeking the provision of detailed sub-group analysis, and hence a total sample size of n=500 is the target. Of this total, n=400 questionnaires will be sought via 'official' sources such as medical institutions and specialists, and n=100 will be sought via support groups.

The RFT specified that the data should deliver results to a 95% confidence level. Based on the projected population of probable anaphylactics¹, a sample of n=400² will allow for variations of 10% (+/- 5%). This means that there is a 95% probability (ie. 95% confidence) that the actual population percentage will not vary by any more than 5% in either direction from that recorded by the sample.

The number to be distributed was calculated based on an estimated response rate of 50%. Mailing out n=1000 self-completion questionnaires (n=800 via official sources and n=200 via support groups), and achieving n=500 returns.

The sample distribution is shown in Tables 2.2a – 2.2f.

¹ Based on the incidence statistics provided by FSANZ in the RFT (FSANZ 2002).

² The calculation is based solely on the proportion of the sample that is attained via 'official' sources due to concerns about the representativeness of those who respond via support groups.

The calculations of sample size are based on the Australian and New Zealand population statistics shown in Table 2.2a.

Table 2.2a Population characteristics for Australia and New Zealand

		Australia	New Zealand
Population (million)	June 2000	19.2	3.8
0-14 years (%)	June 2000	20.5	22.9
15-64 years (%)	June 2000	67.2	65.3
65 years and over (%)	June 2000	12.3	11.8

Sources: Australian Demographic Statistics, June 2000 (Cat. no. 3101.0); Statistics New Zealand, Demographic Trends, 2000, Wellington.

To spread the sample required across Australia and New Zealand in the correct proportions, the total population of both countries must be considered.

Based on these population figures and the prevalence rates provided in the RFT (FSANZ 2002), the proportions for the total sample required in each of the countries are shown in the following tables.

Table 2.2b Preliminary calculations for sample proportions

PROJECTED ANAPHYLACTICS	TOTAL	Australia	New Zealand
Total population	23,000,000	19,200,000	3,800,000
0-14 years	4,770,000	3,900,000	870,000
5% of children aged 0-14 (10% of children aged up to 7)	238,500	195,000	43,500
15+ years	18,230,000	15,300,000	2,930,000
1% of those aged 15+	182,300	153,000	29,300
Estimated anaphylactic population	420,800	348,000	72,800
Proportion of population by country		83%	17%

Of the total sample (n=500), 83% needs to be derived from Australia and 17% from New Zealand, as shown in Table 2.2c.

Table 2.2c How the sample is to be divided between the two countries (proportional)

SAMPLE SOURCE	TOTAL TO BE ACHIEVED	Australia	New Zealand
% of total required	100%	83%	17%
	n	n	n
Official sources (ie medical institutions, private clinicians)	400	332	68
Support groups	100	83	17
	500	415	85

When the sample is drawn from each Country, State and Territory in the correct proportion, it is not possible to compare between locations because the sample size is insufficient. A minimum of n=100 per location is recommended for sub-group comparisons.

Therefore, in order to enable some cross-country comparisons, albeit at a decreased level of confidence, it was suggested that the sample from 'official' sources be boosted for New Zealand. This involves shifting fifteen questionnaires from Australia to New Zealand, as shown in Table 2.2d.

Table 2.2d Proposed boosted sample for New Zealand

SAMPLE SOURCE	TOTAL TO BE ACHIEVED	Australia	New Zealand
% of total required	100%	79% (adjusted)	21% (adjusted)
	n	n	n
Official sources (ie medical institutions, private clinicians)	400	332-15 =317	68+15 =83
Support groups	100	83	17
	500	400	100

As shown above, this would mean that when the official and support group samples were combined, a total of n=100 responses would be obtained from New Zealand.

To attain the specified sample, and based on an estimated response rate of 50%, the number of questionnaire packs mailed out must be doubled, and this is shown in Table 2.2e.

Table 2.2e Calculations for 'boosted' sample from official sources

	TOTAL	Total sample required	Total mail out required	To be mailed out via medical institutions	To be mailed out via private clinicians
	%	n	n	n	n
TOTAL	100%	400	800	400	400
Australia	79%	317	634	317	317
<i>New South Wales</i>	<i>28.0%</i>	<i>100</i>	<i>200</i>	<i>100</i>	<i>100</i>
<i>Victoria</i>	<i>20.6%</i>	<i>80</i>	<i>160</i>	<i>80</i>	<i>80</i>
<i>Queensland</i>	<i>15.4%</i>	<i>60</i>	<i>120</i>	<i>60</i>	<i>60</i>
<i>South Australia</i>	<i>6.5%</i>	<i>26</i>	<i>52</i>	<i>26</i>	<i>26</i>
<i>Western Australia</i>	<i>8.2%</i>	<i>33</i>	<i>66</i>	<i>33</i>	<i>33</i>
<i>Tasmania</i>	<i>2.0%</i>	<i>10</i>	<i>20</i>	<i>10</i>	<i>10</i>
<i>Northern Territory</i>	<i>0.8%</i>	<i>NA</i>	<i>NA</i>	<i>NA</i>	<i>NA</i>
<i>Australian Capital Territory</i>	<i>1.3%</i>	<i>8</i>	<i>16</i>	<i>8</i>	<i>8</i>
New Zealand	21%	83	166	83	83

It should be noted that the Northern Territory, although comprising 0.8% of the total sample, is not included in the figures, since it was not possible to locate any official organisations (or private clinicians) that were suitable to take part. Hence their allocations of questionnaires have been redistributed to Tasmania and Australian Capital Territory.

Note: The final mail out sample size for each individual recruiter depends upon the number of collection points eventually arranged in each location (Country, State or Territory).

The number of questionnaires to be obtained from support groups is shown in Table 2.2f.

Table 2.2f Calculations for proportional sample from support groups

	TOTAL	Total sample required	Total mail out via support groups
	%	n	n
TOTAL REQUIRED	100%	100	200
Australia	83%	83	166
<i>New South Wales</i>	<i>28.0%</i>	<i>28</i>	<i>56</i>
<i>Victoria</i>	<i>20.6%</i>	<i>21</i>	<i>42</i>
<i>Queensland</i>	<i>15.4%</i>	<i>15</i>	<i>30</i>
<i>South Australia</i>	<i>6.5%</i>	<i>7</i>	<i>14</i>
<i>Western Australia</i>	<i>8.2%</i>	<i>8</i>	<i>16</i>
<i>Tasmania</i>	<i>2.0%</i>	<i>2</i>	<i>4</i>
<i>Northern Territory</i>	<i>0.8%</i>	<i>NA</i>	<i>NA</i>
<i>Australian Capital Territory</i>	<i>1.3%</i>	<i>1+1</i>	<i>2+2</i>
New Zealand	17%	17	34

When the completed questionnaires are returned and the information they contain has been entered, the data will then be weighted to represent their proper proportions in the sample as shown in Table 2.2e.

Due to uncertainty about the likely response rates utilising the methods specified, it is impossible to predict the actual final sample size that will be achieved with any degree of accuracy, and hence the calculations shown in the tables are estimates only.

2.3. Validity and reliability

The issues of validity and reliability were addressed by:

- Adopting a methodology that can be replicated;
- Having a widespread number of sample collection points (allowing collection of information proportionally by state and country);
- Pre-testing the questionnaire with actual respondents meeting the survey selection criteria to ensure the issues are clearly understood; and
- Maintaining quality standards such as:
 - Controlling the questionnaire distribution process to the greatest degree that is possible under the circumstances;
 - Ensuring that the completed questionnaires are handled properly on receipt;
 - Ensuring that appropriate code frames are developed from a sound proportion of open-ended responses;
 - Ensuring that all open-ended responses are coded by an experienced coder;
 - Ensuring that questionnaire checking is conducted prior to data entry; and
 - Employing double-punch techniques to provide an accurate data file.

3 FINDING PARTICIPANTS

Because the prevalence in the general population of those at risk of an anaphylactic reaction is very small (FSANZ 2002), the more usual means of surveying (ie telephone or intercept) were not viable options for this study. Potential respondents were therefore accessed via alternative, targeted sources.

To ensure that the survey is as representative as possible, the research design incorporated many **distribution points**, attempting coverage of every State and Territory in Australia and both islands of New Zealand.

Whilst this involved a large amount of liaison and administration time, it also enabled a smaller impost on medical establishment staff, by spreading the required sample across locations.

The methodology was therefore designed to include the following distribution points in both Australia and New Zealand:

- **Major hospitals or medical institutions** in Australia and New Zealand (one adult hospital and one children's hospital in each location, where possible);
- All of those **allergy specialists or immunologists** who consent to be involved (accessed via their professional association Australasian Society of Clinical Immunology and Allergy Inc [ASCIA]); and
- The major **relevant support groups** such as Food Anaphylaxis Children's Training and Support (FACTS) and Allergy New Zealand (Allergy NZ).

3.1. Contact procedures

Different procedures were required for each of the different types of questionnaire distribution points.

Medical institutions

Initial contact was made by NFO Donovan Research to obtain information on how to make submissions to each respective hospital / regional ethics committee, and to identify the appropriate person to approach within each hospital, to support the survey at that location.

The relevant ethics applications were completed by Ms Shareen Lata at FSANZ and submitted to each committee by the established deadlines. FSANZ also addressed the follow-up queries and requests for additional information from each committee.

Private specialists

Private specialists were approached via an email that was distributed by ASCIA. The email, similar to the letter that was sent to medical institutions, explained the purpose of the survey and requested the medical specialists support for the survey.

The response received was minimal. Hence, the FSANZ project officer subsequently initiated a follow-up call and email distributed via ASCIA in an attempt to increase the participation rate.

Support groups

One large support group was located in each country to provide broad coverage in their respective countries. Only n=100 completed questionnaires in total were required from support groups and it was initially deemed unnecessary to contact more than two support groups.

NFO Donovan Research approached the support groups. For Allergy NZ, a paid advertisement was placed in their newsletter: *Allergy Today (Issue 103, Summer 2002)*. A copy of this advertisement is included in Appendix B.

For FACTS, a donation was made to the organisation for them to insert a similar advertisement in their newsletter *News Facts (December 2002)*.

Each organisation had the opportunity to review the questionnaire before the advertising was placed in their newsletter. Both organisations were very supportive of the survey, and their assistance is greatly appreciated by the Project Team.

In addition, members of the Australian Food and Grocery Council (i.e. large manufacturing firms such as Nestle, Kraft, Unilever, Cerebos, etc) volunteered to inform consumers calling for product information about the survey, and to give them the NFO Donovan free call phone number for them to request a questionnaire.

3.2. Criteria for selecting participants

Official data sources (i.e. medical institutions and private specialists)

For each of the official data collection avenues, participants (patients or clients) are to be selected by the appropriate medical specialists (hereinafter referred to as recruiter) based on selection criteria developed in consultation with the FSANZ project team and other allergy specialists.

Clients to be included are to:

- ◆ Be aged over 1 year old;
- ◆ Be 'at risk' of anaphylactic reaction to certain foods or food ingredients;
- ◆ Have been seen at the clinic in the past 2 years; and
- ◆ Comply with the definition of anaphylaxis to ensure consistency,

To ensure that a broad cross-section of food allergies are covered, recruiters are to be asked to select clients that roughly represent the proportion of each allergy typically seen at their clinic. This should reduce the likelihood of attaining participants with the most common of food allergies, such as peanut allergies.

Recruiters will be also asked to address the questionnaire pack to the parent or next-of-kin / carer where the client is aged 14 or less.

A copy of the detailed selection criteria (Questionnaire Pack Instructions) is included in Appendix B.

Support groups

The use of advertisements in the support group magazines yielded fewer responses than expected, with a total of 75 calls received (53 from Australia and 22 from NZ). It is assumed that the NZ calls derived from Allergy NZ members and the Australian calls derived from FACTS members.

To supplement the numbers attained via the advertisements in the support group publications, the editor of News Facts (Australia) was asked to select an additional n=116 members at random. They were sent the requisite number of questionnaires to be distributed to each State and Territory and asked to mail the pre-paid questionnaires.

The additional numbers required from each State were:

<i>New South Wales</i>	<i>24</i>
<i>Victoria</i>	<i>35</i>
<i>Queensland</i>	<i>24</i>
<i>South Australia</i>	<i>12</i>
<i>Western Australia</i>	<i>15</i>
<i>Tasmania</i>	<i>5</i>
<i>Australian Capital Territory</i>	<i>1</i>

For the New Zealand sample an additional n=14 were required. Some of the potential support group participants who had phoned and left their contact number were called and asked to distribute one extra questionnaire to an eligible friend or acquaintance, where possible.

Randomising is a technique to ensure representativeness, however since the sampling method for the support group sample was self-selecting anyway (people called the helpline in response to an ad), it was not deemed essential to specify a randomising procedure to attain the remainder. It was not possible to make this sample representative, because the nature of the membership of the support groups (ie whether actually at risk of anaphylaxis) is not known.

Note that the support group sample will be analysed separately from that achieved via medical institutions.

4 DATA COLLECTION PROCEDURE

Each medical establishment or private specialist will be paid a set fee (\$10) per questionnaire distributed, for:

- selecting the names of potential respondents from their patient lists,
- mailing them a questionnaire, and then
- mailing them a reminder card two weeks later.

The number of questionnaires to be mailed out by each organisation will be determined by the number of organisations who agree to participate and the size of the target population for each location (State or Territory in Australia³).

For the two support groups, a payment was made for the insertion of an advertisement into their respective newsletters asking for participants to call a FREECALL 1800 number (in Australia) or FREECALL 0800 (in New Zealand). NFO Donovan Research will then send them a questionnaire pack. All contact details will be destroyed once the questionnaire is despatched, in accordance with the project's ethics in human research requirements (NHMRC, 2002).

4.1. Distribution of questionnaires

Once the number of collection points and the sample mail out required from each have been decided, the contact person at each distribution point will be sent a *distribution point kit* that contains:

- A **step-by-step checklist** for how to do what is required (including how to select potential respondents using the definition detailed herein);
- The required number of sealed **questionnaire packs** (plus one unsealed for their records);
- Blank postage-paid **reminder cards** for each questionnaire mailed out (the contact person is advised to address these at the same time as the questionnaire, but to mail them out two weeks later); and
- A **reply-paid notification card** for use when the recruiter has completed mailing out their quota of questionnaires. This notification card serves as a trigger to generate the payment of \$AUD/NZD10 per questionnaire, once they have completed each of the steps requested.

³ *The New Zealand sample was approached as one unit, because of its small sample size overall and the limited availability of appropriate hospitals and medical specialists.*

Each *questionnaire pack* will comprise a pre-stamped, sealed envelope that contains:

- The questionnaire;
- A reply-paid envelope addressed to NFO Donovan Research;
- A letter from FSANZ explaining that the packages were sent out blind (ie that the patient's contact details were not released to us) and encouraging them to participate.
- Two parental consent forms, one for retention by the participant and the other to be returned with the questionnaire by those aged 15 to 18 years old who are main grocery buyers.

All questionnaires are numbered and NFO Donovan Research holds a record of the range of questionnaire numbers that are sent to each participating organisation. This provides an audit mechanism as a form of quality control. The reader is reminded however, that for this aspect of the survey, the researchers cannot at any point identify individual participants and hence this process provides only limited control.

4.2. Delivery of distribution packs

The distribution packs are to be sent by express post or air courier to the nominated contact person or recruiter at each distribution point.

4.3. Data collection period

Whilst at the inception of this project we sought to shorten the data collection period to a single exercise to enable as much data as possible to be collected prior to 20 December 2002, as the project progressed it became exceedingly difficult to meet this proposed deadline, due to the delays in getting the necessary approvals from the relevant ethics bodies. This will need to be taken into account for any follow-up survey.

The length of time taken by some agencies in approving the ethics submissions meant that the mail-outs to recruiters were staggered, with materials being sent to each institution as their ethics approvals were advised. This process commenced in mid-March 2003.

Although a 6-week in-field period was originally allocated it is anticipated that overall, this will not be sufficient, due to the staggered mail-outs. Each progressive mail-out will therefore need to have a notification attached that advises of any extension to the deadline. The total data collection period required is therefore not known at the time this report was prepared.

Recruiters are instructed to mail out the reminder cards 2 weeks after the questionnaires are mailed.

4.4. Support services for participants

FREECALL helpline

In order to provide some assistance to participants, the questionnaire contains details of a FREECALL number that can be used in Australia - 1800 688 122 and 0800 230 012 in New Zealand.

NO translation services are available for those from a Culturally and Linguistically Diverse (CALD) background. CALD groups require specific provisions for their inclusion in such a survey and this was not defined in the RFT. However, there are instructions on the front of the questionnaire to the effect that participants can seek the help of their family or friends to complete the survey.

New Zealand

A Maori contact person was provided by NFO Donovan Research in New Zealand to deal with particular inquiries. Contact with this person will be facilitated through a call to the 0800 number provided.

FSANZ contact details

The name, contact number and email address for the relevant FSANZ project officer was also provided to provide an additional access point for any queries about the validity or authenticity of the survey, or to request further information about the survey and subsequently, its findings.

5 ETHICS APPROVALS

This project was somewhat unusual in that it required approvals from several hospital or regional ethics committees, as it involved a health issue, food anaphylaxis and required the cooperation of staff (medical specialists or recruiters) based within medical institutions. Accordingly, the questionnaire and research parameters had to be approved by every institution involved.

The Commonwealth Department of Health and Ageing Ethics Committee initially approved the survey. Once approval was obtained from the Commonwealth Ethics Committee, submissions were made to individual hospital and regional ethics committees.

This clearance process took a considerable amount of time and ultimately resulted in a delay in the start date.

5.1. Ethics applications submitted

Institutions from which approvals were required are shown in the Table following.

AUSTRALIA:
1. Department of Health and Ageing Ethics Committee
New South Wales
2. <i>Central Sydney Area Health Service Ethics Review Committee (The Royal Prince Alfred Hospital)</i>
3. <i>The Children's Hospital at Westmead Ethics Committee (The Children's Hospital at Westmead)</i>
Victoria
4. <i>Royal Children's Hospital Campus Ethic in Human Research Committee (The Royal Children's Hospital)</i>
Queensland
5. <i>Royal Children's Hospital and Health Service District Ethics Committee (The Royal Children's Hospital)</i>
South Australia
6. <i>Flinders Clinical Research Ethics Committee (Flinders Medical Centre)</i>
7. <i>Women and Children's Hospital Research Ethics Committee (The Women and Children's Hospital)</i>
Western Australia
8. <i>Princess Margaret Hospital Ethics Committee (Princess Margaret Hospital)</i>
9. <i>Sir Charles Gairdner Human Research Ethics Committee (Sir Charles Gairdner Hospital)</i>

Tasmania

10. *Southern Tasmanian Health and Medical Research Ethics Committee (The Royal Hobart Hospital)*

Australian Capital Territory

11. *ACT Health and Community Care Human Research Ethics Committee (The Canberra Hospital)*

No medical establishment that treats allergies could be located in the Northern Territory and hence it is not included in the research. However, Northern Territory respondents may be picked up via newsletters in the support group sample or in the institutional sample where they may have attended a clinic in another State.

NEW ZEALAND:

12. *Auckland Ethics Committee (Auckland Hospital and Starship Children's Hospital)*

13. *Canterbury Ethics Committee (Christchurch Hospital)*

14. *Auckland District Health Board Maori Research Review Committee and Te Committee Whakarite*

Only four hospitals in NZ were identified as offering allergy or immunology services in NZ. However, only 3 New Zealand hospitals were recruited as the fourth hospital, Wellington Hospital did not have an Immunologist/Allergist at the time of this survey.

5.2. Clinician support for the ethics applications

Prior to submitting applications for ethics approvals, it was necessary for the Project team to identify specialist clinicians within each medical establishment and seek their support for the project. This was largely undertaken by NFO Donovan Research in the first instance, and was taken over by FSANZ in the latter stages.

The Project Research Team would particularly like to express thanks to the supporting clinicians in each of the medical institutions, without whose support the study could never have been completed.

6 PRIVACY ISSUES

In accordance with the *Privacy Act 1988 (Australia)* and the *Privacy Act 1993 (New Zealand)*, the survey methodology that was adopted was designed to ensure the privacy of all participants.

Although from the outset it was intended that the survey be repeated at some future time, it was not deemed imperative that the same participants be included in any follow-up research. It was therefore not necessary to develop procedures to facilitate longitudinal surveying.

Accordingly, institutions and private clinicians who participate are not required to keep the contact details of those who are surveyed. Any future survey will therefore need to be undertaken with fresh participants.

6.1. Distribution points

Strategies to preserve the privacy of participants were devised for each avenue. Each is discussed in turn:

- **Medical institutions**
Initial distribution points were largely identified using publicly available information, and hence there are no specific requirements in terms of the Privacy Principles in relation to the organisation.
- **Private specialists**
The specialists who were included were first contacted via ASCIA and given the opportunity to have their clients (patients) participate.
- **Support groups**
Initial distribution points were largely identified using publicly available information, and hence there are no specific requirements in terms of the Privacy Principles in relation to the organisation.

6.2. Participants who are patients

Of most pressing concern for official sources was the issue of **patient privacy and the preservation of doctor – patient confidentiality**, as patients are understandably sensitive about the release of their medical details to third parties.

The methodology described herein was designed to minimise any concerns in this regard. Patient confidentiality is preserved because no individual person's details are passed to NFO Donovan Research by the nominating organisation⁴.

⁴ *The one exception to this is when a mailed-out package may be returned to NFO Donovan Research (return to sender) due to incorrect address details, in which case the personal details are incorrect and hence not subject to any special provisions. In this case, the address label will be destroyed on receipt or shortly thereafter, and no record made of the name or other details.*

6.3. All participants

In accordance with the relevant Privacy Acts and Principles, the letter to be contained in the questionnaire pack to participants included statements to the effect that:

- Their participation is voluntary;
- Their personal details have not been passed on from the medical agency to the research company (patients only);
- Any information collected for the survey will be used for research purposes only;
- Their responses will be anonymous; and
- There are clearly stated mechanisms for complaints.

Copies of the field stationery are included in Appendix B.

7 THE QUESTIONNAIRE

7.1. Development

The questionnaire was developed primarily NFO Donovan Research, in consultation with the FSANZ Project Team.

NFO Donovan Research had retained two specialist consultants (Ms Vicki Dalton, who is a dietitian specialising in paediatric allergens, employed at the Royal Children's Hospital in Melbourne, and Ms Judith Myers, a dietetic allergen specialist at the Royal Children's Hospital in Melbourne) for the purpose of assisting with the process of questionnaire design and analysis and interpretation of the results.

7.2. Pre-testing of instrument

Once the questionnaire had been developed to a suitably advanced stage it was tested initially by individual researchers unconnected to the project and then in a group situation with either those with serious food allergy (in accordance with the definition provided earlier) or parents of children with such an allergy.

7.2.1. Procedure

The pre-test was conducted at the offices of NFO Donovan Research in Perth (Australia) amongst one focus group of seven potential respondents. Participants were recruited by word of mouth networking amongst the friends of staff and snowballing to their friends. All potential respondents were asked to volunteer themselves for inclusion if they were interested in taking part. Thus all participants were aware of the voluntary nature of the research.

Each participant was posted a package containing the materials that would be sent in the final mailout to consumers (i.e. questionnaire, information letter, two copies of the consent form). They were requested to complete the questionnaire and then bring it along to the discussion.

Participants were paid \$40 for their time and input.

7.2.2. Outcome

The focus group was well attended and yielded useful information to further refine the questionnaire.

Overall there were no major problems, with most participants indicating that the questionnaire was comprehensive and easy to complete.

The main area of concern was the misinterpretation of the meaning of the word 'diagnosis'. Some participants took it to mean a formal medical opinion whereas others thought of it more generally as an issue of identification. This caused *some* to give different answers than they would have if they had adopted the other meaning.

There were several areas of confusion:

- The limited pre-codes available for adults whose allergies were discovered by parents;
- Participants from households where they were one of multiple sufferers had difficulty in knowing from whose perspective they were answering at each point; and
- Participants from households where they were the only sufferer found it confusing where the questionnaire asked for all the allergies in the household (some answered correctly and some did not).

The problems identified above were remedied by:

- Substituting the word 'diagnosis' for more general terms such as when the allergy was first discovered or identified;

Q9	How was the food allergy first identified for the <u>person with the most serious food allergy</u>? PLEASE TICK <u>ALL THAT APPLY</u>.	
	Had a reaction	<input type="checkbox"/> 1
	From parent (s)	<input type="checkbox"/> 2
	From an alternative health practitioner (eg Naturopath)	<input type="checkbox"/> 3
	Worked it out for self.....	<input type="checkbox"/> 4
	Others (PLEASE WRITE IN).....	
	
	Don't know / can't recall	<input type="checkbox"/> 9

- Or alternatively, using a more explicit term 'formal medical diagnosis' to indicate which particular circumstance was intended;

Q11a	Has a formal medical diagnosis been made for the <u>person with the most serious food allergy</u> at any time? PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO THE NEXT QUESTION.	
	Yes.....	<input type="checkbox"/>
	No.....	<input type="checkbox"/> 2

- Adding suitable pre-codes for adults who have had the allergy since childhood;
- Changing the order of the questions at the start of the questionnaire so that all food allergies in the household was asked first, followed by the most serious food allergies. This allows the respondent to be focussed on the person with the most serious allergies throughout the remaining questions (until directed otherwise);
- Using additional text instructions.

- An additional problem was that where the questionnaire sought to measure the effectiveness of the statements 'may contain traces of nuts' (Q28a) and 'made in the same premises as products containing nuts' (Q29a), some conceptual difficulty was experienced in that some seemed to answer from their own perspective rather than from that of a person with a nut allergy, as requested.

This was addressed by making the wording more general:

Q28a Now consider the statement 'made in the same premises as products containing ...'? In your opinion, how useful would this statement be to you if you had an allergy to the particular ingredient listed? Would you say ...? PLEASE TICK ONE BOX ONLY.

Not very useful because it doesn't say whether the ingredient I am allergic to is definitely in the product or not ₁

Quite useful because it reminds me I may be eating a product containing the ingredient I am allergic to..... ₂

Very useful because I am told that there is a chance that the ingredient I am allergic to is present..... ₃

Not sure / don't know ₉

Although no one expressed any particular difficulty with the labelling exercise (Q30), on examination of the completed questionnaires it was later discovered that one or two had not circled the problem ingredient as they were instructed. It was therefore decided to reword the instructions and rearrange the layout, as shown below, in an attempt to make it easier to follow.

Q30 For this question we would like you to examine each of the labels in turn and do two things:

1 ↓

Circle any ingredients that you think might be unsuitable for any person(s) in your household with an allergy. Even if you don't circle any ingredient, please answer part 2.

2 ↓

Indicate your assessment of the product.

LABEL 1: BREAD

INGREDIENTS

UNBLEACHED BAKER'S FLOUR, YEAST, SALT, VEGETABLE OILS, SOYA FLOUR, EMULSIFIERS (481, 472e), PRESERVATIVE (282), VITAMIN (THIAMIN), WATER ADDED. NO ARTIFICIAL FLAVOURS.

→

(40)

I would avoid this product ₁

This product is suitable..... ₂

Don't know..... ₉

Two questionnaires are used, one for Australia and one for New Zealand. There is very little variation between the two. Different demographic information is collected for each country (location, ethnic origin, and education levels). In the New Zealand questionnaire there is also an additional statement added at Q16 relating to the Manufactured Food Database.

Copies of the questionnaires (Australian and New Zealand versions) are included in Appendix A.

8 FIELD DOCUMENTATION

Various letters and documents had to be devised for the conduct of the survey:

- ◆ A letter to medical institutions requesting their support for the survey;
- ◆ A letter to private specialists asking them to participate;
- ◆ Sampling instructions (instructions for medical institutions and private specialists on how to select participants and manage the paperwork involved);
- ◆ A letter to participants (the 'Survey Information Sheet');
- ◆ A parental consent form (for where the person answering was the person with an allergy, and aged under 18 but over 14); and
- ◆ Reminder cards.

Copies of each of these are included in Appendix B.

9 REFERENCES AND BACKGROUND INFORMATION

Food Standards Australia New Zealand. 2002, Request for Tender 2002/4: Quantitative Consumer Research on Allergen Labelling, [online]. Available: http://www.foodstandards.gov.au/srcfiles/RFT_Allergy_labelling.pdf. [2002, June 10].

National Health and Medical Research. 2002. 'Human Research Ethic Handbook', AusInfo, Canberra.

Although not referred to explicitly in the text, the following paper also assisted in informing the research design:

Preeti J, Modifi S & Sicherer S. 2002, 'Interpretation of commercial food ingredient labels by parents of food-allergic children', *Journal of Allergy Clinical Immunology*, vol 108, no 8; pp. 1019-1021.

APPENDIX B

- 1. NEW ZEALAND QUESTIONNAIRE**
- 2. NEW ZEALAND INFORMATION LETTER**
- 3. NEW ZEALAND CONSENT FORM**

2003

Benchmark Food Allergen Labelling Survey

for



FOOD STANDARDS
Australia New Zealand
Te Mana Kounga Kai – Ahitereiria me Aotearoa

Welcome to the FSANZ Benchmark Food Allergen Labelling Survey 2003

Food Standards Australia New Zealand (FSANZ) has asked NFO Donovan Research to conduct a survey on its behalf into issues relating to food labelling for people with allergies to certain foods or ingredients. You have been selected for inclusion in the survey because either you or someone else in your family (*whanau*) has a food allergy.

The survey is mainly about how helpful you find the labelling information that is provided on packaged food and drink products for making suitable food choices. It is not a test of your product knowledge but of how well the food labelling works.

Your responses are very important as they will help FSANZ further improve food standards in New Zealand and Australia.

WHO SHOULD COMPLETE THE SURVEY?

The main grocery buyer for the household should complete the survey.

WHAT IF I NEED HELP?

Friends (*hoa*) or family members (*whanau*) can help you complete the form, or you can ring this Free Call number: **0800 230 012** (New Zealand).

WHO SHOULD I TALK TO FOR MORE INFORMATION ABOUT THE SURVEY?

You can contact FSANZ by phone on 04-473 9942 (reception) or email shareen.lata@foodstandards.gov.au.

WHERE CAN I MAKE A COMPLAINT IF I AM NOT HAPPY ABOUT THE SURVEY?

If you have any queries or concerns regarding your rights as a participant in this survey, you may wish to contact a Health and Disability Advocate on 0800 555 050 (Northland to Franklin) or 0800 377 766 (South Island) or 377 7501 (Christchurch). For Auckland District Health Board Maori Health Support, please contact Mata Forbes (Coordinator / Advisor-Maori Health Services) on (09) 307 4949 extn 7292. Please quote project number AKX/02/00/348.

This study has received ethical approval from the Auckland Ethics Committee on behalf of the Canterbury Ethics Committee.

ARE MY ANSWERS CONFIDENTIAL?

This survey has been designed in line with the privacy laws of New Zealand and Australia. The completed questionnaires will remain anonymous. Any information you provide to us will be used for research purposes only.

Note: you may have received this questionnaire from several different sources. If you have, we ask that you complete only one questionnaire.

Please read all the questions carefully and follow the instructions after each question. The instructions are in bold.

Where you see this symbol, there is very important information on whether or not you need to answer certain questions. Please read the information and follow the instructions.



Your contribution to this survey is valuable. Please answer the questions and send back your completed form to us in the reply paid envelope by 30 May, 2003. You do not need a postage stamp.

IF YOU HAVE RECEIVED THIS QUESTIONNAIRE AND ARE NOT THE MAIN GROCERY BUYER, PLEASE GIVE THIS QUESTIONNAIRE TO THE PERSON(S) WHO MAINLY OR JOINTLY DOES THE FOOD SHOPPING FOR YOUR HOUSEHOLD.

SECTION A
Background

OFFICE USE
WAVE 1(1)
Country 1(2)
QNA (3-6)
(8-11)

Q1 Please tick any of the following statements that are true. YOU MAY NEED TO TICK MORE THAN ONE BOX.

- I am the main grocery buyer ₁
- I am jointly responsible for grocery purchases ₂
- I have a serious food allergy ₃
- I am the person to whom the envelope was addressed ₄

Q2 How many people in total in your household have a serious food allergy *? (12-13)

WRITE IN NUMBER OF PEOPLE.



***By serious food allergy we mean a reaction that involves one or more of the following symptoms due to exposure to a particular food or food ingredient (allergens):**

- difficulty breathing or throat swelling,
- swelling or itching of lips or tongue,
- hives, skin rashes or eczema,
- stomach cramps, vomiting or diarrhoea, or
- faintness or collapse

IF ONLY ONE PERSON IN YOUR HOUSEHOLD HAS A SERIOUS FOOD ALLERGY OF THE TYPE DESCRIBED, PLEASE GO TO Q5.

Q3 If there is more than one person with a food allergy in your household, please indicate all the food allergies for all members of the household. (14-37)

PLEASE TICK AS MANY BOXES AS APPLY OR WRITE IN THE SPACE PROVIDED.

- | | |
|--|---|
| Peanut (groundnuts) <input type="checkbox"/> ₀₁ | Tree nuts (eg cashews, walnuts)..... <input type="checkbox"/> ₀₆ |
| Milk <input type="checkbox"/> ₀₂ | Fish <input type="checkbox"/> ₀₇ |
| Soy <input type="checkbox"/> ₀₃ | Shellfish..... <input type="checkbox"/> ₀₈ |
| Wheat..... <input type="checkbox"/> ₀₄ | Sulphites (food additives 220-225, 228) .. <input type="checkbox"/> ₀₉ |
| Egg..... <input type="checkbox"/> ₀₅ | Sesame Seeds <input type="checkbox"/> ₁₀ |
| Other (PLEASE WRITE IN) _____ | _____ |

Q4 What food allergy/allergies, if any, could result in a potentially life threatening reaction to any person in your household with a food allergy?

PLEASE TICK AS MANY BOXES AS APPLY OR WRITE IN THE SPACE PROVIDED.

(38-61)

- | | |
|--|---|
| Peanut (groundnuts) <input type="checkbox"/> ₀₁ | Tree nuts (eg cashews, walnuts)..... <input type="checkbox"/> ₀₆ |
| Milk <input type="checkbox"/> ₀₂ | Fish <input type="checkbox"/> ₀₇ |
| Soy <input type="checkbox"/> ₀₃ | Shellfish..... <input type="checkbox"/> ₀₈ |
| Wheat..... <input type="checkbox"/> ₀₄ | Sulphites (food additives 220-225, 228) .. <input type="checkbox"/> ₀₉ |
| Egg..... <input type="checkbox"/> ₀₅ | Sesame Seeds <input type="checkbox"/> ₁₀ |
| Other (PLEASE WRITE IN) _____ | _____ |

WE WOULD NOW LIKE YOU TO THINK ABOUT THE PERSON IN YOUR HOUSEHOLD WHO HAS THE MOST SERIOUS ALLERGY TO A SPECIFIC FOOD(S) OR FOOD INGREDIENT(S) AS YOU COMPLETE THESE QUESTIONS.

Q5 The person with the most serious food allergy is ... **PLEASE TICK ONE BOX ONLY.** (62)

IF MORE THAN ONE PERSON IN HOUSEHOLD HAS A SERIOUS FOOD ALLERGY, PLEASE SELECT ONE PERSON ONLY WHEN

- Me ₁
- My partner ₂
- My child (for example biological-, foster-, step-, etc) ₃
- My parent (for example mum, dad, step-, foster-, etc) ₄
- My grandchild (for example biological-, foster-, step-, etc) ... ₅
- Other (PLEASE WRITE IN) _____

Q6 What is the sex of the person with the most serious food allergy? **PLEASE TICK ONE BOX ONLY.**

- Male ₁
- (63)
- Female..... ₂

Q7 What is the age of the person with the most serious food allergy? **PLEASE TICK ONE BOX ONLY.**

- Under age 3 years ₁
- 3-5 years ₂
- (64)
- 6-12 years..... ₃
- 13-17 years ₄
- 18 – 24 years..... ₅
- 25 years or more ₆

Q8 What sort(s) of food allergy does the person with the most serious food allergy have? **PLEASE TICK ALL THAT APPLY.**

- Peanuts (groundnuts) ₀₁
- Milk ₀₂
- Soy ₀₃
- Wheat..... ₀₄
- Egg (eg raw or cooked egg white or yolk)..... ₀₅
- Tree nuts (eg cashews, walnuts) ₀₆
- Fish ₀₇
- Shellfish ₀₈
- Sulphites (food additives 220-225, 228)..... ₀₉
- Sesame seeds ₁₀

OFFICE USE
RPT (1-6)
CARD 2 (7)

Other (PLEASE WRITE IN) _____ (8-31)

Q9 How was the food allergy first identified for the person with the most serious food allergy? **PLEASE TICK ALL THAT APPLY.**

- Had a reaction ₁
- (32-37)
- From parent (s) ₂
- From an alternative health practitioner (eg Naturopath) ₃
- Worked it out for self ₄
- Other (PLEASE WRITE IN) _____

Don't know / can't recall..... 

Q10 Approximately how long ago was the food allergy first identified for the person with the most serious food allergy?
PLEASE TICK ONE BOX ONLY.

- Less than 6 months ago ₁
..... (38)
- More than 6 months but less than a year ago ₂
- More than a year but less than two years ago..... ₃
- More than two years ago ₄
- Can't remember ₉

Q11a Has a formal medical diagnosis been made for the person with the most serious food allergy at any time?
PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO THE NEXT QUESTION.

- Yes..... ₁ → **GO TO Q11b** (39)
- No..... ₂ → **GO TO Q12**

Q11b Who made the formal diagnosis for the person with the most serious food allergy?
PLEASE TICK ALL BOXES THAT APPLY.

- A GP / doctor / medical practitioner ₁
..... (40-43)
- A doctor specialising in allergies ₂
- A dietitian ₃
- An alternative health practitioner (eg Naturopath) ₄
- Other (PLEASE WRITE IN) _____

- Don't know / can't recall..... ₉

Q11c How was the formal diagnosis made for that person?
PLEASE TICK ALL BOXES THAT APPLY.

- Skin prick test ₁
..... (44-47)
- RAST (Blood test)..... ₂
- Elimination diet..... ₃
- Other (PLEASE WRITE IN) _____

- Don't know / can't recall..... ₉

EVERYONE ANSWER

Q12 Has the person with the most serious food allergy become less allergic since the formal diagnosis?
PLEASE TICK ANY BOXES THAT APPLY.

- Reactions are less severe to all food items ₁
..... (48-53)
- Reactions are less severe to some food items ₂
- Reactions are less frequent to all food items..... ₃
- Reactions are less frequent to some food items ₄
- Is no longer allergic at all ₅
- No, is still allergic..... ₆
- Don't know / haven't tried or tested ₉

Q13a Has the person with the most serious food allergy had a severe allergic reaction since the allergy was identified?

PLEASE TICK ONE BOX AND FOLLOW DIRECTION TO THE NEXT QUESTION.

- Yes..... ₁ → **GO TO Q13b** (54)
- No..... ₂ → **GO TO Q14**

Don't know / can't recall.....  **GO TO Q14**

Q13b If yes, can you please describe the circumstances in which this happened?
PLEASE WRITE IN.

(55-62)

SECTION B
 Managing the allergy

Q14 Which of the following words tell you that the ingredients that the person with the most serious food allergy needs to avoid, may be present in the food product?
PLEASE TICK ALL THE BOXES THAT APPLY.

(63-80)

Whey <input type="checkbox"/> ₀₁	Casein <input type="checkbox"/> ₁₀	Thickener <input type="checkbox"/> ₁₉
Tofu <input type="checkbox"/> ₀₂	Albumin <input type="checkbox"/> ₁₁	Textured vegetable protein <input type="checkbox"/> ₂₀
Couscous <input type="checkbox"/> ₀₃	Lactose <input type="checkbox"/> ₁₂	Tempeh <input type="checkbox"/> ₂₁
Ovalbumin <input type="checkbox"/> ₀₄	Lecithin <input type="checkbox"/> ₁₃	Starch <input type="checkbox"/> ₂₂
Tamari <input type="checkbox"/> ₀₅	Cornflour <input type="checkbox"/> ₁₄	Butterfat <input type="checkbox"/> ₂₃
Maltodextrin <input type="checkbox"/> ₀₆	Semolina <input type="checkbox"/> ₁₅	Anchovies <input type="checkbox"/> ₂₄
Praline <input type="checkbox"/> ₀₇	Tahini <input type="checkbox"/> ₁₆	Surimi <input type="checkbox"/> ₂₅
Baker's flour <input type="checkbox"/> ₀₈	Icing sugar mix <input type="checkbox"/> ₁₇	Marzipan <input type="checkbox"/> ₂₆
Vegetable oil <input type="checkbox"/> ₀₉	Lactalbumin <input type="checkbox"/> ₁₈	Polenta <input type="checkbox"/> ₂₇
Other (PLEASE WRITE IN) _____	_____	_____



WE'D NOW LIKE YOU TO CONSIDER YOUR WHOLE HOUSEHOLD IN ANSWERING THE REMAINING QUESTIONS.

Q15 Considering all the members of your household who have food allergies, as far as you know, how would each person(s) in your household with food allergy/allergies approach eating foods with the following ingredient(s)?

OFFICE USE

RPT (1-6)

CARD 4 (7)

PLEASE TICK ONE BOX FOR EACH OF THE PROBLEM INGREDIENTS FOR YOUR HOUSEHOLD.

	They try, but can't avoid it completely	They never eat it knowingly	They never eat it at all	Don't know	
Peanuts (groundnuts)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(8)
Milk	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(9)
Soy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(10)
Wheat	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(11)
Egg	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(12)
Tree nuts (eg cashews, walnuts)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(13)
Fish	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(14)
Shellfish	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(15)
Sulphites (food additives 220-225, 228)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(16)
Sesame seeds	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(17)
Other (PLEASE WRITE IN) _____	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(18)
_____	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(19)

Q16 As the person who mainly buys the groceries, how often do you do the following things to help manage the food allergy/allergies of all the persons in your household?

PLEASE TICK ONE BOX FOR EACH STATEMENT.

	Always	Often	Occasionally	Never	Don't know	
Buy unprocessed foods where possible.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(20)
Buy foods in sealed packages where possible	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(21)
Read food labels carefully.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(22)
Contact the food manufacturer about what's in a food	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(23)
Buy loose or bulk foods.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(24)
Check food lists provided by allergy support group(s).....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(25)
Buy same brand of product (s) known from past experience to be allergy free	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(26)
Check food lists provided by the Manufactured Food Database.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(27)

Q17a Are there any broad product categories (eg dairy foods, bread, etc) for which you particularly need to read labels because the majority of them are likely to cause problems for the person(s) with the allergy/allergies?

PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO THE NEXT APPLICABLE QUESTION.

(28)

- Yes, I have to check some product categories..... ₁ → **GO TO Q17b**
- No, I have to check all product categories
- Don't know / can't recall / not applicable..... ₉ → **GO TO Q18**

Q17b If yes, please tick which of the following broad product categories you check for that reason.

TICK ALL BOXES THAT APPLY.

(29-78)

Dairy products	<input type="checkbox"/> ₀₁	Canned foods	<input type="checkbox"/> ₁₄	Breakfast cereals	<input type="checkbox"/> ₂₆
Vegetable oils	<input type="checkbox"/> ₀₂	Breads	<input type="checkbox"/> ₁₅	Pasta	<input type="checkbox"/> ₂₇
Margarines	<input type="checkbox"/> ₀₃	Mayonnaises	<input type="checkbox"/> ₁₆	Noodles.....	<input type="checkbox"/> ₂₈
Butter / dairy spreads	<input type="checkbox"/> ₀₄	Frozen foods	<input type="checkbox"/> ₁₇	Rice	<input type="checkbox"/> ₂₉
Cordials	<input type="checkbox"/> ₀₅	Spreads	<input type="checkbox"/> ₁₈	Sweet biscuits.....	<input type="checkbox"/> ₃₀
Soft drinks	<input type="checkbox"/> ₀₆	Fruit juices.....	<input type="checkbox"/> ₁₉	Confectionery.....	<input type="checkbox"/> ₃₁
Savoury biscuits/crackers ...	<input type="checkbox"/> ₀₇	Savoury snack foods	<input type="checkbox"/> ₂₀	Infant formula.....	<input type="checkbox"/> ₃₂
Baby foods	<input type="checkbox"/> ₀₈	Soups	<input type="checkbox"/> ₂₁	Pre-prepared meals.....	<input type="checkbox"/> ₃₃
Smoked / cured meats	<input type="checkbox"/> ₀₉	Cakes/ muffins/ pastries ..	<input type="checkbox"/> ₂₂	Chocolates	<input type="checkbox"/> ₃₄
Sauces (eg chilli, BBQ, Worcestershire).....	<input type="checkbox"/> ₁₀	Muesli	<input type="checkbox"/> ₂₃	Cook / simmer / pasta sauces	<input type="checkbox"/> ₃₅
Sausages	<input type="checkbox"/> ₁₁	Fish and fish products.....	<input type="checkbox"/> ₂₄	Eggs and egg products	<input type="checkbox"/> ₃₆
Alcoholic drinks	<input type="checkbox"/> ₁₂	Ice cream	<input type="checkbox"/> ₂₅	Desserts.....	<input type="checkbox"/> ₃₇
Dried fruit	<input type="checkbox"/> ₁₃	Other(PLEASE WRITE IN)			

SECTION C
Knowledge and information



WE'D LIKE YOU TO NOW THINK ABOUT WHEN A SERIOUS FOOD ALLERGY FIRST BECAME AN ISSUE IN YOUR HOUSEHOLD.

Q18 When a serious food allergy first became an issue in your household, where did you get the relevant information about what food(s) and food ingredient(s) needed to be avoided? PLEASE TICK ALL BOXES THAT APPLY.

- From a GP / doctor / medical practitioner..... ₀₁ (8-27)
- From a doctor specialising in allergies ₀₂
- From a dietitian ₀₃
- From parent(s) ₀₄
- From an allergy support group ₀₅
- From an alternative health practitioner (ie like a naturopath, iridologist, etc) ₀₆
- From book(s)..... ₀₇
- From the web / Internet ₀₈
- From a friend / acquaintance ₀₉
- From the Manufactured Food Database..... ₁₀
- Other (PLEASE WRITE IN) _____
- _____
- _____
- _____
- Don't know / can't recall..... ₉₉

Q19a When a serious food allergy was first identified, was it easy or difficult to get the information you needed to help you avoid the foods of concern?

PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO NEXT APPLICABLE QUESTION. (28)

- It was easy to find out what foods needed to be avoided ₁ → GO TO Q19b
- It was difficult to find out what foods needed to be avoided ₂ → GO TO Q19b
- Don't know / can't recall ₉ → GO TO Q20a

Q19b What made it easy / difficult? PLEASE WRITE IN.

(29-36)

Q20a Were you shown at any time how to identify the ingredient(s) of concern, using food labels?

PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO NEXT APPLICABLE QUESTION. (37)

- Yes..... ₁ → GO TO Q20b
- No..... ₂ → GO TO Q21
- Don't know / can't recall..... ₉ → GO TO Q21

Q20b If you were shown how to identify the ingredient(s) of concern when using food labels, who provided this assistance?

PLEASE TICK ALL BOXES THAT APPLY.

- My GP / doctor / medical practitioner ₀₁ (38-50)
- A doctor specialising in allergies ₀₂
- A dietitian ₀₃
- An alternative health practitioner..... ₀₄
- An allergy support group ₀₅
- A friend/acquaintance ₀₆
- Parent(s) ₀₇
- Other (PLEASE WRITE IN) _____

- Don't know / can't recall..... ₉₉

Q21a Have you joined any group that provides information about food allergies?

PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO NEXT APPLICABLE QUESTION. (78)

- Yes ₁ → **GO TO Q21b**
- No ₂ → **GO TO Q22**
- Don't know / can't recall..... ₉ → **GO TO Q22**

Q21b What is the name of the group you joined?

PLEASE WRITE IN.

_____ (79-84)

SECTION D

Food labels

Q22 Here are a number of things people have said about selecting food products. Please tell me how strongly you agree or disagree with each statement. PLEASE TICK ONE BOX FOR EACH STATEMENT.

		Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree		Don't know	
I've always been able to find any information I need on a food or drink label	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	(8)
When I read the labels on food products, I just focus on one or two key things, such as the levels of fat or if there are preservatives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	(9)
Generally speaking, it's easy to understand and use the information on food labels.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	(10)
I find some information on food labels really useful or important	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	(11)
It's hard to tell which parts of the label are advertising and which are standard information manufacturers have to put on.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	(12)
I don't have enough time to read food labels when I'm shopping, even if I wanted to.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	(13)
I'm very interested in food label information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	(14)

Q23 When buying packaged foods in general, how often do you look at the food labels? PLEASE TICK ONE BOX ONLY.

(15)

Only when I buy a product for the first time.....

Only occasionally when I buy a product.....

Most of the times I buy a product.....

Every time I buy a product.....

Can't say / Don't know

Q24 How much do you feel you can trust the information that is given on food labels? Please give an overall assessment. PLEASE TICK ONE BOX ONLY.

I completely trust what the labels say

I'm pretty sure I can trust what the labels say

I'm not at all sure whether to trust the labels or not

Can't say / Don't know

Q25 In general, when reading food labels because of concerns about allergens, how often are you unsure about food items or particular ingredients? PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO THE NEXT QUESTION.

(17)

Always unsure..... → **GO TO Q26**

Often unsure..... → **GO TO Q26**

Sometimes unsure..... → **GO TO Q26**

Never unsure..... → **GO TO Q27a**

Don't know

Q26 If you are unsure about what is written in the ingredient list, which of the following do you do?

PLEASE TICK ALL BOXES THAT APPLY.

- Avoid using / eating the food ₀₁ (18-27)
- Ring the manufacturer and ask ₀₂
- Ring your dietitian or doctor ₀₃
- Ring a support group ₀₄
- Ring a friend ₀₆
- Try a small amount / give a small amount to the person with the allergy ₀₇
- Eat the food anyway / give the food to the person with the allergy ₀₈
- Don't know ₉₉
- Other (PLEASE WRITE IN) _____

Q27a Consider the statement 'may contain traces of ...' which might appear on a product label. If you had an allergy to the particular ingredient mentioned, how useful is this statement to you?

PLEASE TICK ONE BOX ONLY.

- Not very useful because it doesn't say whether the ingredient I am allergic to is definitely in the product or not ₁ (28)
- Quite useful because it reminds me I may be eating a product containing the ingredient I am allergic to ₂
- Very useful because I am told that there is a chance that the ingredient I am allergic to is present ₃
- Not sure / don't know ₉

Q27b What would you do if a label on a product said it may contain traces of ... [the ingredient you are allergic to]?

PLEASE TICK ONE BOX ONLY.

- Always avoid ₁ (29)
- Sometimes / usually avoid ₂
- Always use ₃
- Not sure / don't know ₉

Q28a Now consider the statement 'made in the same premises as products containing ...'? If you had an allergy to the particular ingredient mentioned, how useful is this statement to you?

PLEASE TICK ONE BOX ONLY.

- Not very useful because it doesn't say whether the ingredient I am allergic to is definitely in the product or not ₁ (30)
- Quite useful because it reminds me I may be eating a product containing the ingredient I am allergic to ₂
- Very useful because I am told that there is a chance that the ingredient I am allergic to is present ₃
- Not sure / don't know ₉

Q28b What would you do if a label on a product said it was 'made in the same premises as products containing ... [the ingredient you are allergic to]'

PLEASE TICK ONE BOX ONLY.

- Always avoid ₁ (31)
- Sometimes / usually avoid ₂
- Always use ₃
- Not sure / don't know ₉

Q29a Now consider the statement 'made on the same equipment as products containing ...'? If you had an allergy to the particular ingredient mentioned, how useful is this statement to you? PLEASE TICK ONE BOX ONLY.

- Not very useful because it doesn't say whether the ingredient I am allergic to is definitely in the product or not ₁ (32)
- Quite useful because it reminds me I may be eating a product containing the ingredient I am allergic to ₂
- Very useful because I am told that there is a chance that the ingredient I am allergic to is present ₃
- Not sure / don't know ₉

Q29b What would you do if a label on a product said it was 'made on the same equipment as products containing ... [the ingredient you are allergic to]'? PLEASE TICK ONE BOX ONLY.

- Always avoid ₁ (33)
- Sometimes / usually avoid..... ₂
- Always use..... ₃
- Not sure / don't know ₉



THIS QUESTION IS MAINLY ABOUT HOW HELPFUL THE LABELLING INFORMATION PROVIDED ON PACKAGED FOOD AND DRINK PRODUCTS IS FOR IDENTIFYING FOODS THAT ARE SUITABLE FOR THE PEOPLE IN YOUR HOUSEHOLD WITH ALLERGIES. IT IS NOT A TEST OF YOUR PRODUCT KNOWLEDGE BUT OF HOW WELL THE LABELLING WORKS.

Q30 For this question we would like you to examine each of the labels in turn and do two things:



Circle any ingredients that you think might be unsuitable for any person(s) in your household with an allergy. Even if you don't circle any ingredient, please answer part 2.



Indicate your assessment of the product.

LABEL 1: BREAD (34-41)
INGREDIENTS
 UNBLEACHED BAKER'S FLOUR, YEAST, SALT, VEGETABLE OILS, SOYA FLOUR, EMULSIFIERS (481, 472e), PRESERVATIVE (282), VITAMIN (THIAMIN),



(42)

I would avoid this product ₁

This product is suitable ₂

Don't know..... ₉

LABEL 2: RYE BREAD (43-50)
INGREDIENTS
 UNBLEACHED BAKER'S FLOUR, YEAST, RYE MEAL, RYE FLOUR, VEGETABLE OILS, SALT, GLUTEN, VINEGAR, SOYA FLOUR, SEMOLINA, EMULSIFIERS (471, 481),



(51)

I would avoid this product ₁

This product is suitable ₂

Don't know..... ₉

LABEL 3: CHEESE (52-59)
INGREDIENTS
 Soy extract, vegetable oils, casein, sea salt, mineral salt (339), food acid, flavour, colour (annatto),



(60)

I would avoid this product ₁

This product is suitable ₂

Don't know..... ₉

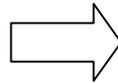


Circle any ingredients that you think might be unsuitable for any person(s) in your household with an allergy. Even if you don't circle any ingredient, please answer part 2.



Indicate your assessment of the product.

LABEL 4: MAYONNAISE (61-68)
INGREDIENTS
 SUGAR, VINEGAR, VEGETABLE OIL, THICKENER (1422), SALT, EGG, MUSTARD, VEGETABLE GUM (415), MILK SOLIDS NON-FAT, COLOURS (101, 160A), ANTIOXIDANT (320), WATER ADDED.



(69)

I would avoid this product ₁
 This product is suitable ₂
 Don't know..... ₉

LABEL 5: SPREAD (70-77)
INGREDIENTS
 SUGAR, VEGETABLE OILS, HAZELNUTS, SKIM MILK POWDER, LOW FAT COCOA, EMULSIFIER, WATER ADDED.



(78)

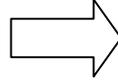
I would avoid this product ₁
 This product is suitable ₂
 Don't know..... ₉

OFFICE USE

RPT (1-6)

CARD_6 (7)

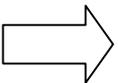
LABEL 6: SOY MILK (8-15)
INGREDIENTS
 WATER, SOY PROTEIN ISOLATE, SUNFLOWER OIL, MALTODEXTRIN, SUGAR, MINERAL SALTS (339, 340, 509, 529), FOOD ACIDS (332, 338), VITAMINS (VITAMINS A, B2, B12).



(16)

I would avoid this product ₁
 This product is suitable ₂
 Don't know..... ₉

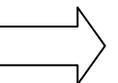
LABEL 7: MARGARINE (17-24)
INGREDIENTS
 Sunflower oil, vegetable oils, water, salt, milk solids, emulsifiers (471), natural food acid, preservative (202), natural colours, vitamins (a, d), flavour.



(25)

I would avoid this product ₁
 This product is suitable ₂
 Don't know ₉

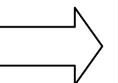
LABEL 8: DRINK (26-33)
INGREDIENTS
 SUGAR, MALTODEXTRIN, COCOA, WHEY POWDER, BARLEY AND MALT EXTRACT, MINERALS (CALCIUM PHOSPHATE, IRON PYROPHOSPHATE), VITAMINS (A, B1, B2, D3, NIACIN). ALL NATURAL INGREDIENTS, NO ARTIFICIAL COLOURS OR FLAVOURS.



(34)

I would avoid this product..... ₁
 This product is suitable..... ₂
 Don't know ₉

LABEL 9: MARZIPAN (35-43)
INGREDIENTS
 Sugar, almonds, glucose syrup, glucose.



(44)

I would avoid this product ₁
 This product is suitable ₂
 Don't know ₉

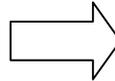


Circle any ingredients that you think might be unsuitable for any person(s) in your household with an allergy. Even if you don't circle any ingredient, please answer part 2.



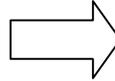
Indicate your assessment of the product.

LABEL 10: SAUCE (45-52)
INGREDIENTS
 VINEGAR, MOLASSES, SUGAR, SALT, ANCHOVIES, TAMARINDS, SHALLOTS, GARLIC, SPICES, FLAVOURINGS, WATER ADDED.



(53)
 I would avoid this product..... ₁
 This product is suitable..... ₂
 Don't know ₉

LABEL 11: SAUCE (54-61)
INGREDIENTS
 WATER, SUGAR, REHYDRATED VEGETABLES, PEANUT BUTTER, RECONSTITUTED LEMON JUICE, DESSICATED COCONUT, HYDROLYSED VEGETABLE PROTEIN, FOOD ACID (260), SALT, SPICES, SOY SAUCE, EMULSIFIER, VEGETABLE GUMS.



(62)
 I would avoid this product..... ₁
 This product is suitable..... ₂
 Don't know ₉

LABEL 12: MUESLI BAR (63-70)
INGREDIENTS
 Oats, glucose syrup, sugar, fruit, vegetable oil, puffed cereal, rolled wheat, humectant, roasted almonds, honey, desiccated coconut, skim milk powder, natural emulsifier, flavour, food acid, natural colour. May contain traces of peanuts and other nuts.



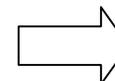
(71)
 I would avoid this product ₁
 This product is suitable ₂
 Don't know ₉

LABEL 13: CONFECTIONERY (72-79)
INGREDIENTS
 SUGAR, FULL CREAM MILK POWDER, COCOA BUTTER, COCOA MASS, EMULSIFIERS (322, 476), FLAVOURING. MAY CONTAIN TRACES OF NUTS, EGG OR SEED.



(80)
 I would avoid this product ₁
 This product is suitable ₂
 Don't know ₉

LABEL 14: PIE / PASTIE (8-15)
INGREDIENTS
 Wheat flour, water, chicken, vegetables (corn, peas, carrot), reconstituted onion, shortening, food acid (330), flavour, antioxidant (306), colour (160a), thickener (1422), textured soy protein, salt, garlic, flavours, hydrolysed vegetable protein, rice flour, mineral salts (341, 451), sugar, chilli, ginger, raising agent (500), herbs, preservative (281), spices, vegetable powders, yeast extract, emulsifier (481), maltodextrin, dextrose, flavour enhancer (635), acid (330), vegetable gums (415, 412), colour (160b).



(16)
 I would avoid this product..... ₁
 This product is suitable..... ₂
 Don't know ₉

OFFICE USE
 RPT (1-6)
 CARD_7_(7)

SECTION E
Labelling issues

Q31a While trying to identify foods that are suitable for the person(s) with the allergy, are there any other labelling issues that have caused you concern?

PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO NEXT APPLICABLE QUESTION. (17)

Yes..... **1** → **GO TO Q31b**

No **2** → **GO TO Q32**

Q31b If yes, what problems do you encounter when trying to identify foods that are suitable for the person(s) with an allergy?

PLEASE WRITE IN.

(18-27)

Q32 Here are a number of problems that people have said they have encountered when selecting different food products. Please indicate how often, if at all, this has happened to you.

PLEASE TICK ONE BOX FOR EACH STATEMENT.

	Often happens	Sometimes happens	Seldom happens	Never happens	Don't know	
I have seen the very ingredient I need to avoid, in the actual product, even though it is not listed as an ingredient on the label.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 9	(28)
A packaged product I have been using safely for ages suddenly has a statement saying it contains the ingredient(s) I need to avoid	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 9	(29)
The package I brought home contains something completely different to what the product label said	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 9	(30)
Different sized packages of the same product have different ingredients listed on them.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 9	(31)
A label on an outside package of a product varies from an individual package label inside	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 9	(32)
A reaction occurred from a product that didn't appear to have the problem ingredient(s) listed on the label.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 9	(33)
Some products have different names on their label for the ingredient(s) I need to avoid.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 9	(34)
Sometimes the listed ingredients 'spices' and 'natural flavours' include the ingredient(s) I need to avoid.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 9	(35)

Q33a In general, have you noticed any changes to the way allergens (foods or ingredients that cause allergies) are listed on food labels in the past twelve months?
PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO NEXT APPLICABLE QUESTION. (36)

- Yes ₁ → **GO TO Q33b**
- No ₂ → **GO TO Q34**
- Don't know..... ₉ → **GO TO Q34**

Q33b If yes, what sorts of things have you noticed?
PLEASE WRITE IN.

..... (37-46)

.....

.....

.....

.....

Q33c If yes, do the things you have mentioned make it any easier for you to identify products that do not contain the ingredient(s) of concern?
PLEASE TICK ONE BOX ONLY. (47)

- Yes, suitable products are now easier to identify ₁ → **GO TO Q33d**
- No, the changes I have noted have made no difference to how easy it is to identify suitable products ₂ → **GO TO Q34**
- No, the changes noted have made it harder to identify suitable products ₃ → **GO TO Q33d**
- Don't know ₉ → **GO TO Q34**

Q33d Why was it easier / harder?
PLEASE WRITE IN.

..... (48-57)

.....

.....

.....

.....

Q34 Are there any other things you'd like to see on food labels? Do you have any suggestions about how food labels can be improved to make it easier for you to both find products that contain the problem ingredient or locate products that do not contain that ingredient?
PLEASE WRITE IN.

..... (58-67)

.....

.....

.....

.....

.....

.....

IF THERE IS NOT ENOUGH SPACE, YOU MAY CONTINUE ON THE INSIDE FRONT COVER.

SECTION F
Demographics – main grocery buyer

In order for us to obtain a comprehensive profile of the people surveyed it is important for us to collect some additional demographic information. It would therefore be of great benefit to this survey if you would answer the following additional questions. If you are the person with the serious food allergy, you may have answered a few of the questions previously, however please complete them again. Thank you for your assistance.

Q35 Which of these age groups are you in? PLEASE TICK ONE BOX ONLY.

- 15-19 years ₁ (68)
- 20-24 years ₂
- 25-34 years ₃
- 35-44 years ₄
- 45-54 years ₅
- 55-64 years ₆
- 65-74 years ₇
- 75 years or over ₈

Q36 What is the highest education level that you have achieved? PLEASE TICK ONE BOX ONLY.

- Never attended school ₁ (69)
- Primary school only ₂
- Secondary school up to Form 5 ₃
- Secondary school up to Form 6 or 7 ₄
- Trade qualifications ₅
- Certificate (non-trade) / diploma ₆
- Bachelor degree ₇
- Higher qualifications ₈

Q37 Which of these statements best describes your annual total household income (before tax)? PLEASE TICK ONE BOX ONLY.

- Less than \$25,000 ₁ (70)
- \$25,000 to \$39,999 ₂
- \$40,000 to \$74,999 ₃
- \$75,000 to \$100,000 ₄
- More than \$100,000 ₅

Q38a Please read each of the following descriptions carefully and tick the box which best describes your household. If none fit your household, tick the bottom box and describe your household to us. PLEASE TICK ONE BOX ONLY.

- Single person, living alone ₁ (71)
- Single person, living with one or more children ₂
- Couple living without children ₃
- Couple living with one or more children ₄
- Group home of unrelated adults ₅
- Other **(Please tick and describe your household)** ₇

Q38b If you have children living with you, what are their ages? PLEASE TICK ALL THAT APPLY.

- Less than 3 years ₁ (72)
- 3-7 years ₂
- 8-11 years ₃
- 12-15 years ₄
- 16-17 years ₅
- 18 years and over ₆

Q39 Are you descended from a New Zealand Maori or belong to a Pacific Islander ethnic group? FOR PERSONS OF BOTH MAORI AND PACIFIC ISLAND DESCENT, PLEASE MARK BOTH 'YES' BOXES.

- No ₁ (73)
- Yes, a NZ Maori descendent..... ₄
- Yes, of Pacific Islander ethnicity ₅

Q40 Which language do you mainly speak at home?

- English ₀₁ (74-76)
- Other (**PLEASE WRITE IN**) ₀₂

Q41 Please indicate your location. PLEASE TICK ONE BOX ONLY.

- North Island ₀₉ South Island ₁₀ (77-78)

Q42 Which of these statements best describes where you live. PLEASE TICK ONE BOX ONLY.

- A city ₁ (79)
- A large regional centre..... ₂
- A small town, rural or remote area ₃

Q43 Finally, please tick whether you are male or female. PLEASE TICK ONE BOX ONLY.

- Male..... ₁ (80)
- Female ₂

Thank you very much for your help



Please send back your completed form in the reply paid envelope enclosed (it doesn't need a stamp) to return to us by 30 May, 2003

OFFICE USE

(81)

I..... 1

P..... 2

S..... 3

**INFORMATION LETTER
PLEASE RETAIN FOR YOUR RECORDS**

Dear Sir / Madam

I am writing to invite you to participate in a survey about the labelling of foods that contain potential allergens, such as peanuts, milk, eggs and fish products. The survey will provide important information about how food labels are used by those who have allergic reactions to foods or ingredients in food products.

The Survey

The allergen labelling survey will be conducted across New Zealand and Australia, on behalf of Food Standards Australia New Zealand (FSANZ) by NFO Donovan Research Pty Ltd. We intend to gain a better insight into your understanding of the allergen labelling requirements for food products. The information that you may provide us in this survey will assist us to maintain a high standard of public safety in New Zealand and Australia through better labelling of foods.

The results of this survey will be published in late 2003 and will be available for download from the FSANZ website. The information that you may provide will remain anonymous and will be treated with strict confidence by NFO Donovan Research. At no stage will you be identified or the information linked to you.

Role of FSANZ

FSANZ (formerly Australia New Zealand Food Authority) is responsible for protecting the health and safety of the people in New Zealand and Australia through the development of food standards for both countries, and through related functions. We are a bi-national independent statutory authority that develops food standards for composition, labelling and contaminants, including microbiological limits, that apply to all foods produced or imported for sale in New Zealand and Australia.

Method of Contacting You

This letter has been sent to you directly by the health professional or organisation that selected you to be included in the survey. This is because either you or someone in your household has been diagnosed as being allergic to certain foods or food ingredients. Your contact details have not been revealed to NFO Donovan Research or to FSANZ.

If you have contacted NFO Donovan Research directly to participate in this survey, your contact details were destroyed as soon as this questionnaire pack was sent to you.

If you are not the main grocery buyer, please pass this questionnaire pack on to the person who does most of the food shopping in your household.

Questionnaire Pack

Aside from this information letter, in this package you should have also received a questionnaire, a reply paid envelope and two copies of a consent form. **If you are completing the survey as the main grocery buyer and are less than 18 years of age, the consent form needs to be signed by your parent or guardian. Please return a signed copy of consent form with your completed questionnaire. The other copy is for your records.**

If you are over 18 years of age, you do not need to complete the consent form.

Assistance with the Questionnaire

Should you have any questions about the survey or are unsure how to complete the questionnaire, please call NFO Donovan Research **0800 230 012** within New Zealand. You will not be charged for this telephone call unless you call from a mobile phone. Your family members and/or friends can help you complete the questionnaire. You may also ask NFO Donovan Research to provide an interpreter.

Further Information

You can find information about this survey on the FSANZ website:

<http://www.foodstandards.govt.nz>.

You may also contact FSANZ directly should you require any further information regarding this survey. Our contact details are: Ms Shareen Lata (Evaluation Project Officer), phone +64 4 473 9942 (reception) or e-mail shareen.lata@foodstandards.gov.au.

Your Rights

If you have any queries or concerns regarding your rights as a participant in this survey, you may wish to contact a Health and Disability Advocate on telephone 0800 555 050 (Northland to Franklin), 0800 377 766 (South Island) or 377 7501 (Christchurch).

For Auckland District Health Board Maori Support, please contact Mata Forbes, RGON; Coordinator/Advisor, Maori Health Services, Auckland Hospital, Grafton on phone (09) 307 4949 ext 7292 or mobile 021 348 432. *Te Komiti Whakarite* at the Christchurch Hospital has supported this survey.

Please quote Project Number AKX/02/00/348 for any queries regarding this survey.

This study has received ethical approval from the Auckland Ethics Committee on behalf of the Canterbury Ethics Committee.

Voluntary Participation

By completing the questionnaire you are agreeing to participate in the survey. Please note that you are not obliged to participate in this survey and can withdraw at any time. However, FSANZ will greatly appreciate any information you provide us, as it will help us further improve food standards in New Zealand and Australia.

I thank you for your contribution to this valuable survey.

Yours sincerely



Dr Marion Healy
Chief Scientist

CONSENT FORM

ALLERGEN LABELLING SURVEY

(Only to be completed if the main grocery buyer in the household, who is completing the questionnaire is under 18 years of age)

I.....
hereby consent to my child (*tamaiti*) participate in the above named survey.

1. I have been given clear information (written) about this survey and have been given time to consider whether my child (*tamaiti*) should take part.
2. I have also been provided with contact details for NFO Donovan Research should I require assistance with the questionnaire. I can ask for an interpreter to assist me with survey questionnaire.
3. I understand that I (or my child) may not directly benefit by taking part in this survey.
4. I agree that the information I (or my child) provide in this survey will be published and I (or my child) will not be identified. The information I (or my child) provide will be confidential and anonymous.
5. I understand that my (or my child's) participation in this survey is voluntary (by choice). I (or my child) can refuse participation in the survey without any consequences to my family (*whanau*) or me.
6. I understand that there will be no payments made to me (or my child) for taking part in this survey.
7. I have been able to ask NFO Donovan Research questions and all questions have been answered satisfactorily. I was able to ask for an interpreter and the interpreter answered my questions satisfactorily.
8. I am aware that I can contact Food Standards Australia New Zealand (contact details on the information letter) should I require any further information about this survey or a copy of the published report.
9. I am aware that I can also make a complaint regarding this survey. This information is provided in the information letter.
10. I am aware that I should retain one of the copies of the Consent Form and the Information Letter.

Signed.....
(Parent/Guardian)

Date.....

**PLEASE RETURN TO
NFO DONOVAN RESEARCH**

Level 4, 108 The Terrace
Wellington
PO Box 559
Wellington

13 Richardson Street
West Perth WA 6005
AUSTRALIA
Tel +61 8 9322 2466
Fax +61 2 9481 6781

CONSENT FORM

ALLERGEN LABELLING SURVEY

(Only to be completed if the main grocery buyer in the household, who is completing the questionnaire is under 18 years of age)

I.....
hereby consent to my child (*tamaiti*) participate in the above named survey.

11. I have been given clear information (written) about this survey and have been given time to consider whether my child (*tamaiti*) should take part.
12. I have also been provided with contact details for NFO Donovan Research should I require assistance with the questionnaire. I can ask for an interpreter to assist me with survey questionnaire.
13. I understand that I (or my child) may not directly benefit by taking part in this survey.
14. I agree that the information I (or my child) provide in this survey will be published and I (or my child) will not be identified. The information I (or my child) provide will be confidential and anonymous.
15. I understand that my (or my child's) participation in this survey is voluntary (by choice). I (or my child) can refuse participation in the survey without any consequences to my family (*whanau*) or me.
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17. I have been able to ask NFO Donovan Research questions and all questions have been answered satisfactorily. I was able to ask for a interpreter and the interpreter answered my questions satisfactorily.
18. I am aware that I can contact Food Standards Australia New Zealand (contact details on the information letter) should I require any further information about this survey or a copy of the published report.
19. I am aware that I can also make a complaint regarding this survey. This information is provided in the information letter.
20. I am aware that I should retain one of the copies of the Consent Form and the Information Letter.

Signed..... Date.....
(Parent/Guardian)

PLEASE RETAIN FOR YOUR
RECORDS

APPENDIX C

- 1. AUSTRALIAN QUESTIONNAIRE**
- 2. AUSTRALIAN INFORMATION LETTER**
- 3. AUSTRALIAN CONSENT FORM**

2003

Benchmark Food Allergen Labelling Survey

for



FOOD STANDARDS
Australia New Zealand
Te Mana Kounga Kai – Ahitereiria me Aotearoa

Welcome to the FSANZ Benchmark Food Allergen Labelling Survey 2003

Food Standards Australia New Zealand (FSANZ) has asked NFO Donovan Research to conduct a survey on its behalf into issues relating to food labelling for people with allergies to certain foods or ingredients. You have been selected for inclusion in the survey because either you or someone else in your family has a food allergy.

The survey is mainly about how helpful you find the labelling information that is provided on packaged food and drink products for making suitable food choices. It is not a test of your product knowledge but of how well the food labelling works.

Your responses are very important as they will help FSANZ further improve food labelling standards in Australia and New Zealand.

WHO SHOULD COMPLETE THE SURVEY?

The main grocery buyer for the household should complete the survey.

WHAT IF I NEED HELP?

Friends or family members can help you complete the form, or you can ring this Free Call number: **1800 688 122** (Australia).

WHO SHOULD I TALK TO FOR MORE INFORMATION ABOUT THE SURVEY?

You can contact Shareen Lata at FSANZ by phone on (02) 6271 2219 or email shareen.lata@foodstandards.gov.au.

WHERE CAN I MAKE A COMPLAINT IF I AM NOT HAPPY ABOUT THE SURVEY?

You may call the Australian Department of Health and Ageing Ethics Committee Secretariat on (02) 6271 4324. Please quote project number 5/2002.

ARE MY ANSWERS CONFIDENTIAL?

This survey has been designed in line with the privacy laws of Australia and New Zealand. The completed questionnaires will remain anonymous. Any information you provide to us will be used for research purposes only.

Note: you may have received this questionnaire from several different sources. If you have, we ask that you complete only one questionnaire.

Please read all the questions carefully and follow the instructions after each question. The instructions are in bold.



Where you see this symbol, there is very important information on whether or not you need to answer certain questions. Please read the information and follow the instructions.

Your contribution to this survey is valuable. Please answer the questions and send back your completed form to us in the reply paid envelope by 17 April, 2003. You do not need a postage stamp.

IF YOU HAVE RECEIVED THIS QUESTIONNAIRE AND ARE NOT THE MAIN GROCERY BUYER, PLEASE GIVE THIS QUESTIONNAIRE TO THE PERSON(S) WHO MAINLY OR JOINTLY DOES THE FOOD SHOPPING FOR YOUR HOUSEHOLD.

SECTION A
Background

OFFICE USE
WAVE 1(1)
Country 1-(2)
QNA (3-6)
(8-11)

Q1 Please tick any of the following statements that are true. YOU MAY NEED TO TICK MORE THAN ONE BOX.

- I am the main grocery buyer ₁
- I am jointly responsible for grocery purchases ₂
- I have a serious food allergy ₃
- I am the person to whom the envelope was addressed ₄

Q2 How many people in total in your household have a serious food allergy *? (12-13)

WRITE IN NUMBER OF PEOPLE.



***By serious food allergy we mean a reaction that involves one or more of the following symptoms due to exposure to a particular food or food ingredient (allergens):**

- difficulty breathing or throat swelling,
- swelling or itching of lips or tongue,
- hives, skin rashes or eczema,
- stomach cramps, vomiting or diarrhoea, or
- faintness or collapse

IF ONLY ONE PERSON IN YOUR HOUSEHOLD HAS A SERIOUS FOOD ALLERGY OF THE TYPE DESCRIBED, PLEASE GO TO Q5.

Q3 If there is more than one person with a food allergy in your household, please indicate all the food allergies for all members of the household. (14-37)

PLEASE TICK AS MANY BOXES AS APPLY OR WRITE IN THE SPACE PROVIDED.

- | | |
|--|---|
| Peanut (groundnuts) <input type="checkbox"/> ₀₁ | Tree nuts (eg cashews, walnuts)..... <input type="checkbox"/> ₀₆ |
| Milk <input type="checkbox"/> ₀₂ | Fish <input type="checkbox"/> ₀₇ |
| Soy <input type="checkbox"/> ₀₃ | Shellfish..... <input type="checkbox"/> ₀₈ |
| Wheat..... <input type="checkbox"/> ₀₄ | Sulphites (food additives 220-225, 228) .. <input type="checkbox"/> ₀₉ |
| Egg..... <input type="checkbox"/> ₀₅ | Sesame Seeds <input type="checkbox"/> ₁₀ |
| Other (PLEASE WRITE IN) _____ | _____ |

Q4 What food allergy/allergies, if any, could result in a potentially life threatening reaction to any person in your household with a food allergy?

PLEASE TICK AS MANY BOXES AS APPLY OR WRITE IN THE SPACE PROVIDED.

(38-61)

- | | |
|--|---|
| Peanut (groundnuts) <input type="checkbox"/> ₀₁ | Tree nuts (eg cashews, walnuts)..... <input type="checkbox"/> ₀₆ |
| Milk <input type="checkbox"/> ₀₂ | Fish <input type="checkbox"/> ₀₇ |
| Soy <input type="checkbox"/> ₀₃ | Shellfish..... <input type="checkbox"/> ₀₈ |
| Wheat..... <input type="checkbox"/> ₀₄ | Sulphites (food additives 220-225, 228) .. <input type="checkbox"/> ₀₉ |
| Egg..... <input type="checkbox"/> ₀₅ | Sesame Seeds <input type="checkbox"/> ₁₀ |
| Other (PLEASE WRITE IN) _____ | _____ |



WE WOULD NOW LIKE YOU TO THINK ABOUT THE PERSON IN YOUR HOUSEHOLD WHO HAS THE MOST SERIOUS ALLERGY TO A SPECIFIC FOOD(S) OR FOOD INGREDIENT(S) AS YOU COMPLETE THESE QUESTIONS.

Q5 The person with the most serious food allergy is ... PLEASE TICK ONE BOX ONLY. (62)

IF MORE THAN ONE PERSON IN HOUSEHOLD HAS A SERIOUS FOOD ALLERGY, PLEASE SELECT ONE PERSON ONLY WHEN ANSWERING Q6 TO Q14.

- Me ₁
- My partner ₂
- My child (for example biological-, foster-, step-, etc) ₃
- My parent (for example mum, dad, step-, foster-, etc) ₄
- My grandchild (for example biological-, foster-, step-, etc) ₅
- Other (PLEASE WRITE IN) _____

Q6 What is the sex of the person with the most serious food allergy? PLEASE TICK ONE BOX ONLY.

- Male ₁
- (63)
- Female..... ₂

Q7 What is the age of the person with the most serious food allergy? PLEASE TICK ONE BOX ONLY.

- Under age 3 years ₁
- 3-5 years ₂
- (64)
- 6-12 years..... ₃
- 13-17 years ₄
- 18 – 24 years..... ₅
- 25 years or more ₆

Q8 What sort(s) of food allergy does the person with the most serious food allergy have? PLEASE TICK ALL THAT APPLY.

OFFICE USE
RPT (1-6)
CARD 2 (7)

- Peanuts (groundnuts) ₀₁
- Milk ₀₂
- Soy ₀₃
- Wheat..... ₀₄
- Egg (eg raw or cooked egg white or yolk)..... ₀₅
- Tree nuts (eg cashews, walnuts) ₀₆
- Fish ₀₇
- Shellfish ₀₈
- Sulphites (food additives 220-225, 228)..... ₀₉
- Sesame seeds ₁₀

Other (PLEASE WRITE IN) _____ (8-31)

Q9 How was the food allergy first identified for the person with the most serious food allergy? PLEASE TICK ALL THAT APPLY.

- Had a reaction ₁
- (32-37)
- From parent (s) ₂
- From an alternative health practitioner (eg Naturopath) ₃
- Worked it out for self ₄
- Other (PLEASE WRITE IN) _____

Don't know / can't recall..... 

Q10 Approximately how long ago was the food allergy first identified for the person with the most serious food allergy?
PLEASE TICK ONE BOX ONLY.

- Less than 6 months ago ₁
..... (38)
- More than 6 months but less than a year ago ₂
- More than a year but less than two years ago..... ₃
- More than two years ago ₄
- Can't remember ₉

Q11a Has a formal medical diagnosis been made for the person with the most serious food allergy at any time?
PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO THE NEXT QUESTION.

- Yes..... ₁ → **GO TO Q11b** (39)
- No..... ₂ → **GO TO Q12**

Q11b Who made the formal diagnosis for the person with the most serious food allergy?
PLEASE TICK ALL BOXES THAT APPLY.

- A GP / doctor / medical practitioner ₁
..... (40-43)
- A doctor specialising in allergies ₂
- A dietitian ₃
- An alternative health practitioner (eg Naturopath) ₄
- Other (PLEASE WRITE IN) _____

- Don't know / can't recall..... ₉

Q11c How was the formal diagnosis made for that person?
PLEASE TICK ALL BOXES THAT APPLY.

- Skin prick test ₁
..... (44-47)
- RAST (Blood test)..... ₂
- Elimination diet..... ₃
- Other (PLEASE WRITE IN) _____

- Don't know / can't recall..... ₉

EVERYONE ANSWER

Q12 Has the person with the most serious food allergy become less allergic since the formal diagnosis?
PLEASE TICK ANY BOXES THAT APPLY.

- Reactions are less severe to all food items ₁
..... (48-53)
- Reactions are less severe to some food items ₂
- Reactions are less frequent to all food items..... ₃
- Reactions are less frequent to some food items ₄
- Is no longer allergic at all ₅
- No, is still allergic..... ₆
- Don't know / haven't tried or tested..... ₉

Q13a Has the person with the most serious food allergy had a severe allergic reaction since the allergy was identified?
PLEASE TICK ONE BOX AND FOLLOW DIRECTION TO THE NEXT QUESTION.

(54)

- Yes..... ₁ → **GO TO Q13b**
- No..... ₂ → **GO TO Q14**
- Don't know / can't recall..... ₉ → **GO TO Q14**

Q13b If yes, can you please describe the circumstances in which this happened?
PLEASE WRITE IN.

(55-62)

SECTION B
Managing the allergy

Q14 Which of the following words tell you that the ingredients that the person with the most serious food allergy needs to avoid, may be present in the food product?
PLEASE TICK ALL THE BOXES THAT APPLY.

(63-80)

Whey..... <input type="checkbox"/> ₀₁	Casein..... <input type="checkbox"/> ₁₀	Thickener..... <input type="checkbox"/> ₁₉
Tofu..... <input type="checkbox"/> ₀₂	Albumin..... <input type="checkbox"/> ₁₁	Textured vegetable protein..... <input type="checkbox"/> ₂₀
Couscous..... <input type="checkbox"/> ₀₃	Lactose..... <input type="checkbox"/> ₁₂	Tempeh..... <input type="checkbox"/> ₂₁
Ovalbumin..... <input type="checkbox"/> ₀₄	Lecithin..... <input type="checkbox"/> ₁₃	Starch..... <input type="checkbox"/> ₂₂
Tamari..... <input type="checkbox"/> ₀₅	Cornflour..... <input type="checkbox"/> ₁₄	Butterfat..... <input type="checkbox"/> ₂₃
Maltodextrin..... <input type="checkbox"/> ₀₆	Semolina..... <input type="checkbox"/> ₁₅	Anchovies..... <input type="checkbox"/> ₂₄
Praline..... <input type="checkbox"/> ₀₇	Tahini..... <input type="checkbox"/> ₁₆	Surimi..... <input type="checkbox"/> ₂₅
Baker's flour..... <input type="checkbox"/> ₀₈	Icing sugar mix..... <input type="checkbox"/> ₁₇	Marzipan..... <input type="checkbox"/> ₂₆
Vegetable oil..... <input type="checkbox"/> ₀₉	Lactalbumin..... <input type="checkbox"/> ₁₈	Polenta..... <input type="checkbox"/> ₂₇
Other (PLEASE WRITE IN) _____	_____	_____



WE'D NOW LIKE YOU TO CONSIDER YOUR WHOLE HOUSEHOLD IN ANSWERING THE REMAINING QUESTIONS.

Q15 Considering all the members of your household who have food allergies, as far as you know, how would each person(s) in your household with food allergy/allergies approach eating foods with the following ingredient(s)?

OFFICE USE

RPT (1-6)

CARD 4 (7)

PLEASE TICK ONE BOX FOR EACH OF THE PROBLEM INGREDIENTS FOR YOUR HOUSEHOLD.

	They try, but can't avoid it completely	They never eat it knowingly	They never eat it at all	Don't know	
Peanuts (groundnuts)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(8)
Milk	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(9)
Soy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(10)
Wheat	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(11)
Egg	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(12)
Tree nuts (eg cashews, walnuts)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(13)
Fish	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(14)
Shellfish	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(15)
Sulphites (food additives 220-225, 228)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(16)
Sesame seeds	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₉	(17)

Other (PLEASE WRITE IN)

_____ ₁..... ₂..... ₃..... ₉ (18)

_____ ₁..... ₂..... ₃..... ₉ (19)

Q16 As the person who mainly buys the groceries, how often do you do the following things to help manage the food allergy/allergies of all the persons in your household?

PLEASE TICK ONE BOX FOR EACH STATEMENT.

	Always	Often	Occasionally	Never	Don't know	
Buy unprocessed foods where possible.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(20)
Buy foods in sealed packages where possible	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(21)
Read food labels carefully.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(22)
Contact the food manufacturer about what's in a food	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(23)
Buy loose or bulk foods.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(24)
Check food lists provided by allergy support group(s).....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(25)
Buy same brand of product (s) known from past experience to be allergy free	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(26)

Q17a Are there any broad product categories (eg dairy foods, bread, etc) for which you particularly need to read labels because the majority of them are likely to cause problems for the person(s) with the allergy/allergies?

OFFICE USE

PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO THE NEXT APPLICABLE QUESTION.

27=Ø
(28)

Yes, I have to check some product categories..... ₁ → **GO TO Q17b**

No, I have to check all product categories

Don't know / can't recall / not applicable..... ₉ → **GO TO Q18**

Q17b If yes, please tick which of the following broad product categories you check for that reason.

TICK ALL BOXES THAT APPLY.

(29-78)

Dairy products	<input type="checkbox"/> ₀₁	Canned foods	<input type="checkbox"/> ₁₄	Breakfast cereals	<input type="checkbox"/> ₂₆
Vegetable oils	<input type="checkbox"/> ₀₂	Breads	<input type="checkbox"/> ₁₅	Pasta	<input type="checkbox"/> ₂₇
Margarines	<input type="checkbox"/> ₀₃	Mayonnaises	<input type="checkbox"/> ₁₆	Noodles.....	<input type="checkbox"/> ₂₈
Butter / dairy spreads	<input type="checkbox"/> ₀₄	Frozen foods	<input type="checkbox"/> ₁₇	Rice	<input type="checkbox"/> ₂₉
Cordials	<input type="checkbox"/> ₀₅	Spreads	<input type="checkbox"/> ₁₈	Sweet biscuits.....	<input type="checkbox"/> ₃₀
Soft drinks	<input type="checkbox"/> ₀₆	Fruit juices.....	<input type="checkbox"/> ₁₉	Confectionery.....	<input type="checkbox"/> ₃₁
Savoury biscuits/crackers ...	<input type="checkbox"/> ₀₇	Savoury snack foods	<input type="checkbox"/> ₂₀	Infant formula.....	<input type="checkbox"/> ₃₂
Baby foods	<input type="checkbox"/> ₀₈	Soups	<input type="checkbox"/> ₂₁	Pre-prepared meals.....	<input type="checkbox"/> ₃₃
Smoked / cured meats	<input type="checkbox"/> ₀₉	Cakes/ muffins/ pastries ..	<input type="checkbox"/> ₂₂	Chocolates	<input type="checkbox"/> ₃₄
Sauces (eg chilli, BBQ, Worcestershire).....	<input type="checkbox"/> ₁₀	Muesli	<input type="checkbox"/> ₂₃	Cook / simmer / pasta sauces	<input type="checkbox"/> ₃₅

Sausages	<input type="checkbox"/> ₁₁	Fish and fish products.....	<input type="checkbox"/> ₂₄	Eggs and egg products	<input type="checkbox"/> ₃₆
Alcoholic drinks	<input type="checkbox"/> ₁₂	Ice cream	<input type="checkbox"/> ₂₅	Desserts.....	<input type="checkbox"/> ₃₇
Dried fruit	<input type="checkbox"/> ₁₃	Other(PLEASE WRITE IN)			
_____		_____		_____	
_____		_____		_____	

SECTION C
Knowledge and information

OFFICE USE
RPT (1-6)
CARD 3 (7)



WE'D LIKE YOU TO NOW THINK ABOUT WHEN A SERIOUS FOOD ALLERGY FIRST BECAME AN ISSUE IN YOUR HOUSEHOLD.

Q18 When a serious food allergy first became an issue in your household, where did you get the relevant information about what food(s) and food ingredient(s) needed to be avoided? PLEASE TICK ALL BOXES THAT APPLY.

From a GP / doctor / medical practitioner.....	<input type="checkbox"/> ₀₁	(8-27)
From a doctor specialising in allergies	<input type="checkbox"/> ₀₂	
From a dietitian	<input type="checkbox"/> ₀₃	
From parent(s)	<input type="checkbox"/> ₀₄	
From an allergy support group	<input type="checkbox"/> ₀₅	
From an alternative health practitioner (ie like a naturopath, iridologist, etc)	<input type="checkbox"/> ₀₆	
From book(s).....	<input type="checkbox"/> ₀₇	
From the web / Internet	<input type="checkbox"/> ₀₈	
From a friend / acquaintance	<input type="checkbox"/> ₀₉	
Other (PLEASE WRITE IN) _____		

Don't know / can't recall.....	<input type="checkbox"/> ₉₉	

Q19a When a serious food allergy was first identified, was it easy or difficult to get the information you needed to help you avoid the foods of concern?

PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO NEXT APPLICABLE QUESTION. (28)

It was <u>easy</u> to find out what foods needed to be avoided	<input type="checkbox"/> ₁	→ GO TO Q19b
It was <u>difficult</u> to find out what foods needed to be avoided	<input type="checkbox"/> ₂	→ GO TO Q19b
Don't know / can't recall	<input type="checkbox"/> ₉	→ GO TO Q20a

Q19b What made it easy / difficult? PLEASE WRITE IN.

(29-36)

Q20a Were you shown at any time how to identify the ingredient(s) of concern, using food labels?

PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO NEXT APPLICABLE QUESTION. (37)

- Yes..... ₁ → **GO TO Q20b**
- No..... ₂ → **GO TO Q21**
- Don't know / can't recall..... ₉ → **GO TO Q21**

Q20b If you were shown how to identify the ingredient(s) of concern when using food labels, who provided this assistance?

PLEASE TICK ALL BOXES THAT APPLY.

- My GP / doctor / medical practitioner ₀₁ (38-50)
- A doctor specialising in allergies ₀₂
- A dietitian ₀₃
- An alternative health practitioner..... ₀₄
- An allergy support group ₀₅
- A friend/acquaintance ₀₆
- Parent(s) ₀₇
- Other (PLEASE WRITE IN) _____

- Don't know / can't recall..... ₉₉

Q21a Have you joined any group that provides information about food allergies?

PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO NEXT APPLICABLE QUESTION. (78)

- Yes..... ₁ → **GO TO Q21b**
- No..... ₂ → **GO TO Q22**
- Don't know / can't recall..... ₉ → **GO TO Q22**

Q21b What is the name of the group you joined?

PLEASE WRITE IN.

_____ (79-84)

SECTION D
Food labels

Q22 Here are a number of things people have said about selecting food products. Please tell me how strongly you agree or disagree with each statement. PLEASE TICK ONE BOX FOR EACH STATEMENT.

	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know	
I've always been able to find any information I need on a food or drink label	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₉	(8)
When I read the labels on food products, I just focus on one or two key things, such as the levels of fat or if there are preservatives	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₉	(9)
Generally speaking, it's easy to understand and use the information on food labels	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₉	(10)
I find some information on food labels really useful or important	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₉	(11)
It's hard to tell which parts of the label are advertising and which are standard information manufacturers have to put on	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₉	(12)
I don't have enough time to read food labels when I'm shopping, even if I wanted to	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₉	(13)
I'm very interested in food label information	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₉	(14)

Q23 When buying packaged foods in general, how often do you look at the food labels? PLEASE TICK ONE BOX ONLY. (15)

Only when I buy a product <u>for the first time</u>	<input type="checkbox"/> ₄
<u>Only occasionally</u> when I buy a product	<input type="checkbox"/> ₂
<u>Most of the times</u> I buy a product	<input type="checkbox"/> ₃
<u>Every time</u> I buy a product	<input type="checkbox"/> ₄
Can't say / Don't know	<input type="checkbox"/> ₉

Q24 How much do you feel you can trust the information that is given on food labels? Please give an overall assessment. PLEASE TICK ONE BOX ONLY.

I completely trust what the labels say	<input type="checkbox"/> ₁	(16)
I'm pretty sure I can trust what the labels say	<input type="checkbox"/> ₂	
I'm not at all sure whether to trust the labels or not	<input type="checkbox"/> ₃	
Can't say / Don't know	<input type="checkbox"/> ₉	

Q25 In general, when reading food labels because of concerns about allergens, how often are you unsure about food items or particular ingredients?

PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO THE NEXT QUESTION.

(17)

- Always unsure 1 → **GO TO Q26**
- Often unsure 2 → **GO TO Q26**
- Sometimes unsure 3 → **GO TO Q26**
- Never unsure 4 → **GO TO Q27a**
- Don't know 9 → **GO TO Q27a**

Q26 If you are unsure about what is written in the ingredient list, which of the following do you do?

PLEASE TICK ALL BOXES THAT APPLY.

- Avoid using / eating the food 01 (18-27)
- Ring the manufacturer and ask 02
- Ring your dietitian or doctor 03
- Ring a support group 04
- Ring a friend 06
- Try a small amount / give a small amount to the person with the allergy 07
- Eat the food anyway / give the food to the person with the allergy 08
- Don't know 99
- Other (PLEASE WRITE IN) _____

Q27a Consider the statement 'may contain traces of ...' which might appear on a product label. If you had an allergy to the particular ingredient mentioned, how useful is this statement to you?

PLEASE TICK ONE BOX ONLY.

- Not very useful because it doesn't say whether the ingredient I am allergic to is definitely in the product or not 1 (28)
- Quite useful because it reminds me I may be eating a product containing the ingredient I am allergic to 2
- Very useful because I am told that there is a chance that the ingredient I am allergic to is present 3
- Not sure / don't know 9

Q27b What would you do if a label on a product said it may contain traces of ... [the ingredient you are allergic to]?

PLEASE TICK ONE BOX ONLY.

- Always avoid 1 (29)
- Sometimes / usually avoid 2
- Always use 3
- Not sure / don't know 9

Q28a Now consider the statement 'made in the same premises as products containing ...'? If you had an allergy to the particular ingredient mentioned, how useful is this statement to you?

PLEASE TICK ONE BOX ONLY.

- Not very useful because it doesn't say whether the ingredient I am allergic to is definitely in the product or not ₁ (30)
- Quite useful because it reminds me I may be eating a product containing the ingredient I am allergic to ₂
- Very useful because I am told that there is a chance that the ingredient I am allergic to is present ₃
- Not sure / don't know ₉

Q28b What would you do if a label on a product said it was 'made in the same premises as products containing ... [the ingredient you are allergic to]'?

PLEASE TICK ONE BOX ONLY.

- Always avoid ₁ (31)
- Sometimes / usually avoid..... ₂
- Always use..... ₃
- Not sure / don't know ₉

Q29a Now consider the statement 'made on the same equipment as products containing ...'? If you had an allergy to the particular ingredient mentioned, how useful is this statement to you? **PLEASE TICK ONE BOX ONLY.**

- Not very useful because it doesn't say whether the ingredient I am allergic to is definitely in the product or not ₁ (32)
- Quite useful because it reminds me I may be eating a product containing the ingredient I am allergic to ₂
- Very useful because I am told that there is a chance that the ingredient I am allergic to is present ₃
- Not sure / don't know ₉

Q29b What would you do if a label on a product said it was 'made on the same equipment as products containing ... [the ingredient you are allergic to]'?

PLEASE TICK ONE BOX ONLY.

- Always avoid ₁ (33)
- Sometimes / usually avoid..... ₂
- Always use..... ₃
- Not sure / don't know ₉
-



THIS QUESTION IS MAINLY ABOUT HOW HELPFUL THE LABELLING INFORMATION PROVIDED ON PACKAGED FOOD AND DRINK PRODUCTS IS FOR IDENTIFYING FOODS THAT ARE SUITABLE FOR THE PEOPLE IN YOUR HOUSEHOLD WITH ALLERGIES. IT IS NOT A TEST OF YOUR PRODUCT KNOWLEDGE BUT OF HOW WELL THE LABELLING WORKS.

Q30 For this question we would like you to examine each of the labels in turn and do two things:

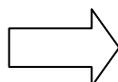


Circle any ingredients that you think might be unsuitable for any person(s) in your household with an allergy. Even if you don't circle any ingredient, please answer part 2.



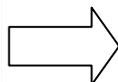
Indicate your assessment of the product.

LABEL 1: BREAD (34-41)
INGREDIENTS
 UNBLEACHED BAKER'S FLOUR, YEAST, SALT, VEGETABLE OILS, SOYA FLOUR, EMULSIFIERS (481, 472e), PRESERVATIVE (282), VITAMIN (THIAMIN), WATER ADDED. NO ARTIFICIAL FLAVOURS.



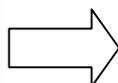
(42)
 I would avoid this product ₁
 This product is suitable ₂
 Don't know ₉

LABEL 2: RYE BREAD (43-50)
INGREDIENTS
 UNBLEACHED BAKER'S FLOUR, YEAST, RYE MEAL, RYE FLOUR, VEGETABLE OILS, SALT, GLUTEN, VINEGAR, SOYA FLOUR, SEMOLINA, EMULSIFIERS (471, 481), VITAMIN (THIAMIN), WATER ADDED.



(51)
 I would avoid this product ₁
 This product is suitable ₂
 Don't know ₉

LABEL 3: CHEESE (52-59)
INGREDIENTS
 Soy extract, vegetable oils, casein, sea salt, mineral salt (339), food acid, flavour, colour (annatto, tumeric), water added.



(60)
 I would avoid this product ₁
 This product is suitable ₂
 Don't know ₉



Circle any ingredients that you think might be unsuitable for any person(s) in your household with an allergy. Even if you don't circle any ingredient, please answer part 2.



Indicate your assessment of the product.

LABEL 4: MAYONNAISE (61-68)
INGREDIENTS
 SUGAR, VINEGAR, VEGETABLE OIL, THICKENER (1422), SALT, EGG, MUSTARD, VEGETABLE GUM (415), MILK SOLIDS NON-FAT, COLOURS (101, 160A), ANTIOXIDANT (320), WATER ADDED.



(69)
 I would avoid this product ₁
 This product is suitable ₂
 Don't know..... ₉

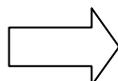
LABEL 5: SPREAD (70-77)
INGREDIENTS
 SUGAR, VEGETABLE OILS, HAZELNUTS, SKIM MILK POWDER, LOW FAT COCOA, EMULSIFIER, WATER ADDED.



(78)
 I would avoid this product ₁
 This product is suitable ₂
 Don't know..... ₉

OFFICE USE
 RPT (1-6)
 CARD_6_(7)

LABEL 6: SOY MILK (8-15)
INGREDIENTS
 WATER, SOY PROTEIN ISOLATE, SUNFLOWER OIL, MALTODEXTRIN, SUGAR, MINERAL SALTS (339, 340, 509, 529), FOOD ACIDS (332, 338), VITAMINS (VITAMINS A, B2, B12).



(16)
 I would avoid this product ₁
 This product is suitable ₂
 Don't know..... ₉

LABEL 7: MARGARINE (17-24)
INGREDIENTS
 Sunflower oil, vegetable oils, water, salt, milk solids, emulsifiers (471), natural food acid, preservative (202), natural colours, vitamins (a, d), flavour.



(25)
 I would avoid this product ₁
 This product is suitable ₂
 Don't know..... ₉

LABEL 8: DRINK (26-33)
INGREDIENTS
 SUGAR, MALTODEXTRIN, COCOA, WHEY POWDER, BARLEY AND MALT EXTRACT, MINERALS (CALCIUM PHOSPHATE, IRON PYROPHOSPHATE), VITAMINS (A, B1, B2, D3, NIACIN). ALL NATURAL INGREDIENTS, NO ARTIFICIAL COLOURS OR FLAVOURS.



(34)
 I would avoid this product ₁
 This product is suitable ₂
 Don't know..... ₉

LABEL 9: MARZIPAN (35-43)
INGREDIENTS
 Sugar, almonds, glucose syrup, glucose.



(44)
 I would avoid this product ₁
 This product is suitable ₂
 Don't know..... ₉

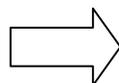


Circle any ingredients that you think might be unsuitable for any person(s) in your household with an allergy. Even if you don't circle any ingredient, please answer part 2.



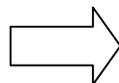
Indicate your assessment of the product.

LABEL 10: SAUCE (45-52)
INGREDIENTS
 VINEGAR, MOLASSES, SUGAR, SALT, ANCHOVIES, TAMARINDS, SHALLOTS, GARLIC, SPICES, FLAVOURINGS, WATER ADDED.



(53)
 I would avoid this product..... ₁
 This product is suitable..... ₂
 Don't know ₉

LABEL 11: SAUCE (54-61)
INGREDIENTS
 WATER, SUGAR, REHYDRATED VEGETABLES, PEANUT BUTTER, RECONSTITUTED LEMON JUICE, DESSICATED COCONUT, HYDROLYSED VEGETABLE PROTEIN, FOOD ACID (260), SALT, SPICES, SOY SAUCE, EMULSIFIER, VEGETABLE GUMS.



(62)
 I would avoid this product..... ₁
 This product is suitable..... ₂
 Don't know ₉

LABEL 12: MUESLI BAR (63-70)
INGREDIENTS
 Oats, glucose syrup, sugar, fruit, vegetable oil, puffed cereal, rolled wheat, humectant, roasted almonds, honey, desiccated coconut, skim milk powder, natural emulsifier, flavour, food acid, natural colour. May contain traces of peanuts and other nuts.



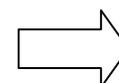
(71)
 I would avoid this product ₁
 This product is suitable ₂
 Don't know..... ₉

LABEL 13: CONFECTIONERY (72-79)
INGREDIENTS
 SUGAR, FULL CREAM MILK POWDER, COCOA BUTTER, COCOA MASS, EMULSIFIERS (322, 476), FLAVOURING. MAY CONTAIN TRACES OF NUTS, EGG OR SEED.



(80)
 I would avoid this product ₁
 This product is suitable ₂
 Don't know..... ₉

LABEL 14: PIE / PASTIE (8-15)
INGREDIENTS
 Wheat flour, water, chicken, vegetables (corn, peas, carrot), reconstituted onion, shortening, food acid (330), flavour, antioxidant (306), colour (160a), thickener (1422), textured soy protein, salt, garlic, flavours, hydrolysed vegetable protein, rice flour, mineral salts (341, 451), sugar, chilli, ginger, raising agent (500), herbs, preservative (281), spices, vegetable powders, yeast extract, emulsifier (481), maltodextrin, dextrose, flavour enhancer (635), acid (330), vegetable gums (415, 412), colour (160b).



(16)
 I would avoid this product..... ₁
 This product is suitable..... ₂
 Don't know ₉

OFFICE USE
 RPT (1-6)
 CARD 7 (7)

SECTION E
Labelling issues

Q31a While trying to identify foods that are suitable for the person(s) with the allergy, are there any other labelling issues that have caused you concern?

PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO NEXT APPLICABLE QUESTION. (17)

Yes ₁ → **GO TO Q31b**
 No ₂ → **GO TO Q32**

Q31b If yes, what problems do you encounter when trying to identify foods that are suitable for the person(s) with an allergy?

PLEASE WRITE IN.

(18-27)

Q32 Here are a number of problems that people have said they have encountered when selecting different food products. Please indicate how often, if at all, this has happened to you.

PLEASE TICK ONE BOX FOR EACH STATEMENT.

	Often happens	Sometimes happens	Seldom happens	Never happens	Don't know	
I have seen the very ingredient I need to avoid, in the actual product, even though it is not listed as an ingredient on the label.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(28)
A packaged product I have been using safely for ages suddenly has a statement saying it contains the ingredient(s) I need to avoid	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(29)
The package I brought home contains something completely different to what the product label said	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(30)
Different sized packages of the same product have different ingredients listed on them	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(31)
A label on an outside package of a product varies from an individual package label inside	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(32)
A reaction occurred from a product that didn't appear to have the problem ingredient(s) listed on the label.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(33)
Some products have different names on their label for the ingredient(s) I need to avoid.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₉	(34)

Sometimes the listed ingredients 'spices' and 'natural flavours' include the ingredient(s) I need to avoid..... ₁..... ₂..... ₃..... ₄..... ₉ (35)

Q33a In general, have you noticed any changes to the way allergens (foods or ingredients that cause allergies) are listed on food labels in the past twelve months?
PLEASE TICK ONE BOX ONLY AND FOLLOW DIRECTION TO NEXT APPLICABLE QUESTION. (36)

- Yes ₁ → **GO TO Q33b**
- No ₂ → **GO TO Q34**
- Don't know..... ₉ → **GO TO Q34**

Q33b If yes, what sorts of things have you noticed?
PLEASE WRITE IN.

..... (37-46)

.....

.....

.....

Q33c If yes, do the things you have mentioned make it any easier for you to identify products that do not contain the ingredient(s) of concern?
PLEASE TICK ONE BOX ONLY. (47)

- Yes, suitable products are now easier to identify ₁ → **GO TO Q33d**
- No, the changes I have noted have made no difference to how easy it is to identify suitable products ₂ → **GO TO Q34**
- No, the changes noted have made it harder to identify suitable products ₃ → **GO TO Q33d**
- Don't know ₉ → **GO TO Q34**

Q33d Why was it easier / harder?
PLEASE WRITE IN.

..... (48-57)

.....

.....

.....

Q34 Are there any other things you'd like to see on food labels? Do you have any suggestions about how food labels can be improved to make it easier for you to both find products that contain the problem ingredient or locate products that do not contain that ingredient?
PLEASE WRITE IN.

..... (58-67)

.....

.....

.....

IF THERE IS NOT ENOUGH SPACE, YOU MAY CONTINUE ON THE INSIDE FRONT COVER.

SECTION F
Demographics – main grocery buyer

In order for us to obtain a comprehensive profile of the people surveyed it is important for us to collect some additional information about your household. It would therefore be of great benefit to this survey if you would answer the following additional questions. If you are the person with the serious food allergy, you may have answered a few of the questions previously, however please complete them again. Thank you for your assistance.

**Q35 Which of these age groups are you in?
PLEASE TICK ONE BOX ONLY.**

- 15-19 years ₁ (68)
- 20-24 years ₂
- 25-34 years ₃
- 35-44 years ₄
- 45-54 years ₅
- 55-64 years ₆
- 65-74 years ₇
- 75 years or over ₈

**Q36 What is the highest education level that you have achieved?
PLEASE TICK ONE BOX ONLY.**

- Never attended school ₁ (69)
- Primary school only ₂
- Secondary school up to Year 10 ₃
- Secondary school up to Year 11 or 12 ₄
- Trade qualifications ₅
- Certificate (non-trade) / diploma ₆
- Bachelor degree ₇
- Higher qualifications ₈

**Q37 Which of these statements best describes your annual total household income (before tax)?
PLEASE TICK ONE BOX ONLY.**

- Less than \$25,000 ₁ (70)
- \$25,000 to \$39,999 ₂
- \$40,000 to \$74,999 ₃
- \$75,000 to \$100,000 ₄
- More than \$100,000 ₅

**Q38a Please read each of the following descriptions carefully and tick the box which best describes your household. If none fit your household, tick the bottom box and describe your household to us.
PLEASE TICK ONE BOX ONLY.**

- Single person, living alone..... ₁ (71)
- Single person, living with one or more children..... ₂
- Couple living without children ₃
- Couple living with one or more children ₄
- Group home of unrelated adults ₅
- Other (PLEASE TICK AND DESCRIBE YOUR HOUSEHOLD).... ₇

**Q38b If you have children living with you, what are their ages?
PLEASE TICK ALL THAT APPLY.**

- Less than 3 years..... ₁ (72)
- 3-7 years..... ₂
- 8-11 years ₃
- 12-15 years ₄
- 16-17 years ₅
- 18 years and over ₆

**Q39 Are you of Aboriginal or Torres Strait Islander origin?
FOR PERSONS OF BOTH ABORIGINAL AND TORRES STRAIT ISLANDER ORIGIN, PLEASE MARK BOTH 'YES' BOXES.**

- No ₁ (73)
- Yes, Aboriginal..... ₂
- Yes, Torres Strait Islander..... ₃

Q40 Which language do you mainly speak at home?

- English ₀₁ (74-76)
- Other (PLEASE WRITE IN)

**Q41 Please indicate your location.
PLEASE TICK ONE BOX ONLY.**

(77-78)

- ACT..... ₀₁ New South Wales ₀₂ Northern Territory ₀₃
- South Australia ₀₄ Tasmania ₀₅ Queensland ₀₆
- Victoria ₀₇ Western Australia ₀₈

**Q42 Which of these statements best describes where you live.
PLEASE TICK ONE BOX ONLY.**

- A city ₁ (79)
- A large regional centre..... ₂
- A small town, rural or remote area ₃

**Q43 Finally, please tick whether you are male or female.
PLEASE TICK ONE BOX ONLY.**

- Male..... ₁ (80)
- Female ₂

Thank you very much for your help



Please send back your completed form in the reply paid envelope enclosed (it doesn't need a stamp) to return to NFO Donovan Research by 17 April, 2003

OFFICE USE

(81)

I.....1

P.....2

S.....3

SURVEY INFORMATION
PLEASE RETAIN FOR YOUR RECORDS

Dear Sir / Madam

I am writing to invite you to participate in a survey about the labelling of foods that contain potential allergens, such as peanuts, milk, eggs and fish products. The survey will provide important information about how food labels are used by those who have allergic reactions to foods or ingredients in food products.

The Survey

The allergen labelling survey will be conducted in all the Australian States and Territories, and in New Zealand, on behalf of Food Standards Australia New Zealand (FSANZ) by NFO Donovan Research Pty Ltd. We intend to gain a better insight into your understanding of the allergen labelling requirements for food products. The information that you may provide us in this survey will assist us to maintain a high standard of public safety in Australia and New Zealand.

The results of this survey will be published in late 2003 and will be available for download from the FSANZ website. The information that you may provide will remain anonymous and will be treated with strict confidence by NFO Donovan Research. At no stage will you be identified or the information linked to you.

Role of FSANZ

FSANZ (formerly Australia New Zealand Food Authority) is responsible for protecting the health and safety of the people in Australia and New Zealand through the development of food standards for both countries, and through related functions. We are a bi-national independent statutory authority that develops food standards for composition, labelling and contaminants, including microbiological limits, that apply to all foods produced or imported for sale in Australia and New Zealand.

Method of Contacting You

This letter has been sent to you directly by the health professional or organisation that selected you to be included in the survey. This is because either you or someone in your household has been diagnosed as being allergic to certain foods or food ingredients. Your contact details have not been revealed to NFO Donovan Research or to FSANZ.

If you have contacted NFO Donovan Research directly to participate in this survey, your contact details were destroyed as soon as this questionnaire pack was sent to you.

If you are not the main grocery buyer, please pass the questionnaire pack on to the person who does most of the food shopping in your household.

Questionnaire Pack

Aside from this information letter, in this package you should also have received a questionnaire, a reply paid envelope and two copies of a consent form. **If you are completing the survey as the main grocery buyer and are less than 18 years of age, the consent form needs to be signed by your parent or guardian.**

Please return the signed consent form with your completed questionnaire. The other copy is for your records.

If you are over 18 years of age, you do not need to complete the consent form.

Assistance with the Questionnaire

Should you have any questions about the survey or are unsure how to complete the questionnaire, please call NFO Donovan Research on **1800 688 122** within Australia. You will not be charged for this phone call unless you call from a mobile phone. Your family members and/or friends can help you complete the questionnaire.

Further Information

You can find information about this survey on the FSANZ website:

<http://www.foodstandards.gov.au>.

You may also contact FSANZ directly should you require any further information regarding this survey. Our contact details are: Ms Shareen Lata (Evaluation Project Officer), phone +61 2 6271 2219 or e-mail shareen.lata@foodstandards.gov.au.

Your rights

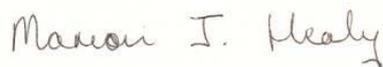
If you have any queries or concerns regarding your rights as a participant in this survey, you may wish to contact the Commonwealth Department of Health and Ageing Ethics Committee secretariat by phone on +61 2 6271 4324 or by post MDP 66, GPO Box 9848, Canberra ACT 2601, Australia. Please quote Project Number 5/2002.

Voluntary Participation

Please note that you are not obliged to participate in this survey. However, FSANZ will greatly appreciate any information you may provide us, as it will help us further improve food standards in Australia and New Zealand.

I thank you for your contribution in this valuable survey.

Yours sincerely



Dr Marion Healy
Chief Scientist

CONSENT FORM

ALLERGEN LABELLING SURVEY

(Only to be completed if the main grocery buyer in the household, who is completing the questionnaire is under 18 years of age)

I.....
hereby consent to my child participate in the above named survey.

- 1) I have been given clear information (written) about this survey and have been given time to consider whether my child should take part.
- 2) I have also been provided with contact details for NFO Donovan Research should I require assistance with the questionnaire.
- 3) I understand that I (or my child) may not directly benefit by taking part in this survey.
- 4) I agree that the information I provide in this survey will be published and I (or my child) will not be identified. The information I provide will be confidential and anonymous.
- 5) I understand that my (or my child's) participation in this survey is voluntary (by choice). I (or my child) can refuse participation in the survey without any consequences to my family or me.
- 6) I understand that there will be no payments made either to me (or my child) for taking part in this survey.
- 7) I have been able to ask NFO Donovan Research questions and all questions have been answered satisfactorily.
- 8) I am aware that I can contact Food Standards Australia New Zealand (contact details on the information letter) should I require any further information about this survey or a copy of the published report.
- 9) I am aware that I can also make a complaint regarding this survey. This information is provided in the information letter.
- 10) I am aware that I should retain one of the copies of the Consent Form and the Information Letter.

Signed.....
(Parent/Guardian)

Date.....

**PLEASE RETURN TO
NFO DONOVAN RESEARCH**

CONSENT FORM

ALLERGEN LABELLING SURVEY

(Only to be completed if the main grocery buyer in the household, who is completing the questionnaire is under 18 years of age)

I.....
hereby consent to my child participate in the above named survey.

- 11) I have been given clear information (written) about this survey and have been given time to consider whether my child should take part.
- 12) I have also been provided with contact details for NFO Donovan Research should I require assistance with the questionnaire.
- 13) I understand that I (or my child) may not directly benefit by taking part in this survey.
- 14) I agree that the information I provide in this survey will be published and I (or my child) will not be identified. The information I provide will be confidential and anonymous.
- 15) I understand that my (or my child's) participation in this survey is voluntary (by choice). I (or my child) can refuse participation in the survey without any consequences to my family or me.
- 16) I understand that there will be no payments made either to me (or my child) for taking part in this survey.
- 17) I have been able to ask NFO Donovan Research questions and all questions have been answered satisfactorily.
- 18) I am aware that I can contact Food Standards Australia New Zealand (contact details on the information letter) should I require any further information about this survey or a copy of the published report.
- 19) I am aware that I can also make a complaint regarding this survey. This information is provided in the information letter.
- 20) I am aware that I should retain one of the copies of the Consent Form and the Information Letter.

Signed..... Date..... (Parent/Guardian)

**PLEASE RETAIN FOR
YOUR RECORDS**

APPENDIX D RECRUITMENT CRITERIA

FSANZ ALLERGEN LABELLING SURVEY SAMPLING AND MAILOUT INSTRUCTIONS

Dear «Doctor_Contact»

Thank you for agreeing to help NFO Donovan Research distribute this survey questionnaire to clients with serious food allergies on behalf of Food Standards Australia New Zealand (FSANZ)

The FSANZ allergen labelling survey aims to assess people's awareness, understanding and behaviour in relation to food labels when purchasing food for themselves or for someone in their household who has a serious allergy to food or food ingredients, all of which affect the management of allergies in the household.

In this package, you should have received:

- «Sample_size» questionnaire packs for distribution to your clients (plus one for your records), each pack containing;
- *Questionnaire*
- *Information letter from FSANZ;*
- *Reply paid envelope;* and
- *Consent form for participants below 18 years of age*
- «Sample_size» reminder cards for distribution to your clients (plus one for your records); and
- One acknowledgment card to be posted to the NFO Donovan Research advising of the number of questionnaires posted to your clients and date of postage, with a copy at the end of this sheet for you to retain.

Who should get this questionnaire ?

From your records, can you please identify «Sample_size» clients who are 'at risk' of anaphylactic reaction to certain foods or food ingredients and who are currently over 1 year of age. Please select clients who have been seen at the clinic in the past 2 years.

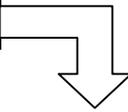
We want to include a broad cross-section of the population who are 'at risk' of anaphylactic reactions to food or food ingredients, so that we can assess the effectiveness of labelling for all types of allergies. Please select clients to roughly represent the proportion of each food allergy typically seen at your clinic.

Thus, if for example a third of the clients seen at your clinic have an egg allergy, then that proportion of the total number of questionnaires you have been asked to send out should be sent to clients with an egg allergy, selected at random from your client records from the previous 2 years. If a client has more than one allergy that may cause anaphylaxis, they should be included as part of the sample for the least common allergy seen at your clinic

As we recognise that client records will not be standardised across each different medical centre, it is not possible to give detailed instructions about how you can obtain an appropriate sample of clients within the criteria specified. We must leave this to your discretion and professional judgement, however if further direction is required, you can call NFO Donovan Research on the number provided below and we will be happy to discuss it with you.

As we recognise that client records will not be standardised across each different medical centre, it is not possible to give detailed instructions about how you can obtain an appropriate sample of clients within the criteria specified. We must leave this to your discretion and professional judgement, however if further direction is required, you can call NFO Donovan Research on the number provided below and we will be happy to discuss it with you.

1. Identify the clients to whom the questionnaire will be sent (as per the criteria above).
2. Prepare 2 address labels for each client.
3. For each client selected, attach 1 address label to a Questionnaire Pack and the other label to a Reminder Card (retain for 2 weeks).
4. Complete details on the Acknowledgment Card and on the end of this instruction sheet (for your records).
5. Post Questionnaire Packs to clients.
6. Post the Acknowledgment Card to NFO Donovan Research (note the date of postage on this sheet).
7. Post Reminder Cards to clients 2 weeks after posting the Questionnaire Packs (note the date of postage on this sheet).

Total number of questionnaires mailed out:	<input style="width: 80%;" type="text"/>	
Date questionnaires posted:	<input style="width: 80%;" type="text" value="/ /2003"/>	
Allergies covered:	#↓	Have you posted the acknowledgment Card posted to:
Peanut (groundnuts)	<input style="width: 60px; height: 20px;" type="text"/>	 NFO <small>WORLDGROUP</small> Donovan Research, 13 Richardson Street, WEST PERTH WA 6005
Milk	<input style="width: 60px; height: 20px;" type="text"/>	
Soy	<input style="width: 60px; height: 20px;" type="text"/>	
Wheat	<input style="width: 60px; height: 20px;" type="text"/>	
Egg	<input style="width: 60px; height: 20px;" type="text"/>	
Tree nuts	<input style="width: 60px; height: 20px;" type="text"/>	
Fish	<input style="width: 60px; height: 20px;" type="text"/>	
Shellfish	<input style="width: 60px; height: 20px;" type="text"/>	
Sulphites	<input style="width: 60px; height: 20px;" type="text"/>	
Sesame seeds	<input style="width: 60px; height: 20px;" type="text"/>	
Other	<input style="width: 60px; height: 20px;" type="text"/>	
Date Reminder Cards posted:	<input style="width: 80%;" type="text" value="/ /2003"/>	YES <input style="width: 20px; height: 20px;" type="checkbox"/>