Supporting people at risk of severe allergies

# Consumer Perception of Thresholds 

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## What I will cover...

- Who we are
- Background to a global survey on consumer perception of thresholds
- Headline results of the survey
- Focus on the results from the UK
- What the findings tell us


## Who we are

- The only UK-wide charity solely supporting people at risk from severe allergic reactions
- For 20 years we've provided information/ support to patients and carers
- We work with healthcare professionals, the food industry/ pharmaceutical companies for better understanding of severe allergies
- We empower patients, carers and healthcare professionals through our Allergy Wise online training
- We actively campaign for better allergy care


## Global Survey on Thresholds Objectives

- Gather information on consumer perspective of food allergen thresholds from many countries
- Use results to advance the dialogue amongst key stakeholders (i.e. food industry, clinicians, regulators and patient groups)
- Help identify ways to effectively communicate threshold concepts to consumers and get their feedback
- Results helpful to inform discussions
- Not a scientific research study


## Survey: Process

- Coordinated by Anaphylaxis Canada
- Committee - Canada, US, UK, Australia, Belgium, Italy
- Local medical advisors reviewed questions.
- Recruitment: patient organisation members, websites, social media, 1 group placed a newspaper ad
- Most used Survey Monkey
- Survey open for a two week period


## Respondents from each country

 that took part in the survey

- France
- Ireland

■ Italy
South Africa

- India

■ EFA: Denmark/Norway

## Respondents - Total: 9,689

- Parents: 81\%
- Food allergic individuals: 24\%
- Had an allergic reactions: 94\%

Symptoms ranged from mild to moderate.

- Had a severe allergic reaction: 68\%
- Such as anaphylaxis; difficulty breathing, swelling of the tongue, lips, face or throat.

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## Top food allergies

## - Peanut

No.1: US, Canada, Germany, Australia, New Zealand, Netherlands, UK, Ireland, South Africa

- Tree Nuts

No.1: Netherlands, France

- Milk

No.1: Spain, Israel, Chile, Italy

- Wheat

No.1: India

- Eggs and fish also high in most countries


## International Results



No. adults in the household with food allergies


## Number of children (<18 yrs) in the household with food allergies



Individuals asked if they would purchase a food containing their the allergen(s) if they could be assured that the amount of that allergen present in the food would not be capable of triggering an allergic reaction


Individuals asked if they would purchase a food containing their allergen(s) if they could be assured that the amount of that allergen present in the food would only be capable of triggering a mild allergic reaction (e.g. tingly lips or an itchy throat)


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## UK Survey Results



## Who has the allergy(ies)?



■ I have food allergy(ies)

■ Have a child with food allergy(ies)

- Have a partner/spouse with food allergy(ies)
- Have a relative with food allergy(ies)
- Care for someone who has food allergy(ies)


## How many adults in the household have food allergies?



## How many children (i.e. up to 18 yrs) in your household have food allergies?

$■ 0$ children

■ child

- 2 children
(0)\%

■ 3 children
(0)\%

4 children
(0)\%

5 children

161 people answered question


166 people answered question

## Other food allergies identified

- Kiwi
- Lentils
- Barley \&Pulses
- Tomato
- Potato
- Banana
- Cucumber
- Strawberries
- Oats
- Sulphites
- Chillies
- Apples
- Alcohol
- Grapes
- Peppers
- Parsnip
- Pomegranate
- Orange
- Food colouring
- Avocado
- Chickpeas
- Seeds
- Garlic
- Bean sprouts
- Carrots
- Yeast
- Coconut
- Pineapple

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## Who diagnosed the food allergy(ies)?



166 people answered question

## How long ago was the diagnosis of the food allergy?

- <1 year

■ 1-3 years

4-9 years

10+ years
30.1\%

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## Has anyone in the household ever experienced an allergic reaction to a food?



## ever experienced a severe food allergy reaction (e.g. Anaphylaxis)

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## Do you purchase pre-cooked or processed food, such as biscuits, breads, canned goods, sweets, cereals, etc?



- Yes
$\square$ No


## How knowledgeable do you think you are about allergen thresholds?



## Based on what you know about, how do you feel about thresholds?

"Not good, I think every individual reacts different, you can't set a threshold for all"
"If someone has an anaphylactic allergy then I would believe the 'threshold' would be zero!"
"I would like it to be more clear"
"Not enough to comment, we have been advised to avoid any allergens so that's what we do"
"I find them extremely confusing! I need to know what they mean for us everyone's allergies are different."
"Don't know enough about them and not willing to take the risk with my children but may do as they get older"

# Percentage of individuals who stated they would 'Never' purchase a product with these statements 

- Contains: 98\%
- Not suitable for allergen (e.g. nut) allergy sufferers: $\mathbf{8 1 \%}$
- Manufactured on the same equipment as products containing allergen: 75\%
- May contain: 70\%
- Manufactured in a facility that also processes allergen: $\mathbf{5 3 \%}$
- Packaged in a facility that also packages products containing allergen: 51\%
- Good manufacturing practices used to segregate ingredients in a facility that also processes allergen: 17\%

Consumers interpret meaning and risk based on statement.

Percentage of individuals who stated they would 'Always' purchase a product with these statement

Majority, not all, would purchase:

- Free From Allergen: 87\%
- Allergen Free: 86\%

- No consistent standards in place for 'free from' claims as not regulated

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Would you purchase a food that contains the allergen(s) you are avoiding if you could be assured that the amount of that allergen present in the food is not capable of triggering an allergic reaction?
Yes
$\square$ No
$\square I$ don't know

153 people answered question


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Would you purchase a food that that contains the allergen(s) you are avoiding if you could be assured that the amount of that allergen present in the food is only capable of triggering a mild allergic reaction, such as tingly lips or an itchy throat?


## Consumer Perspective of Thresholds

Most consumers are finding it difficult to understand 'threshold':

- Common advice is to avoid allergenic foods
- How much is too much? (Unknown)
- Threshold concept creates confusion and concern which are reflected in responses and comments
- Consumers admit that they are not knowledgeable about this area


## Consumer Perspectives of Thresholds

- Majority of responders are not comfortable with thresholds.
- They need more information, presented in a language they can understand, and want to be able to make informed decisions
- Most people would like to see:
- Clearer and consistent labelling (standardized)
- Labels they can trust


## Food labelling

- Variation in precautionary statements: Some with, others without
- Frustration amongst consumers with too many "may contain" type statements
- Choices are restricted - many ignore precautionary warnings


## View of the Anaphylaxis Campaign

- Consistent risk management approaches using agreed action levels based on good science will provide optimal protection to allergic consumers
- Increasing information, including that drawn from conducting oral food challenges, offer a realistic possibility of agreement among stakeholders in the future
- A massive communications exercise is required with consumers, clinicians and the food industry if thresholds are to be successfully implemented


## Communication challenges for patients, carers and health care professionals

- The need to convey that zero risk is not achievable
- The possible effect of extrinsic factors on threshold levels
$>$ asthma
> exercise
>medications such as NSAID,
>alcohol



## Any questions?

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